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**Supporting carers of people with dementia:   
a multiple methods evaluation and feasibility study**

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**Abstract**

**Background**

Unpaid carers are the mainstay of support for people with dementia. Admiral Nursing (AN) is the only specialist nursing service that specifically focuses on supporting such carers, but evidence of its effectiveness, costs, and relationships to other health and social care services is limited. This project aimed to address this gap and explore the feasibility of full-scale formal evaluation.

**Objectives**

* Explore relationships between characteristics of carers and people with dementia, service type and input, and outcomes.
* Develop and test data collection methods for subsequent economic evaluation.
* Explore the effect on outcomes and costs of AN, as against usual care
* Explore the perceived system-wide impact of specialist support for carers of people with dementia, as against usual care.
* Implement new data collection methods in AN, and that could be used by other services, to facilitate evaluation.

**Design**

A mixed methods study, using secondary analysis of an administrative data set, and primary (cross-sectional) quantitative and qualitative data collection.

**Setting**

Qualitative research with carers in four areas of England; survey of carers in 32 local authority areas (16 with and 16 without AN); qualitative interviews with professionals in four areas.

**Participants**

Thirty-five carers of people with dementia and 20 professionals were interviewed qualitatively; 346 carers completed in-scope questionnaires (46% through AN services and 54% from matched non-AN areas).

**Interventions**

Specialist nursing support for carers of people with dementia (with AN as an exemplar), against usual care.

**Main outcome measures**

ASCOT Carer, EQ-5D-5L and the Caregiver Self-Efficacy for Managing Dementia Scale.

**Data sources**

Dementia UK’s Admiral Nursing administrative dataset.

**Results**

ANs are successfully targeting the most complex cases. They work predominantly with older carers who have the main responsibility for the person with dementia, are heavily involved in caring activity, and who may be at risk.

Three outcome areas important to carers of people with dementia and potentially affected by receiving support are carer self-efficacy; carer quality of life; and carer mental and physical health.

Carers receiving AN in the survey were older, more heavily involved in caring and had poorer outcomes than carers not in receipt of AN. When these differences were controlled for, AN carers had better outcomes although they did not reach statistical significance, and their health and social care costs were similar.

The perceived system-wide impact of services, such as AN, is not well understood by professional stakeholders.

**Limitations**

Challenges were experienced in identifying similar carers in AN and non-AN areas and in the cross-sectional nature of the work.

**Conclusions**

Specialist nursing support to carers of people with dementia may enable them to continue providing care to the end or very close to the end of the dementia journey. The outcomes for such carers may be no different from or even slightly better than those of similar carers without this support, while their costs to health and social care services are the same.

**Future work**

Future research could investigate the impact of specialist support for carers on admission to long-term care. There is also a need for more work to encourage routine use of the selected outcome measures in dementia service delivery.

**Study registration**

N/A.

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List of abbreviations

AD – Alzheimer’s Disease

AN – Admiral Nursing

ASCOT – Adult Social Care Outcomes Tool

CCG – Clinical Commissioning Group

CES – Carer Experience Scale

CIC – Community Interest Company

CIPFA – The Chartered Institute of Public Finance & Accountancy

CPN – Community Psychiatric Nurse

CQoL – Carer-related Quality of Life

EQ-5D – EuroQol-5 Dimensions

GP – General Practitioner

HRA – Health Research Authority

HRQoL – Health-related Quality of Life

ICECAP-A – ICEpop CAPability measure for Adults

ICECAP-O – ICEpop CAPability measure for Older people

ICER – Incremental Cost-Effectiveness Ratio

INTERDEM - Early detection and timely INTERvention in DEMentia

IV – Instrumental Variables

JDR – Join Dementia Research

KPI – Key Performance Indicator

LA – Local Authority

MRC – Medical Research Council

NHS – National Health Service

NICE – National Institute for Health and Care Excellence

ONS – Office for National Statistics

PSM – Propensity Score Matching

PSS – Personal Social Services

PWD – Person With Dementia

QALY – Quality-Adjusted Life Year

QoL – Quality of Life

RCT – Randomised Controlled Trial

SCH – Survey of Carers in Households

SEMD – Caregivers’ Self-Efficacy Measure in Dementia

SERVEFF – Domain in the SEMD relating to efficacy in accessing and using services

SSXEFF – Domain in the SEMD relating to efficacy in managing dementia

TiDE – Together in Dementia Everyday

WP – Work Package

Plain English Summary

Unpaid carers are the most valuable resource we have in dementia care, yet little is known about how best to support them. Different types of service are available across England. Admiral Nursing is the only specialist nursing dementia service with a focus on supporting carers.

Our research asked:

* What are the costs and benefits of specialist nursing for carers of people with dementia?

To answer this we collected new information from carers and professionals, and looked at existing information collected by Admiral Nurses.

From the existing data we saw that Admiral Nurses are successfully targeting the most complex cases and, on average, the needs of carers being supported by Admiral Nurses reduced over time. However, we did not have the right information to link this reduction to the activity of the Admiral Nurses.

In interviews and focus groups with 35 carers of people with dementia we heard how the support they get can influence their health, quality of life and confidence in caring. Having contact with a professional who understands dementia *and* has the time to get to know their situation could improve confidence and help carers to feel supported. In-depth interviews with 20 professionals found that the wider impact of services like Admiral Nursing are not well understood.

Our survey, completed by 346 current carers of people with dementia, showed the heavy burden that carers carry, the low levels of support that they get from health and social care services, and the financial impact of paying for services. Carers who used Admiral Nursing were older and more heavily involved in caring than other carers. Despite this, their quality of life may be better than those of carers without Admiral Nursing support, while the costs of the other services they use are similar.

**293 words**

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 work to a core set of values to support carers and family members of people with dementia. All ANs are mental health nurses who have specialised in the care of people with dementia and their carers. ANs provide emotional support and helping 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 coordinated 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 full-scale, summative evaluation, such as a randomised controlled trial, before developing understanding about 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:

**1.** Explore the processes, individual and system-wide impacts, and effect on outcomes and costs of specialist support for carers of people with dementia (using the largest such service - AN - as an exemplar).

**2.** Produce guidance to inform service delivery, organisation, practice, and commissioning of specialist support for such carers.

The study objectives were to:

**1.** Carry out secondary analysis of an existing administrative database maintained by AN, to explore relationships between the characteristics of carers and people with dementia, AN service type and input, and outcomes.

**2.** Using qualitative methods with carers, develop and test data collection methods to inform survey development and cost- effectiveness evaluation.

**3.** 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 determine the feasibility of a large-scale evaluation.

**4.** Using qualitative methods explore the perceived system-wide impact of providing specialist support services for carers of people with dementia, as against usual care.

**5.** Implement new data collection methods in AN, to facilitate future evaluative research and that could be used by other service providers.

**6.** 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).

WP1

This WP prepared Dementia UK’s AN administrative dataset for research purposes and used their routinely collected data to help 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 socio-demographic 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 ANs. Preparing data for analysis involved structural change, the creation of coding frameworks, and combining data sets where necessary. Most analysis was descriptive, but longitudinal data on need were analysed to explore change over three time points, using Friedman’s test and Wilcoxon signed-rank, post hoc tests with Bonferroni adjustment.

WP2

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, for both our survey in WP3 and when used in service settings (WP5).

In-depth qualitative research with 35 carers of people with dementia explored the outcomes 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, data reduction through summarisation and synthesis to analyse the data and identify outcomes important to carers that would 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 sub-sample of these carers tested these measures and the survey questionnaire. We also collected feedback from our virtual carer advisers and steering group. Carers were asked about the feasibility of completing a questionnaire electronically and in hard copy.

WP3

The questionnaire for the survey was developed and tested as part of WP2.

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’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 organizations, *Join Dementia Research* and *Together in Dementia Everyday.*

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

The outcomes and cost of services data were then analysed further using STATA and adopting a number of approaches to deal with differences between the two groups, including regression, propensity score matching and instrumental variable analysis.

WP4

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 AN provides. 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 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.

WP5

WP5 was designed to ensure that the learning from this research informed practice and supported future evaluation. We worked with Dementia UK to inform their data collection processes using the framework established in WP2 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.

WP6

WP6 centred on a stakeholder workshop, where we presented findings of all elements of the research and worked with stakeholders to identify key messages arising from the research and discussed data collection at a local level to inform both service development and evaluation.

Results

WP1

Data on 24,825 cases, in 15 different data sets, were received from Dementia UK, 85% of which related to closed cases, 14% to current cases and 1% to cases on waiting lists. Not all data sets contained information on all cases. Three-hundred and fifty eight cases had needs assessment data for at least three time points and were used to examine change over time. A third of carers were over 75 caring for someone over 75 years of age, and the predominant relationship between carer and person with dementia was spouse or partner. Over a third of referrals to AN came from mental health services and almost a fifth were self-referrals. 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 ‘at risk’ at some point in their contact with the service. ANs 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.

WP2

The aim of this WP was to establish a data collection framework for the survey in WP3. 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, measured by the Caregiver Self-Efficacy for Managing Dementia (SEMD) scale
2. Carer quality of life, measured by ASCOT Carer
3. Carer mental and physical health, measured by EQ-5D-5L.

WP3

In-scope and usable questionnaires were received from 346 carers, of which 46% were from AN service users and 54% 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 identified in a recent, nationally representative sample survey of all types of carers. The AN carers were older than the non-AN carers and more likely to: be the main carer; be caring for a spouse/partner; be caring for someone in the same household; report financial difficulties; provide both personal and physical care; and care for more than 18 hours a 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, lack of a replacement for a break, and greater reported severity of dementia symptoms.

AN carers tended to have greater needs in terms of type and total hours of care provided. Having controlled for differences in characteristics across AN vs. non-AN carers, AN carers appeared to have better outcomes, but these did not reach statistical significance. Few differences in costs to health and social care for AN and non-AN carers were found, or for the people with dementia that they cared for. However, we did not discount co-payment for social care, which in some cases was substantial. The estimated cost of providing an AN service, per carer per year, was £709-£742.

WP4

Case studies in four sites with a spread of ethnic diversity and rural/urban mix participated - two with AN services and two without. Across the four areas, 58 professional stakeholders in key positions were identified, 20 of whom eventually were 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, since 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. ANs were valued, but 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 where specialist nurses, such as ANs, worked with and mentored less qualified support workers and escalated/de-escalated cases as and when necessary, without discharging them. It remains to be seen whether the wider impact of such an approach can be demonstrated.

WP5

We delivered training to members of one AN team in the use of our three chosen carer outcome measures (see WP2), 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.

WP6

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

Conclusions

This multi-method project has thrown important new light onto specialist nursing support for the carers of people with dementia who are most heavily involved in caring and, in most cases, 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 appropriate when we tested them cognitively, and were completed well in the survey. They have already proved 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 AN and non-AN carers. 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 opens promising space for future evaluation in an area where randomised controlled trial (RCT) 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 on carers supporting someone who was still living at home. However, all 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.

**2620 words**

Chapter 1 Introduction

Carers are the mainstay of the support system for disabled and frail children and adults. The UK 2011 Census identified almost six million people who defined themselves as carers, over half of whom cared for more than 50 hours a week. In total, UK carers provide the equivalent of 17 million working hours of care per week. Further, both the population of carers overall and the proportion who provide the longest hours of care have increased since the 2001 Census.1

Carers are most likely to be over the age of 50, more likely than others of the same age to report poor or indifferent health, and while people who become carers are more likely than others to be in poor health before they become carers,2 caring (further) affects both physical and mental health.3

Evidence of the effectiveness of specific ‘carer interventions’ is poor (see below), but we do know that mainstream services for the people carers support also help carers themselves.4, 5 However, the most recent, nationally representative survey of carers showed that just 11 per cent of the people being supported by carers had a visit from a paid home help or care worker at least once a month. While in most cases carers said that visits from home carers were ‘not needed’, 25 per cent of those not in contact did express some type of need. The proportions receiving visits from all other types of health or social care staff at least once a month were even smaller, and with similar levels of expressed need for most.6 Further analysis of these data has compared them with a similar 1985 survey. This has shown that, despite an intensification in caring activity and impact over the past 30 years, and policy preoccupations with supporting carers, smaller proportions of the people that carers help now receive health and social care support, and smaller proportions of carers experience respite.7

Carers of people with dementia are potentially an even more disadvantaged group than the generality of carers. They experience repeated transitions in their personal, social, economic and psychological lives as the dementia journey progresses, and a substantial literature has documented the impact of becoming and being a carer for a person with dementia.8 They are more likely to report negative physical and psychological outcomes than otherwise similar carers who support people without dementia.9, 10, 11 Spouses who care for partners with dementia are themselves often elderly and frail, while some of those who care for parents may also still have responsibility for their own children.

Without carers, the health and social care system would be hard pressed to provide alternative care for people with dementia.12, 13 However, despite considerable policy interest in dementia over recent years,13, 14, 15 and a (largely separate) policy stream designed to ensure carers are supported,16, 17, 18, 19 evidence about how best to support carers through the dementia ‘journey’ remains elusive. This is largely due to the relative paucity and poor quality of existing evaluative research.20, 21, 22 A particular weakness in the evidence base is the lack of studies that can throw any light onto the cost-effectiveness of interventions to support carers. Where there is evidence of effectiveness there is rarely evidence of costs, whether to health and social care services or to carers and families themselves.

There is one dementia-specific, specialist nursing service in the UK that targets support at the carers of people with dementia – Admiral Nursing – and it is this that we have evaluated here.

What is Admiral Nursing and what do we know about its impact?

Admiral Nursing (AN), based within the charity Dementia UK, is the only UK-based, dementia-specific, specialist nursing service that targets carers of people with dementia. The service was first piloted in Westminster in 1990 and currently provides support via 72 teams (staffed by 184 nurses) around the country.

AN services vary in their composition, remit, funding models, case mix and other key characteristics, although all work to a core set of values to support carers and family members of people with dementia. Some are commissioned and/or hosted by the National Health Service (NHS), others by local authorities or third sector organisations. AN services are currently found in memory assessment services, community AN teams, care homes, hospitals, palliative and end-of-life care settings, and third sector settings. The service also runs a national helpline (Admiral Nursing DIRECT) which was established in 2008 and is currently staffed by an additional 31 nurses.

Dementia UK describes the AN service thus:

Admiral Nurses are specialist dementia nurses who work closely with families living with the effects of dementia. They provide psychological support, expert advice and information to help families understand and deal with their thoughts, feelings and behaviour and to adapt to the changing situation. Admiral Nurses seek to improve the quality of life for people living with dementia and their families by using a range of interventions to help people live positively with the condition and to develop skills to improve communication and maintain relationships. Admiral Nurses also uniquely join up different parts of the health and social care system and enable the needs of family carers and people with dementia to be addressed in a coordinated way. They provide consultancy and education to professionals to model best practice and improve dementia care in a variety of care settings.23

All Admiral Nurses are mental health nurses who have specialised in the care of people with dementia. However, while they do increasingly work with people with dementia, their main objective is to support carers and family members of the person with dementia.

A recent systematic evidence synthesis by Bunn and colleagues scoped the existing literature about AN to determine, among other things, the scope, nature and key attributes of the AN role.24 This work identified two main themes that underpinned ANs’ work with carers:

* Relational support (including taking a carer-centred approach, providing individually tailored support, and being a ‘friend’) and;
* Co-ordination and personalisation of support (including facilitating access to other services and support, collaborating with other service providers, and advocating on the carer’s behalf).

A third theme related to organisational and delivery issues, including the management of case load, providing care across the dementia journey, definition of the role, and the dynamics of relationships with other parts of the health and social care system for people with dementia.

As these descriptions suggest, Admiral Nursing has all the key characteristics of a complex intervention, as defined in the Medical Research Council guidance on evaluation of such interventions.25{Craig, 2008 #38} It can involve large numbers of (and interactions between its) components, significant numbers and difficulty of behaviours for those who deliver and receive the intervention, targets for change at more than one organisational level, numerous and variable outcomes, and flexible and tailored delivery of the intervention.

The Bunn *et al.* synthesis suggested that carers value the emotional support and education that ANs provide, and that their expectations of what ANs might provide and what they actually do provide largely match. However, it also pointed out that while there has been some qualitative research and one quantitative evaluation of AN outcomes in the past,26 the evidence base on their effectiveness, costs, cost-effectiveness and relationships to other health and social care services was still very limited.

Need for the research

The evidence synthesis from Bunn *et al.*, commissioned by *Dementia UK* itself, showed that few studies provided evidence about outcomes for carers or evaluated the specific inputs of AN services.24 However, the synthesis also found little clear evidence about the cost effectiveness of any other model of community-based support for people with dementia and their carers.

More recently, an updated meta-review of evidence on support for carers suggested that contact between carers of people with dementia and other people who know about dementia may improve some aspects of carers’ mental health and of their perceptions of burden and stress.27 However, very different types of intervention seemed to produce this effect, and it was often not clear what control groups were experiencing as ‘usual care’, making it difficult to come to robust conclusions about how best to provide support.

In 2009, the Department of Health announced a new role, the dementia adviser, which was intended to enable ‘easy access to care, support and advice following diagnosis’13. This model appears to have been widely adopted28 yet navigating the complex health and social care system post-diagnosis remains an obstacle to effective care and support5, 12 and people with dementia have recently been shown to receive less primary, preventative healthcare than people without dementia29. In fact, dementia advisers were never intended to provide intensive support at the level offered by specialist services, such as Admiral Nurses13 and qualitative evidence suggests that there continues to be a demand for a more intensive approach24.

Indeed, a systematic review of case management programmes for people with dementia30 concluded that the intensity of case management interventions was one of two factors determining the magnitude of their effects, the other being the integration level of the system in which the case managers worked.

Most recently, and since our research was completed, the review to update the NICE Guideline on Dementia,31 identified only one cost–utility analysis on the subject of care planning, review and co-ordination for people with dementia or their carers. This analysis did suggest that intensive case management could result in cost savings, but the impact on quality of life was equivocal.32

The review also identified moderate-quality evidence for a reduction in ‘carer burden’, along with improvements in quality of life for people with dementia and reduced rates of entry into residential care for those offered case management versus usual care. Across the studies, larger gains were seen in interventions with more frequent follow-up, where the case manager was a nurse and where contact was made face-to-face in the person’s home.

Previous research has suggested that specialist nurses could be particularly effective in enhancing continuity of care for people with complex conditions33 and that the disease specific knowledge of specialist nurses in particular is highly valued by recipients34. Specht *et al.* compared the outcomes of an existing dementia case management service with a new nurse care management model and found benefits to carer stress, well-being and endurance potential in the nurse care management group. From anecdotal evidence accompanying this study the authors suggested that it could have been having a nurse, in particular, leading the care management of the person with dementia and their carer that led to these differences as the nurse is able to pick up and help manage associated health concerns, but they did not demonstrate this robustly35. A more recent systematic review of the evidence for ‘key worker type support roles’ for people with dementia and their carers concluded that one of the key ingredients for success was the support worker having a skilled background (that is, they were either a nurse, occupational therapist or social worker, trained in dementia).36

The detailed implications for research outlined in the Bunn *et al*. synthesis24 included the need to:

* Evaluate the specific input of AN practitioners, set alongside outcomes for carers;
* Explore the in-reach and training role of AN to acute hospitals, care homes and other practice settings and practitioners;
* Investigate the contribution of AN services from the perspectives of other health and social care stakeholders;
* Understand the profile of carers that AN services support.

The work we report here hoped to throw light onto these type of issues, by building on the earlier evidence and our existing partnership with Dementia UK to develop a rigorous quantitative and qualitative approach to address our main research question:

What are the costs and benefits for carers, families and people with dementia of providing specialist nursing support?

However, in addressing this question, we also wanted to explore the wider effects for health and social care of specialist support services for carers of people with dementia, and the impact that receiving services has on carers’ navigation of other parts of the health and social care system.

As Bunn *et al*. point out24, as others have experienced37 and as we know from our recent research on an intervention in dementia care,38 there are substantial challenges in setting-up and carrying out evaluation of complex interventions, and particularly in the area of dementia care.

Reflecting both the lack of current evidence and the difficulty of generating new evidence, our proposed project, therefore, had a dual purpose. The first was to make best use of existing data to examine outcomes for carers alongside inputs from AN, whilst also exploring the perceived systemic impact of specialist nursing support for carers. The second purpose was to test the feasibility of collecting outcomes and costs data and then to undertake exploratory outcomes and costs comparing the outcomes and costs of specialist nursing to support carers of people with dementia against ‘usual care’, which might include other forms of carer support services.

Exploring how specialist community nursing services can support carers has the potential to reduce financial costs for health and social care services and, more importantly, social, health and financial costs for carers themselves. It also fits closely with current policy preoccupations, not only in relation to dementia and carers, *per se*, but also in relation to the role of specialist, community-based nurses in supporting the health and well-being of adult carers.39 *Compassion in Practice*,among other issues, outlines clearly the need for carers and those they support to receive help from community-based practitioners who are experienced and knowledgeable, for the improved use of specialist roles, and for greater harnessing of expertise to provide good quality support.40 All these, and many other issues outlined in this policy document, have clear relevance to the provision of specialist dementia nursing.

Without carers, the UK health and social care system would be unable to cope with the additional demands placed on it; finding effective and efficient ways of supporting them to continue caring, if this is what they and the person they care for want, is thus of key importance in a country dealing with an ageing population. Yet, despite carers’ potential vulnerability, and repeated policy focus on the need to support them, we seem to be little nearer delivering adequate support than we were when the first national survey of carers was carried out in 1985.41

We currently know very little about the services available to carers of people with dementia across England, how carers engage with them, and whether they answer carers’ needs. This study is a first step in understanding the national picture and preparing for future full-scale evaluation.

Chapter 2 Study design and methods

In this chapter we describe the detailed aims and objectives of the study, its design, and the methods used to carry out the six work packages that made up the project.

Design

In the absence of a secure evidence base for cost-effective interventions to provide support for carers of people with dementia, any high-quality evaluation will provide value. However, as the MRC Guidance on the evaluation of complex interventions advises, it is important not to rush to full-scale, summative evaluation, such as a randomised controlled trial, before developing understanding about the context within which interventions are delivered, their potential effects, and the feasibility of full-scale formal evaluation.25 Developing such understanding is what we aimed to do, by adopting a mixed methods approach, using secondary analysis of an existing administrative data set, along with primary quantitative and qualitative data collection.

We hoped that this approach would allow us to make best use of existing and newly collected data to explore the potential effects and costs of specialist support for carers of people with dementia, while at the same time exploring the feasibility of formal evaluation in subsequent research. The work was thus intended to address two major uncertainties identified in the Bunn *et al*. review24.

**1.** Limited quantitative evidence on effectiveness, costs and cost-effectiveness of AN services, addressed by:

* Secondary analysis of AN’s administrative database to identify preliminary evidence on effectiveness (outcomes) of AN services.
* Survey of carers using AN services and carers in similar areas without AN services to generate preliminary evidence on the effectiveness and costs of AN services.

**2.** Understanding of the relationship of AN to other health and social care services, addressed by:

* Analysis of AN’s administrative database to describe any (other) service support begun or discontinued after input from AN service.
* Analysis of all service receipt by carers using AN services and by carers in similar areas without AN services, using statistical methods to control for possible confounding variables.
* In-depth exploration, in four case study areas, with health and social care commissioners and service providers of the impact of specialist dementia services, including AN, on perceived impact on other health and social care services.

Patient and Public Involvement

This project was made possible by a partnership between the research team and Dementia UK, a third sector organisation that campaigns for and supports people with dementia and their carers. Admiral Nursing is a Dementia UK service and the charity had, for some time, sought support to explore its outcomes. Discussions between the research team and Dementia UK thus formed the basis of the original proposal.

In designing the study we also consulted extensively with carers and people with dementia through the White Rose (Universities of York, Sheffield and Leeds) collaboration on dementia, cognition and care. Specialist nursing support for carers (or, more accurately, its lack) was one of the main priorities for future research identified through consultation. When the current project commenced we continued to work with two of the carers on the White Rose consultation group: both joined the project steering group and have continued to contribute throughout.

We also worked with Together in Dementia Everyday (TiDE), a national network of carers hosted by the Life Story Network Community Interest Company (CIC), to establish a virtual advisory group of seven carers of people with dementia that were consulted throughout the project to advise on study design, project documentation and question wording for the survey. The group facilitator, a former carer herself, linked this group with the project steering group, attending meetings of the latter to present the views of the carers’ group. A further three carers regularly attended the steering group. This arrangement allowed carers to express their views in a facilitated and supportive environment. We found this approach to be of great value: carers have been empowered to be both critical and supportive of the research and their accounts of the lived experience of caring have undoubtedly improved the project.

Towards the end of the project we held a stakeholder workshop to discuss the study findings and their implications. Members of the virtual advisory group, and other carers linked to the project, were invited and supported to attend, and a third of those who booked to attend the day said that they were current or former family carers. This workshop was extremely helpful to the research team in testing out findings, (see Appendix 5) and the presence of so many carers ensured that the implications and next steps were grounded in the real world experiences of those caring for people with dementia.

Aims and objectives

The aims of the project were to:

**1.** Explore the processes, individual and system-wide impacts, and effect on outcomes and costs of specialist support for carers of people with dementia (using the largest such service - AN - as an exemplar).

**2.** Produce guidance to inform service delivery, organisation, practice, and commissioning of specialist support for such carers.

The objectives were, using a mixed methods approach, to:

**1.** Carry out secondary analysis of an existing administrative database maintained by AN to explore relationships between the characteristics of carers and people with dementia, AN service type and input, and outcomes.

**2.** Using qualitative methods (interviews, focus groups and cognitive interviewing) with carers, develop and test data collection methods to inform subsequent cost effectiveness evaluation.

**3.** Conduct a survey of carers of people with dementia with and without access to AN services to explore the effect on outcomes and costs of AN services compared with usual care and determine the feasibility of a large-scale evaluation.

**4.** Using qualitative methods (face-to-face interviews with health and social care stakeholders in four case sites – two with and two without AN services), explore the perceived system-wide impact of providing specialist support services for carers of people with dementia, as against usual care.

**5.** Implement new data collection methods to facilitate future evaluative research in AN, and that could be used by other dementia service providers.

**6.** 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.

Methods

The project had six, interlinked, Work Packages (WPs). In this section we outline the main methods of each, as originally planned. Because of the mixed methods design we adopted, further details of the methods that we actually used are provided in individual chapters below.

Work Package 1: Secondary analysis of AN’s administrative data set

This work package prepared the administrative data maintained by AN for research purposes and then analysed the data to explore the links between carer characteristics, the characteristics of the person with dementia, AN input and outcomes over time (Objective 1).

The data set

AN has maintained a database of its activities with individual carers since 2005. Data on carers’ personal characteristics, support needs, burden and physical and mental health, some details of the person being cared for and on services provided are collected by AN when they carry out their first assessment of carers’ needs and entered in the data record. Data on variables, such as needs, burden and health, as well as AN input are also collected at follow-up, allowing the exploration of outcomes over time. Needs assessment is carried out using AN’s own tool, with standard coding.

On the day the anonymised data were securely transferred to the research team (11th March 2016), it included 24,825 records in an Excel data set, and was made up of both ‘primary’ carers and other family members defined as secondary carers, and cases that were now closed. It also included records that log follow-up data for primary carers. Due to the size of the database, the data were split into several data sets (see *Table 8*) to ease transfer and data manipulation. Dementia UK transformed the data into a format compatible with the data analysis software package that we would be using for analysis (SPSSv24), while ensuring that baseline and follow-up data on individuals remained linked across the data sets.

Based on preliminary discussion with AN, we expected to find data for 1360 carers whose needs were assessed at both baseline and at least one follow-up point. For a small number of carers, the data set also included standardised outcome measures, of which the Zarit Burden Inventory42 is the one most often completed. In September 2014, around three per cent of open cases had a completed Burden Inventory in their record.

Preparation of data for analysis

AN provided a cleaned and anonymised data set containing records of carers who have used the service since 2005. However, as would be the case with any administrative data set, various issues had to be addressed before we could export the data and start analysis for research purposes. These were:

*1. Creation of flat structures for all the data, to allow linking across individual records*

As maintained by AN, each question in the needs assessment tool and the standardised outcome measures is entered on a separate row in the Excel spreadsheet. For example, the answers to questions 1 to 22 for the first carer who completed the Zarit Burden Inventory appear in the first 22 rows of the relevant sheet in the Excel spreadsheet. These data had to be converted into a flat structure (with all 22 answers in a single row) to allow us easily and securely to link the answers to the rest of record for that carer. AN carried out this work, but it created substantial challenges which are described in Chapter 3.

*2. Linking of baseline and follow-up (outcome) records for individual carers*

Each carer in the database has a unique identifier, but follow-up data were recorded in a separate file. We therefore needed to use the identifier to create single records for those carers where follow-up data was available. Although it had originally been planned that AN would carry out this work, it was eventually done at York.

*3. Devise a coding framework for data currently entered as text*

The research team reviewed all the data and liaised with Dementia UK to ensure they understood the concepts and questions behind the data, the mode of data entry – that is, entered by staff or system-generated - and the data codes that existed in the data sets received. For example, data related to needs assessments were already coded from 0 to 3. We accessed the relevant assessment documents and, where appropriate, spoke with members of the Dementia UK data team, to clarify coding systems so were able to determine the meaning of each code (for the example given above, this was 0= no need, 1=Need currently met, 2=Unmet need, 3=Not known).

Some data, such as carer relationship to the person with dementia, country of birth and risk screening, were in text form. These latter forms of data had to be transformed into numerical codes to enable analysis. Two members of the research team (GP and FA) reviewed the text and identified summary categories for these data using filtering commands in Excel, and the data were recoded accordingly.

In two of the data sets – daily activity log and risk screening – the data were qualitative and extensive. To carry out planned analysis we needed to create numerical (categorical) data from the text. We started to develop a coding frame by taking a systematic sample of records, examining the text for commonalities and differences in the text for each ‘question’ and devised and piloted the coding framework. Once the coding framework was finalised, we aimed to apply it to all textual material thereby creating categorical variables. However, after reading the data and identifying the initial codes we felt these data required more in-depth qualitative analysis to maintain data integrity and illustrate the complexity of cases that ANs were dealing with and that clients were experiencing. A summary of these qualitative data is provided in Chapter 3.

*4. Create variables to summarise the type of AN service received*

We had planned to create descriptive variables for the current AN services, using another AN data set that logged service details, including team composition and size, geographical area covered, referral processes, funding source and staff complement. This would have allowed us to explore relationships between service characteristics and outcomes. We encountered considerable challenges in this part of the planned work, mainly due to difficulties accessing information about teams that were in existence at the time we did the work, and the impossibility of obtaining data for teams that no longer existed. We therefore did not, in the end, conduct these analyses.

Analysis

We used analysis of this unique data set, first, to provide a detailed picture of the carers who have used AN services.

We then attempted to use records where needs assessment had been carried out at more than one point to explore how AN input affected outcomes. We had hoped to carry out a range of uni-, bi- and multi-variate (regression) analyses, and establish the links between type and intensity of AN input, service user characteristics and needs, and outcomes. The initial uni- and bivariate analysis were intended to explore patterns of change in outcomes, create change variables and identify service types. The generalised regression and multi-level approaches would then explore the unique and inter-related contributions of carer characteristics, service input and team types to outcomes. For reasons explained in Chapter 3, we were unable to progress beyond the uni- and bi-variate analyses. However, the large amount of work that has gone into turning an administrative data set into something that can be used for research lays the base for multi-variate exploration in the future.

Individual AN services have changed over time – in their characteristics and functions, and since 2005 some have ceased to operate while others have started up. We could not, therefore, use the data simply to ‘describe’ AN services. However, we did use the data to analyse what type of work was done, and used this to develop a picture of the AN service ‘offer’.

All analyses were carried out by the York team.

Work Package 2: Develop and test data collection methods for survey and new data set

This work package was designed to establish a data collection framework and processes for the survey in WP3 (Objective 2).

There were two elements to the package. First, we wanted to establish what outcomes are important to carers in terms of their actual or anticipated use of specialist nursing support. Secondly, we needed to identify ways of measuring those outcomes, in a robust way that was acceptable to and feasible for carers, for both our survey in WP3 and use in service settings (WP5). The in-depth exploration of the acceptability and feasibility of the framework and processes was an essential element, given the acknowledged challenges of evaluative research in dementia care.

Sample

We identified two areas with an AN service and two areas without, and recruited carers in each, aiming for a total sample of around 30 carers, recruited from a wide range of characteristics and circumstances. The details of recruitment processes and outcomes are in Chapter 4.

While we had initially planned to hold focus groups on the University of York campus, we soon realised it would be more convenient for carers to hold them in meeting places (churches, community centres, and so on) local to the carers’ own homes. We also offered carers the option of an individual interview by telephone, or in their home or somewhere else to suit them. We offered to pay for the costs of substitute support for the person with dementia where this would help the carer to participate.

Methods

*Developing the survey*

We talked to carers twice, using focus groups or, where requested, individual interviews.

At the first contact, we used in-depth, qualitative methods to explore with carers the outcomes they would like to experience if receiving support from specialist dementia services focussed on carers. For those who lived in areas without AN services, we first described the support they might get from such a service so that they could focus their responses on this type of service.

At the end of each group or interview, we fed back the learning from the discussion and worked with the carers to finalise the outcomes they would like us to take forward to the next stage of work. We recorded the groups and interviews (with carers’ permission) but did not fully transcribe all of them. After the interviews, we reviewed the recordings, first to ensure that we did not miss any outcomes in the summing up and, secondly, to carry out a brief analysis of the material, under each of the outcomes identified. We used the Framework principles of case and theme-based analysis, data reduction through summarisation and synthesis43 to do this.

We then identified robust, standardised measures that are available to assess the main outcomes that carers had identified. In doing this, we were guided by the work that Early detection and timely INTERvention in DEMentia (INTERDEM) has done to identify good quality outcome measures in dementia care 44. This work and the measures we selected – the EuroQol-5 Dimensions (EQ-5D),45 Adult Social Care Outcomes Tool (ASCOT) Carer,46 the Self-Efficacy Measure47 - are described in detail in Chapter 4.

The questionnaire had a dual purpose within our proposed work. First, it was to collect data on carers of people with dementia in areas with and without AN for WP3 (see below) and secondly, to provide the basis for a draft data collection framework for AN to use routinely (see WP5). The questionnaire included:

* Questions on the demographic and socioeconomic characteristics of the carer and of the person with dementia (for example, age, gender, ethnicity, education and household resource level).
* Instruments that measured the outcomes important to carers (see above and Chapter 4).
* Questions on the time and resource use associated with caring. These included unpaid (informal) care time, out-of-pocket costs for care services, health (for example, hospital appointments, general practitioner (GP) appointments), social care (for example, home care) and non-statutory sector resources. These included questions on specialist dementia services accessed by the carer, both AN and other.

We then carried out cognitive interviews with carers. These explored their understanding of the questionnaire and its acceptability to them. We also talked to them about the feasibility of carers’ completing a questionnaire of this type on-line and in hard copy and the pros and cons of self-completion vs face-to-face or telephone interviews.

We tested the administration of the survey, both electronically and in hard copy, with a small number of carers (n=9) who had been involved with the earlier work and with members of our carers’ virtual advisory group and our steering group.

The survey was developed within, and administered using *Qualtrics* (<http://www.qualtrics.com>). This is sophisticated, internet-based survey software that allowed us to produce high-quality on-line questionnaires. We also produced a paper version of the questionnaire, which is reproduced in Appendix 2.

Work Package 3: Survey and analysis of outcomes and analysis of outcomes and costs

The key aims of WP3 were to address Objective 3 by:

1. Understanding the characteristics of carers, the people with dementia that they support, and their outcomes and costs with and without AN services.
2. Exploring the effect on outcomes and costs of AN by comparing relevant carer outcomes and costs in areas with and without AN services.
3. Evaluating the feasibility of recruiting carers and collecting their outcomes via online and postal questionnaires in future research.

Rationale for our chosen survey design

Our aim in this section of the proposed work was to compare carers of people with dementia who used AN services with those who did not (who received ‘usual care”) both to judge the likely effect of AN services on carers’ outcomes and to assess the costs of AN services against any benefits that might be identified.

AN is the only specialist nursing service for carers of people with dementia, so we felt relatively sure that carers in non-AN areas would not be receiving any carer-focussed, dementia-specific services. Other services that both AN and non-AN carers might use include visits from community-based mental health nurses, home care services and social work input. However, we expected to see substantial heterogeneity, given the diversity of support services for people with dementia and their carers and the diversity of provision across the country. It is possible that AN services might *substitute* for other forms of services that carers might otherwise have received. However, at the outset, we thought it more likely, given the objectives of AN services, that they would enhance carers’ access to other services, via signposting and direct liaison.

We had hoped to strengthen our analysis by also surveying a small number of carers who lived in AN areas but did not use AN services. The substantial challenges of identifying those not using AN services, described in more detail in Chapter 5, meant that we did not achieve this secondary aim.

Choice of design

Our chosen design was a cross-sectional survey. We chose this approach because carers of people with dementia are a precious research resource and longitudinal data collection would impose additional burdens on them and, in all likelihood, reduce response rates over time. However, we intended that the design of the sampling and analysis strategies would allow us to carry out robust cross-sectional comparison between those who did and those who did not use AN services.

First, the sample selection processes aimed to reduce heterogeneity, both within the AN services being evaluated and between carers in areas with and without AN services.

Choice of sampling frame

We generated simple, two stage cluster samples of local authority areas that had ‘standard’ AN services (see below for definition) and broadly similar (matched) local authority areas without AN services. We then intended to carry out proportionate random sampling of current users of AN services in the former and of carers in contact with TiDEin the latter, to generate the respondents for the survey. For reasons described in detail in Chapter 5, identifying carers in non-AN areas was extremely challenging and we were not able to carry out this element of the design. We did, however, carry out proportionate sampling of carers in our selected AN services.

‘Standard’ model of AN services

As outlined in Chapter 1, AN services vary in their composition, remit, funding models, case mix and other key characteristics. For the purposes of this work package, however, we needed to compare outcomes from services that were typical of the majority. We therefore selected areas with AN services that delivered a ‘standard’ model which, after discussion with AN, we defined as services:

* Based in the community (rather than in a long-term care setting);
* Providing support mainly to carers where the person they supported still lived in a private household;
* Funded to provide support to any carer (so excluding third sector funded services that provided support only to a sub-group of carers).

Matched areas

We defined ‘broadly similar’ areas in terms of statistical neighbourhood, as defined by the Chartered Institute of Public Finance and Accountability’s (CIPFA) statistical model (<http://www.cipfastats.net/default_view.asp?content_ref=18003>). Statistical neighbourhood is used by local authorities themselves, and across government, to allow comparisons between authorities that are similar in terms of population size and characteristics, such as age distribution, deprivation and ethnicity. For example, the Department of Health has developed an interactive adult social care efficiency tool (<https://www.gov.uk/government/publications/adult-social-care-efficiency-tool>) that compares local authorities’ performance on service provision to and expenditure on older people and people with a learning disability. It was this latter tool that we eventually used to match areas.

Sample size

Sample size calculation for cross-sectional surveys of populations is simple when the sole aim of the survey is to describe the population within given statistical tolerances. Similarly, sample size calculation is relatively simple when the sole aim is to compare outcomes between equivalent groups which vary only in their receipt of an intervention. However, this latter does also require prior knowledge about or indication of what size of effect one might be expecting, or what average level of a chosen outcome one might expect to see in the selected population prior to intervention.

In our survey, we wished both to describe *and* to draw inferences about what effect using AN services might have on carers of people with dementia. While our sampling strategy (see above) was intended to reduce some of the likely variation between users and non-users of AN services, we also needed to control for any other differences between them that become evident after collecting data. This was so that we could feel confident that we were seeing the effect (if any) of AN services on measured outcomes, and not the effect of some other differences between carers.

It was challenging to find any up-to-date, population-based evidence about the average levels of (say) the quality of life of carers of people with dementia, or UK-based comparative studies that might hint at possible effect sizes from similar types of intervention.

Given these challenges we took a pragmatic approach to sample size calculation, using three different approaches. The first was a simple, population survey sample calculation. The second was a sample calculation for comparative research, using the effect sizes found in a randomised controlled trial of community occupational therapy in the Netherlands48 that aimed to help carers use ‘effective supervision, problem solving, and coping strategies’ with a view to sustain both their own and the person with dementia’s ‘autonomy and social participation’ (p.1003). This intervention also included similar input for the person with dementia and found very substantial differences on a range of outcomes at three-month follow-up. We then assessed how many independent variables could be included in multivariate analysis, based on the sample sizes generated by these two approaches. The results of these calculations are in *Table 9* in Appendix 1.

A pragmatic decision about an achievable sample size, within reasonable resource use, took us to a decision about original sample size somewhere between the two figures of 26 and 640 generated by this process. Assuming that we would need to control for up to 20 independent variables in regression analysis, we calculated that an achieved sample of 320 would be needed to detect differences of the size observed in the Graff *et al*. study.48

We assumed that the response rate in non-AN areas might be lower than that for AN users (say, 50 per cent, rather than the 60 per cent we had achieved in a recent survey of carers in another NIHR-funded project.38 Subsequent discussion with AN prompted us to reduce the anticipated response rate further to 30 per cent. Taken together, to achieve 160 in each group, we needed to sample around 480 carers from AN services and 480 in non-AN areas – a total of 960.

The average caseload per AN team is around 35 carers (personal communication with the AN service). We therefore needed to sample at least 16 teams to achieve our required sample (again, assuming a 30 per cent response rate for this group). This also gave us the recommended minimum of 30 clusters (15 AN areas and 15 matched non-AN areas) for this type of survey design.

AN teams identified carers who were currently using the service in the selected AN areas. A range of approaches was used to identify carers in the non-AN areas (see Chapter 5).

Where the number of cases per AN team was greater than needed for sampling, we used proportionate random sampling to generate the required numbers.

Methods

Survey

In our 16 AN areas we asked the AN services to identify carers of people on their current case load and to facilitate distribution of the questionnaire developed in WP2. We also worked with a range of statutory and non-statutory organisations to identify carers of people with dementia in the 16 matched, non-AN areas. In both cases, we offered the option of electronic and paper-based delivery, depending on individual preferences. Our earlier discussions with AN had suggested that electronic distribution would be the preferred option for AN carers but, in reality, this was not the case as many selected services did not have email addresses for the carers. We therefore ended up with a majority of AN returns on paper and, because of the way we sampled them, a majority of electronic returns from carers in non-AN areas. Further details of this are in Chapter 5 and a paper copy of the paper questionnaire is at Appendix 2.

For paper-based questionnaires, we included a leaflet explaining our study and its objectives, the questionnaire, and a pre-paid envelope for return directly to the research team. For questionnaires delivered electronically, we attached the same leaflet explaining the study to an email, which also provided a unique electronic link to the survey.

We offered carers a voucher for £10 on receipt of their completed questionnaire, to thank them for taking the time and effort to answer the questions and contribute to our research.

Further details of the sample identification and selection and questionnaire administration are in Chapter 5.

*Data entry*

Data gathered via Qualtrics was initially exported as an Excel spreadsheet, which, after some editing, was exported to statistical software (Stata ®, StataCorp LLC) for analysis. Data returned via paper-based questionnaires were checked for quality and then entered into Qualtrics manually.

Analysis

We carried out a number of descriptive and econometric analyses that enabled us to understand the characteristics of carers and the person they support and how these related to their outcomes and costs, with and without AN services. We also used data on responses to the survey to assess the feasibility for future research of collecting data on carers and the people with dementia they care for via online and postal questionnaires.

The analysis plan was designed to include the exploration and analysis of outcomes and costs, and methodological learning.

*Describing outcomes*

The first stage described the characteristics of carers and explored their relationship to outcomes. Uni- and bi-variate analyses explored carers’ demographic and socio-economic characteristics, characteristics of the person with dementia, carer specific variables, such as type and hours of care provided, scores on our selected outcome measures, and resource use and costs.

This preliminary work also allowed us to compare the overall characteristics of the AN carers and people with dementia from carers in non AN areas. This enabled us to specify potential confounding variables for the subsequent analysis of outcomes and costs, as well as to establish the representativeness of carers who had completed the survey.

In the second stage of analysis, we costed the health and social care services used by carers using national unit costs where available or the local unit costs of services otherwise. We carried out descriptive analysis of the resource use and costs used by the carers and evaluated the relationship between carers’ characteristics, characteristics of the person with dementia, outcomes and costs. The relationship between costs to the health and social care sector by type of area (with and without AN), controlling for characteristics of the carer and person with dementia, was of particular interest since it might indicate whether AN services can generate savings in the health and social care sector by providing support to carers.

*Analysis of outcomes and costs*

Building on stages 1 and 2, we then carried out an analysis of outcomes and costs using regression analysis, propensity score matching (PSM), and an instrumental variables (IV) approach in order to establish the associations between the carers’ characteristics, costs and outcomes.

The analysis aimed to evaluate the costs and effects associated with AN compared to usual care for carers. Our focus was carers, given that AN was primarily designed to support carers rather than the person with dementia. A broad perspective was taken to account for the costs falling on the NHS, social services and voluntary sector services.

The aim was that the primary analysis would involve an analysis of outcomes and costs using the NICE reference case for health care interventions using the NHS and Personal Social Services (PSS) perspective.49 This includes the costs falling on the NHS and PSS budgets and the outcomes relevant to carers. The costs falling on the NHS and PSS budgets included hospital appointments, primary care appointments (GP, nurse, and so on), home care funded by the local authority and the AN service itself. Resource use was costed using published, national average unit costs50, 51 and NHS reference costs,52, 53 where available, so that the cost analysis was as generalisable across England as is possible.

In addition, we ran descriptive analysis to compare out-of-pocket costs and other informal (unpaid) care costs across AN and non-AN carers.

*Dealing with comparability and unknown confounders*

Given the non-randomised, cross-sectional nature of the data collection process, quantifying an association between outcomes and the availability of AN services requires us to be sure that carers responding to the survey in areas with and without AN services are comparable in observed and unobserved factors that might affect outcomes.

For this reason, the analysis was in five stages, described in detail in Chapter 6: descriptive analysis, linear regression analysis, PSM, instrumental variables (IV) analysis and sensitivity analysis. We conducted the descriptive analysis to understand the characteristics of the sample and to select the variables to use in the subsequent analyses. With the linear regression analysis, we analysed the associations between having AN services and outcomes and costs, controlling for the observed differences between carers with and without AN services. We used PSM to generate comparable groups of carers with and without AN services.54

Linear regression and PSM can only deal with observed differences in the two groups of carers. We had some concerns that there might be unobserved differences; that is, differences in characteristics on which we could not collect data. The implication was that carers in non-AN areas would not represent carers in AN areas in the absence of AN services, even after controlling for observed characteristics. This is known as selection bias (also confounding or endogeneity).

The IV approach may reduce the risk of selection bias in the presence of good instruments. The instrument was the travel time between the carer and AN provider. Carers living far apart from the AN provider may not be eligible because the service is delimited to a specific geographical area. Moreover, carers living at long travel distances from the AN provider may be less likely to be informed about AN, compared to carers living in proximity of AN teams. Thus carers living nearby AN providers may be more likely to be eligible or to access the service. Similar to Forder *et al.*, we used the type of local authority as an instrument.55 The type of local authority may indeed determine the local authority’s culture and, in turn, the local authority’s propensity to invest in services for carers; the culture, however, will not have a direct effect on the carer’s outcomes.

Work Package 4: Understand the wider impact of specialist support for carers of people with dementia

Specialist dementia services’ effects may extend beyond individual outcomes and resource use, having effects also at a system level. For example, if services enable carers to care for longer, or help them to remain healthy they may reduce costs to both health and social care systems. This work package explored with health and social care stakeholders what they perceived to be the system-wide effects of supporting carers of people with dementia, with a specific emphasis on specialist nursing support of the type AN provides.

Sample

We selected two areas with AN services that delivered a ‘standard’ model, defined in the same way as for WP3 (see p.16).

We then selected two areas that did not have AN services but that were in broadly similar areas to the AN services. We selected areas that were also selected for WP3, with the hope that we could triangulate our qualitative and quantitative findings in these areas (so treating them as case studies). For reasons explained in Chapter 7, it was not possible to triangulate the findings as originally envisaged.

Within each area, we identified the key health and social care stakeholders in dementia care and support for carers. This included both statutory and third sector (for example, senior managers of local Age UK or Carers UK) stakeholders. We started with the main health service or social care commissioner for dementia services in each area and then used snowballing techniques to identify other stakeholders.

We intended to grow the sample until we were learning nothing new (that is, we achieved saturation of the data) and expected to identify between 12 and 15 key stakeholders in each area to achieve saturation. Chapter 7 describes the outcomes of this approach.

Methods

We carried out in-depth, semi-structured interviews with stakeholders which explored the perceived system-wide impact of carer services, such as AN, as against ‘usual care’ (Objective 4).

The interview aide memoire covered the following topics:

* Current provision and cost of support for carers of people with dementia;
* Perceived impact of this support (or its lack) on other health and social care services;
* The balance between the costs and benefits of supporting carers;
* Future plans for (further) developing support for carers of people with dementia.

In the AN areas, we will also covered topics specific to AN, such as commissioning arrangements and intentions.

We also used this stage to explore the feasibility of implementing routine collection of outcome and resource use data.

Analysis

We recorded and transcribed the interviews and analysed them using the Framework Approach43.

Further details about the methods of this WP are in Chapter 7.

Work Package 5: Implement a new data collection system for AN and promote it to other dementia service providers

Using the learning from WP2, we worked with AN services to develop a new data collection framework to provide the data required for future evaluative research while also meeting their administrative needs. 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.

Following the general shape of the survey questionnaire, we expected the framework broadly to include socio-economic data, quality of life measures (both generic and carer-specific), informal carer time, and health and social care resource use, as well as administrative data that describes AN activity and inputs with individual carers. We aimed to pilot the new framework with one AN team to test its feasibility in the field and work with Dementia UK to inform their approach to routine data collection across all services going forward.

Further details about the ways in which this WP was carried out are in Appendix 5.

Work Package 6: Develop best evidence guidance for service commissioning and delivery of support for carers of people with dementia

The final stage of our project was a stakeholder workshop that presented the findings of all elements of our research. We worked with stakeholders during a full-day event to begin drafting a statement about current evidence for specialist support for carers of people with dementia, how different models of support might influence outcomes, and how to collect data at a local level so that it informs both service development and evaluation.

We invited a range of stakeholders including carers, decision-makers from health and social care commissioning and providing organisations (including the third sector), and local and regional policy-makers. Key points from this workshop are presented in Appendix 5.

After the project is completed, the draft guidelines will be circulated to participants and other stakeholders for comment before they are finalised and disseminated as a project output.

Chapter 3 Analysis of the Admiral Nursing administrative data set

Work Package 1 of the project focused on preparing Dementia UK’s Admiral Nursing (AN) administrative dataset for analysis of their routinely collected data for research purposes. The aim of this analysis was to help understand the characteristics of carers who use AN services and of the person they care for, the type and level of input carers receive from AN services, and the outcomes carers experience when using AN services. As outlined in Chapter 2, because of the size of the database, the data were split into several data sets to ease transfer and data manipulation. *Table 8* (see Appendix 1) provides an overview of the data sets received.

Analysis

Each data set was initially analysed separately and, where appropriate and practical, then joined and analysed alongside other data sets.

Some data held within the database were collected at a single point in time and some were longitudinal. Data collected at a single time point - usually at entry to the service – included information about the socio-demographic characteristics of carers, agencies involved in the case at admission to AN, and other family members involved. We analysed these data descriptively.

Likert scale-derived data about the needs of the dyad of the carer and the person with dementia were longitudinal. There were two main data sets with such repeated measures, both related to needs assessment. One data set held data from an older version of the AN service’s own needs assessment form and the other data from a new version of the form. The current needs assessment contained 18 questions and the legacy assessment 19 questions. Most of these were about comparable topics but the response options were different. On the legacy needs assessment, the 5-point Likert scale responses were about whether there was a need that required intervention and the severity/urgency of that need/intervention (that is, none, minimal, some, considerable, urgent). The current needs assessment tool used a 4-point Likert scale to ascertain whether there was a need that might require intervention but did not refer to severity or urgency of that need/intervention (no need, needs currently met, unmet need, not known). The legacy assessment asked a specific question about information in relation to understanding dementia symptoms but this was not included in the current tool. The current tool included a question about risk that was not on the legacy tool (see *Table 10)*. Because of these differences, the two data sets have been analysed separately.

The data sets held legacy needs assessments for 2074 carers and current needs assessments for 2541 carers. Some carers were assessed up to eight times using the legacy needs assessment and up to nine times using the current needs assessment, however the majority had only one assessment recorded (see *Table 11*). To ensure we would be able to detect any changes in needs assessment over time, while retaining an adequate sample size, we limited analysis of assessments to carers’ first three assessments. To be able to do this, we undertook additional restructuring of the data sets.

First, we conducted a match-text analysis on unique identification numbers to identify carers that had been assessed using both assessment formats. This showed that 51 carers were assessed using both the legacy and the current assessments forms. Analysis of these 51 cases across the two datasets confirmed that the legacy needs assessments were completed before the current needs assessments. Thus, we were able to remove the 51 duplicate cases from the current needs assessment data set.

Secondly, when we received the data, they were not in any particular date order. On speaking with the administrator of the database, it became clear that when the data were converted from their original to the required ‘flat’ structure (as outlined in *Chapter 2*), the data had been ordered by the date it was entered onto the system rather than the date assessments were undertaken. To correct this problem, we had to convert the dataset back to its original structure and then re-structure again it into flat format in order of the dates of assessments. Assessments without dates were removed from the dataset being analysed.

Finally, we removed all cases where there were fewer than three assessments on each of the forms. This left us with active datasets of 157 cases for the legacy needs assessment and 201 for the current assessment (see *Table 12*).

These longitudinal data were then subject to descriptive analyses and Friedman’s tests to analyse the variance in responses to need assessment questions over three consecutive time points. This test is appropriate for examining differences in ordinal values over time, where the samples are related (as they are here) and produces a chi-squared statistic. Where results of the Friedman test were significant, we then carried out Wilcoxon signed-rank post hoc tests with Bonferroni adjustment, resulting in a significance level set at p < 0.017, to established which pairs of needs assessment data accounted for the differences.

Cases data set

Of all the data sets, the ‘cases’ data provided the most complete and up-to-date overview of clients of AN services, with information about all 24,825 current and previous clients. Of these, 85 per cent were closed cases (see *Table 13*). Where relevant, findings are presented to enable comparison of closed (previous), open (current) (14%) and waiting list (future) (1%) clients.

Demographics of carers and the people with dementia

Almost three-quarters of carers (71%), whether previous or current clients, were the main carer for the person with dementia. Information about their living situation was recorded for only a quarter of the people with dementia. Most lived with their main carer (57%) or alone (14%). Most carers were female (70%), while the people with dementia were split almost equally in terms of gender (53% female, 47% male). Over three-quarters of carers (77%) were over 55 years of age as, unsurprisingly, were most people with dementia (98%). Almost two-thirds of primary carers were retired but an important minority (15%) were in full-time employment. Ninety-one per cent of both carers and people with dementia were described as white (see *Tables 14-19*).

*Table 20* shows the relationship between the age of carers and age of the people with dementia. Almost one in three carers (32%) were in the oldest age group (aged 75 years of over) and were caring for someone in the oldest age group. The similarity in age is not surprising, given that the majority of carers (88%) receiving support from the AN service were married and were most likely supporting their spouse or partner (*Tables 21 and 22*).

Diagnoses

Seventy per cent of the cases in the cases dataset reported whether the person with dementia had been diagnosed when they were referred to the AN service; almost a half of these had been formally diagnosed. Where a diagnosis was recorded, the most common were Alzheimer’s disease (39%) and vascular dementia (30%). *Table 23* shows that there was little variation in diagnoses among closed, open or waiting list cases.

Service provision

The intensity of input that carers received from ANs was recorded for current clients. In almost half the cases, when the data were entered into the dataset, ANs were still working with carers to determine their longer-term input requirements (45%). Almost a third (31%) were recorded as receiving a medium level of intervention, which could include, for example, monthly one-to-one meetings and planned telephone, email or groups contacts in between (see *Table 24*). Carers classified being in the ‘holding pool’ (13%) had the lowest level of intervention – three to six-monthly telephone or face-to-face contact and contact at other times if initiated if the carer. Eleven per cent of carers were in the intensive category - the highest level of intervention that ANs provide. Intensive support could be monthly or more frequent visits in combination with support group attendance and could include both planned and unplanned contacts and multiagency working.

This analysis suggest that ANs are accessible through different routes and at times when carers need them and thus are able to provide a responsive and flexible service responding to carers’ requirements at different times. By enabling those carers who need the least amount of support to request additional contacts if necessary, ANs empower carers to take the helm as they travel through their caring journey.

Daily activity log data set

Support given by ANs

As outlined in Chapter 2, we undertook a thematic analysis of a sample of the textual data that ANs recorded about their daily work and that was entered in the daily activity log data set. This illustrated the wide variety of tasks that ANs undertook to support carers. We categorised these as:

* assessment and monitoring
* discussion, information provision and advice
* care co-ordination
* emotional support/counselling
* practical support.

ANs also provided education to other services and professionals involved in their clients’ and the wider community’s care and organised and ran carers’ groups. These latter two roles are not discussed here because no detail was provided in the data set to explain what this entailed.

Assessment and monitoring

As the range of data listed in *Table 8* shows, ANs formally assessed carers, their needs for support and the risks they might be experiencing. The textual data from the daily activity log showed that, as appropriate, they also undertook assessments of the person with dementia, such as the Mini Mental State Examination (MMSE), to help in planning and providing support to the carer. In addition to these more formal assessments, ANs monitored carers’ mood and mental health during contacts, so that input could be adapted to respond to carers’ changing needs. One of the key assessments that ANs undertook was risk assessment which we analyse later in the chapter.

Discussion, information provision and advice

One of the central roles that ANs played was spending time with carers, giving them the opportunity to discuss their practical concerns and fears and gain confidence. By drawing on their expertise about dementia to provide relevant and timely information and advice, the data indicated that ANs talked with carers about managing the person with dementia’s behaviour, including safety and changing needs, addressed fears about the future, provided advice about coping strategies, and identified services that might help in caring for the person with dementia and/or supporting the carer.

Care co-ordination

ANs made and ‘chased-up’ referrals to other services on carers’ behalf and also facilitated carers’ ability to lead referrals themselves by providing relevant forms. This helped provide carers and people with dementia with timely access to services. The data indicated that they provided a conduit for communication between the carer/person with dementia and services, providing updates to both sides on progress with referrals and care management decisions, including transitions between different care settings. ANs also took a lead role in co-ordinating care; they liaised with, for example, health, social care, and benefit services, the local authority and community police services. An interesting part of their role was liaison with community policing to implement strategies to minimise risks that people with dementia might face, for example opening the door to untrustworthy people. The work of the police service in relation to dementia is not well explored in the existing literature on dementia care,56 but could serve to reduce both risk to the person with dementia and anxiety to the carer.

Emotional support and counselling

The main way that ANs supported carers emotionally was to spend time listening to them. Their emotional support focussed on helping carers to see that it was beneficial to care for themselves as well as the person with dementia, encouraging them to have confidence in their ability as a carer and being there when carers needed reassurance or guidance about how to deal with a new situation. Their expertise about dementia and the symptoms that might occur meant that ANs were able to reassure carers about behaviour that the person with dementia was displaying and about the future and the services that would be able to support them. They could also help carers to appreciate that respite care for the person with dementia could be beneficial for both of them.

Practical support

ANs also provided practical support to make caring more manageable. Alongside helping carers to understand and complete benefit forms, apply for voucher schemes, and register with their GP as a carer, ANs also helped by visiting the person with dementia when in respite, so carers could have a proper break and be reassured that the person would be visited. Some ANs also helped by collecting and delivering medications and continence aids and taking medical equipment to respite facilities.

These data showed the variety of roles ANs adopted including providing support for people with dementia themselves, to help support their client in their caring role.

Risk screening data set

The sample of data reviewed in the risk assessment dataset showed that up to 40 per cent of dyads were judged to be at some form of risk. Risks could be related to:

* health conditions - such as mobility, sensory impairments, medical conditions - that could increase the risk of falling, infection, constipation and pressure ulcers;
* abuse of the person with dementia, including physical, psychological, financial, sexual, social and verbal abuse;
* intentional or accidental self-harm in terms of dietary intake, alcohol use, wandering, suicidal ideation and refusing care;
* the person with dementia harming others physically, verbally or psychologically. Some carers also expressed concern to ANs about the person with dementia’s sexualised behaviour to strangers, and about their reluctance to give up driving, thus putting other people at risk.

AN records indicated that AN’s advised carers about both minimising the risk of these problems occurring and the impact of the risks on themselves and the person with dementia. ANs also worked with other agencies, such as social service safeguarding teams, police and other health care providers, to minimise risks where appropriate.

Referral data set

Referral data described which services referred the carer to AN services and to what services carers and/or people with dementia were referred. A wide variety of professionals and services, as well as family members, referred carers to AN services. Over a third of referrals came from mental health services, including psychiatrists, community psychiatric nurses and memory clinics (see *Table 25*). However, almost one-fifth of clients self-referred to the service.

ANs referred clients onto other services for particular support, including to social services, occupational therapy and day care services. In their efforts to support the carer, ANs also sometimes referred the person with dementia to other services, including other health care professionals, such as physiotherapists and district nurses, social services, and specialist psychiatric support, including consultant psychiatrists and community psychiatric nurses. It is not possible to be sure from the administrative data whether this referral represented the first contact carers and the person with dementia had with these services or if they were ongoing/previous clients of the service and the AN was making a referral for review or a re-referral. As the next section shows, very few dyads were not using *any* services.

Agencies involved in the case data set

ANs recorded the type of services that were involved with the carer and the person with dementia at the point that they were referred to the AN service. As *Table 26* shows, most dyads received support from at least one service (98%). However, the majority of these (64%) received support from just one service and very few receiving input from five or more services (1%). The range of services that dyads were using when they were referred into the AN service is shown in *Table 27*. Overall, dyads were most likely to use social services, mental health services for older people and community mental health teams. Those dyads who reported using only one service were most likely to be receiving support from social services (43%), mental health services for older people (15%) and community mental health teams (12%) (see *Table 28*).

Other people involved data set

On admission to the AN service, ANs recorded any family members, friends or neighbours who were ‘involved’ in the case but who were not clients of the AN service in their own right. Most carers (98.9%) reported having some support from at least one other family member or friend (see *Table 29*).

From analysis of the ‘cases’ dataset, we know that the majority of primary carers were spouses (44%) or adult children (33%). Given this, it is unsurprising that a large majority of the other people reported as ‘involved’ were adult children (84%) (see *Table 30*). As *Table 31* shows, this pattern was similar when there was only one other person involved.

Needs assessment data set

Descriptive data from the needs assessment are in *Tables 32-33* in Appendix 1, while results of the analysis of variance between the three time-points per question are shown in *Tables 34-35*. Only significant results of analysis of variance, after Bonferroni adjustment, are reported in this section. Analysis showed that responses to 11 questions in the legacy needs assessment and 12 questions in the current needs assessment changed significantly at some point across the first three assessments.

For the first occurrence of this – the second question on the legacy assessment – a fully worked example reporting all the relevant statistics is presented. However, to avoid repeating data that can be found in *Tables 34 and 35*, the remainder are simply summarised in Tables 1 and 2 below.

The Friedman test showed that there was a significant difference between responses to the question about the mental health of the person with dementia across the three time points on the legacy assessment (χ2 = 28.828, df =2, p = <0.001). The post hoc tests (Wilcoxon Signed-Rank tests) showed there was no significant difference between the second and third assessments (Z=-0.093, p=0.926) (significance was set at the higher Bonferroni adjusted level of <0.017) but there was between the first and second assessment (Z=-4.354, p=<0.001) and the first and third assessment (Z=-4.725, p=<0.001). This reflects a reduction in reported need in relation to mental health of people with dementia at the second and third assessment undertaken by ANs (see *Table 34*)). The same topic on the current needs assessment also showed significant difference in the reported level of need (p=0.016) between assessment one and assessment three (see *Table 35*).

Table 1: Summary of results of comparison of outcomes over three time points: legacy needs assessment

|  |  |  |  |
| --- | --- | --- | --- |
| **Outcome domain** | **Significant difference between time 1 and time 2** | **Significant difference between time 2 and time 3** | **Significant difference between time 1 and time 3** |
| 1. Physical health - person with dementia | No | No | No |
| 2. Mental health - person with dementia | Yes | No | Yes |
| 3. Physical health - carer | No | No | No |
| 4. Mental health - carer | No | No | No |
| 5. Medication management | No | Yes | Yes |
| 6. Insight into dementia | Yes | Yes | Yes |
| 7. Dementia symptoms | Yes | Yes | Yes |
| 8. Coping with behaviour/symptoms | Yes | Yes | Yes |
| 9. Communication – professionals and carer | No | No | No |
| 10. Environment/accommodation | No | No | No |
| 11. Financial issues | Yes | Yes | Yes |
| 12. Practical aids | No | No | No |
| 13. Practical support | Yes | No | No |
| 14. Informal support | Yes | No | Yes |
| 15. Adjustment to loss | No | No | No |
| 16. Balancing needs | No | No | No |
| 17. Time for self | No | No | Yes |
| 18 Time for self – longer respite | Yes | Yes | Yes |
| 19. Looking to the future | Yes | No | Yes |

The key change of interest is, of course, that between time one and time three, indicating that change has occurred and has been sustained. Such change was reported in the legacy needs assessment in relation to the mental health of the person with dementia, medication management, carers’ insight into dementia, dementia symptoms, carers’ ability to cope with dementia behaviour and symptoms, financial issues, informal support, carers’ time for self both in the short and longer term, and looking to the future (*Table 8*). In almost all cases, positive progress was evident through all three time points.

Table 2: Summary of results of comparison of outcomes over three time points: current needs assessment

|  |  |  |  |
| --- | --- | --- | --- |
| **Outcome domain** | **Significant difference between time 1 and time 2** | **Significant change between time 2 and  time 3** | **Significant change between time 1 and  time 3** |
| 1. Physical health - person with dementia | No | No | Yes |
| 2. Mental health - person with dementia | No | No | Yes |
| 3. Physical health - carer | Yes | No | Yes |
| 4. Mental health - carer | Yes | No | Yes |
| 5. Medication management | No | No | Yes |
| 6. Insight into dementia | Yes | Yes | Yes |
| 7. Coping with behaviour/symptoms | Yes | Yes | Yes |
| 8. Communication – professionals and carer | - | - | - |
| 9. Environment/accommodation | No | No | Yes |
| 10. Financial issues | - | - | - |
| 11. Practical aids | - | - | - |
| 12. Practical support | No | No | Yes |
| 13. Informal support | Yes | No | Yes |
| 14. Adjustment to loss | No | No | No |
| 15. Balancing needs | Yes | Yes | Yes |
| 16. Time for self | No | No | Yes |
| 17. Looking to the future | - | - | - |
| 18. Risk | - | - | - |

The result of the comparison across the three time points in the current needs assessment data was similar, but with less consistent patterns of change over time. Significant change was observed between the first and third assessments in both physical and mental health of the person with dementia, physical and mental health of the carer, mediation management, insight into dementia, coping with behaviour and dementia symptoms, communication between the carer and professionals, environment and accommodation, practical support, informal support, balancing needs and time for the carer.

All but one of these significant differences reflect a reduction in reported need in the topic asked about. The only difference that appears to indicate that needs increased over the three assessments was related to carers relinquishing their role as primary carers (Q.19 on the legacy needs assessment). The question on a similar topic in the current assessment did not show any significant difference. The apparent increase in need to support carers to relinquish their caring role is, perhaps, unsurprising if this relates to people’s situation becoming more complex and having to consider alternative care arrangements over time.

Comparison of the AN administrative cases with AN carer survey

Having the AN administrative data allowed us to see how successful our survey of carers (see *Chapter 5*) had been in sampling carers who were similar to all AN carers. We therefore compared the sample of AN carers who completed the survey with carers included in the AN database. The carers who responded to the survey were similar to carers included in Dementia UK’s AN administrative database on several key demographic characteristics. However, carers responding to the survey were more likely to be caring for a spouse/partner and less likely to be caring for a parent than carers included in the Dementia UK database. Related to these differences, the people that our survey carers were supporting were older and more likely to be living at home with their main carer than were all AN carers (see Figures 1 and 2 below).

Figure 1: Comparison of carer demographic data in the Dementia UK AN data set and AN carers in our survey

Figure 2: Comparison of demographic data about the person with dementia between the Dementia UK data and survey data

Several factors might explain these differences, for example, that carers self-selected into the survey, while Dementia UK’s database held administrative information about all their clients. Differences in service organisation and delivery in the localities in which carers were recruited might also contribute to these differences. For example, if carers lived in a locality with poor access to residential/care homes or, indeed, greater access to support for caring at home, this could account for more people with dementia being cared for at home well into older age.

Conclusions

Analysis of this Dementia UK database showed that, although wider family members and friends and neighbours will help, the person who was most often the main carer to people with dementia on the AN caseload was their spouse or partner. This explains why almost a third of carers included on the database were over 75 and were caring for someone over 75 years of age. The finding suggests that ANs are successfully targeting the potentially most vulnerable cases This should be of interest to service commissioners, as carers of this age are more likely to have age-related conditions that could be affected by the demands of caring and that could in themselves make their role as a carer fragile.

The needs assessment data indicated that, on average, the needs of carers being supported by ANs reduced over time. We are not able definitively to link reduction in need over time to the input of the ANs, because we do not have direct information about AN input in response to the needs identified and/or the impact of input on carers’ continued level of need. However, as we know from analysis of textual data, ANs do provide the types of support that would likely help to reduce carers’ level of need over time or at least to maintain these where situations become more complex. Despite this, given that we do not know what else might have change in carers’ circumstances, it may be just as feasible to argue that reduction in need is related to other change. Multi-variate analysis of the data which are now fully prepared for this type of analysis may allow us to explore this further in the future.

Cases are triaged to help ANs manage their caseloads and their tiered approach to service provision, whereby those in most need receive greater levels of input, reflects this. This approach enables ANs to be flexible in terms of the types of support they provide and responsive in terms of method and regularity of access. We argue that this empowers carers by enabling them to decide when and how to contact ANs and be involved in decisions about the type of support they, and the person they care for, receive as their needs change throughout their caring journey.

Challenges of using administrative data

The four main problems associated with using these types of data – determining availability, receiving the data, merging multiple data sets and understanding what the data really mean57 – were, for the most part, overcome by us working in partnership with Dementia UK as part of this research project. Nonetheless, we still experienced several challenges working with these data.

First, when the project was developed both Dementia UK and the research team were under the impression that all AN services entered data into the central database. However, once Dementia UK started to prepare the database for research purposes (as outlined in *Chapter 2*), it became apparent that some services had stopped entering information into it. Rather, these AN services were storing information locally on the paper or electronic systems in the organisation in which they were based/commissioned. We are not aware of any systematic bias between services using this database and those who are not, but it is something to be aware of in interpreting our results.

Understanding and transforming the administrative data into a format appropriate for research was extremely time-consuming and required several face-to-face and telephone meetings in addition to many email communications. Understanding the focus and meaning of all variables, questions, response options and pre-coded data was essential and could require several email/telephone communications each day until a thorough understanding was gained. Some of the data sets and/or variables were particularly troublesome. Examples of this are the date variables, as outlined earlier, which were in several formats within the data sets we received. Indeed, in data sets with more than one date field, formats could differ within the data set. This made transferring data to SPSS for analysis challenging and required many attempts before formats were consistent.

There was no information about the factors that triggered reassessment of needs. As ANs provide support tailored to individuals’ needs, it was perhaps unsurprising that times between needs assessments were not consistent between carers. Did ANs complete needs assessments only when they thought carers’ needs changed? While this approach would clearly be right for clinical and service management, it can be problematic for research that seeks to understand how people’s needs change over time.

Further, as the needs assessment tools used by ANs are not standardised measures that have undergone cognitive and/or reliability testing, we do not know whether ANs are interpreting questions and response options similarly over time or between themselves. Nor do we know about the mode of completion. Do ANs complete the assessment with carers or complete it on return to the office? By their nature, these types of service administrative data reflect how a service works and so can limit the analysis we can undertake. Despite this, we have been able to provide a summary of the type of clients that Dementia UK’s Admiral Nursing service supported, an overview of the interventions that ANs offer and an estimate of the changes in dyads’ needs over time.

Chapter 4 The outcomes of carer support and development of the carer questionnaire (Work Package 2)

Introduction

The aims of Work Package 2 were to establish a data collection framework to be used in the survey of carers reported in Chapter 5 (Objective 2). There were two elements to the package:

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, for both our survey in WP3 and use in service settings (WP5).

We began with qualitative research with carers to learn about the outcomes that they felt were influenced by the quality and level of support they received, either from Admiral Nursing (in areas with this service) or from the alternative support available (in areas without Admiral Nursing). This included investigating the outcomes of not receiving support, or receiving poor support. From our analysis, outcome areas were identified and mapped onto pre-existing standardised outcome measures and the selected measures incorporated into a data collection framework. The in-depth exploration of the acceptability and feasibility of the framework was an essential element of this WP, given the acknowledged challenges of evaluative research in dementia care.

Sample

We were aiming for a total sample of around 30 carers recruited from a wide range of characteristics and circumstances. We identified two areas with an Admiral Nursing service (AN areas) and two areas without (non-AN areas). The intention was to recruit seven or eight carers from each area through Admiral Nursing (in the AN areas) and TiDE,a national network of carers of people with dementia, in the non-AN areas. These carers would be invited to take part in a focus group or individual interview either by telephone or face-to-face in their home or another place of their choosing. We offered to pay travel expenses and the costs of substitute support for the person with dementia where this would help the carer to participate. All documents and processes were reviewed and approved by the Health Research Authority (HRA) London - Chelsea Research Ethics Committee (IRAS ID 195413 see documentation here: [https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/1415407/#/](https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/1415407/%23/)).

Methods

We talked to all carers once, and a sub-sample twice. At the initial interviews and focus groups, we used in-depth, qualitative methods to explore with carers the outcomes they had or would like to experience from specialist dementia services focussed on carers, as well as the outcomes of not receiving this or other support. The sessions were structured around established types of carer support58, such as emotional support and financial support as potential ‘inputs’ (see topic guides in documentation here: [https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/1415407/#/](https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/1415407/%23/)). Carers were asked to think about the outcomes of receiving this support, and what happened when they did not get these types of support or the support they received was poor quality. At the end of each focus group or interview, we fed back the learning from the discussion and worked with participants to agree the outcomes they would like us to take forward to the next stage of work.

Focus groups and interviews were audio-recorded (with participants’ permission) and these recordings were reviewed and analysed to finalise the key outcomes. As the data provided by carers were very rich, a portion of the recordings were fully transcribed to allow more in-depth analysis. We used the Framework principles of case and theme-based analysis, data reduction through summarisation and synthesis to do this.43 We then identified robust, standardised measures of relevant carer outcomes and mapped these onto the main outcomes that carers had identified to see which were the best fit.

The second time we spoke to carers was to explore their understanding of the draft questionnaire and its acceptability to them. We carried out in-depth cognitive interviews with a sub-sample of the carers and also collected feedback from our virtual carer advisers and steering group. Carers were asked about the feasibility of completing a questionnaire of this type electronically and in hard copy. We also discussed with them the pros and cons of self-completion vs face-to-face or telephone interviews.

The questionnaire had a dual purpose: first, to collect data from carers of people with dementia in areas with and without Admiral Nursing for WP3, and secondly, to provide the basis for a draft data collection framework for Admiral Nursing to use routinely (see WP5, reported in Appendix 5). The survey was developed within, and administered using *Qualtrics* (<http://www.qualtrics.com>). This is sophisticated, internet-based survey software that enables the user to produce high-quality on-line questionnaires. In addition to outcome measures (the identification of which is set out in detail in the Findings section of this chapter) the survey questionnaire included questions on the demographic and socioeconomic characteristics of the carer and the person with dementia, as well as resource and time use questions associated with caring.

Recruitment

Carers were recruited through Admiral Nursing services in the two AN areas and through alternative routes in the two non-AN areas. Our original intention had been to recruit carers in the non-AN sites through TiDE alone, but this proved challenging. In addition to TiDE we attempted to recruit in these areas through:

* Carers Centres, forums and trusts
* Dementia Action Alliances
* Dementia specific and older people’s voluntary sector organisations
* Local carer led peer support groups (most successful)
* Local papers (unsuccessful)
* Twitter (unsuccessful)
* Facebook (unsuccessful).

Focus groups were smaller than planned (mainly because of carers’ availability) and a larger than expected number of carers opted to be interviewed individually. Across the four sites we carried out:

* Six small focus groups (each had 2-5 participants)
* Thirteen individual interviews.

All of the interviews were conducted by the same researcher, but other members of the team were present at the larger focus groups. In total we spoke to 35 carers, 18 from AN areas and 17 in non-AN areas, as follows:

Eighteen carers from Admiral Nursing sites:

Ratio female/male = 10 female, 8 male

Ratio spouses/adult children = 12 spouses, 6 adult children

Ratio current/former carers = 16 current, 2 former

Six carers were from AN Site 1:

* One focus group with 3 participants
* Three individual interviews.

Twelve carers were from AN Site 2:

* + One focus group with 4 participants
  + One focus group with 2 participants
  + Six individual interviews (2 together).

Seventeen carers from areas without Admiral Nursing:

Ratio female/male = 9 female, 8 male

Ratio spouses/adult children = 10 spouses, 7 adult children

Ratio current/former carers = 11 current, 6 former

Ten carers were from non-AN Site 1:

* One focus group with 5 participants
* One focus group 3 participants
* Two individual interviews.

Seven carers were from non-AN Site 2:

* + One focus group with 5 participants
  + Two individual interviews.

Findings

The outcomes of support identified by carers could be grouped into three broad areas as follows:

1. Confidence in caring (carer self-efficacy)
2. Carer quality of life
3. Carer health (mental and physical).

Once the analysis to identify outcomes was complete, we undertook a mapping exercise to ascertain which tools could most accurately measure these outcomes when self-completed by carers of people with dementia. As is set out below, a shortlist of quality of life measures was mapped onto the findings, leading us to select ASCOT Carer as the most appropriate tool to measure this outcome. For mental and physical health, we chose EQ-5D-5L as a measure that would give us data that could be compared with other studies and used in health economic analysis. Confidence in caring is a less commonly measured outcome, but after some searching we identified the Caregiver Self-Efficacy for Managing Dementia (SEMD) scale47 which mapped well onto our analysis.

The remainder of this chapter sets out the key themes from the qualitative data and explains in more detail how these led us to choose the three outcome measures used in our survey.

1. The impact of carer support on confidence in caregiving (or carer self-efficacy):

Participants were asked what they thought the outcomes of good support were for them and, conversely, what happened when support was poor, or not available. Carers in both the AN and non-AN areas talked about the difficulties they faced in caring and how hard it could be to ‘cope’, access support and plan for the future. Those who had experienced good support described how this could give them the confidence to continue caring in spite of the difficulties they faced. Notably, when participants with an Admiral Nurse were asked to sum up the impact of having this service, confidence was a consistent theme:

Interviewer: *What ultimately … is the result or outcome of you having this Admiral Nurse?*

AN2C7: *Um, I think confidence is a lot of it, confidence that I can get help, confidence that I'm not alone, there's someone out there to help, who fully understands and who is trained in the specific illness.* [From interview in AN area 2]

And from Focus Group 1 in AN area 1:

*I think* [wife] *and I would have been where we are now* [with wife going into a care home] *two or three years ago, had it not been for* [local charity] *and the Admiral Nurse...I wouldn't have felt I had the support to do it* [carry on caring for wife at home]*, I wouldn’t feel I had the confidence to do it….*

Responses relating to carer confidence mapped well onto the two domains of carer self-efficacy used by Fortinsky *et al*. in their Caregiver Self-Efficacy for Managing Dementia scale.47 This is a 10-item scale, which loads onto two separate domains – SXEFF which describes efficacy in relation to managing dementia and SERVEFF which describes efficacy in relation to accessing and using services (see Box 1 below).

Box 1: Caregiver Self-Efficacy for Managing Dementia scale, Fortinsky *et al*. 2002

**Domain 1: Self-efficacy for symptom management**   
(that is, carers’ degree of certainty about how to manage dementia symptoms)

How certain are you right now that you can:

1. Handle any problems your relative has, like memory loss, wandering, or behavior problems?
2. Handle any problems that might come up in the future with your relative’s care?
3. Deal with the frustrations of caring for your relative?
4. Do something to keep your relative as independent as possible?
5. Get answers to all your questions about your relative’s problems?

**Domain 2: Self-efficacy for community support service use**   
(that is, carers’ degree of certainty about how to use community support services)

How certain are you right now that you can:

1. Care for your relative without help from organizations or agencies that provide services?
2. Find organizations or agencies in the community that provide services to help you care for your relative?
3. Get answers to all of your questions about these services?
4. Arrange for these services yourself?
5. Find ways to pay for these services?

Carer self-efficacy domain 1: Self-efficacy for symptom management

Handling the symptoms of dementia, especially distressing behaviour and, to a lesser extent, memory loss and ‘wandering’, were common themes that appeared to influence carers’ confidence in their ability to ‘cope’ and continue caregiving [Item 1]. Confidence to handle these symptoms appeared to be related to the support the carer had access to. A participant who felt she received little support, for example, said:

*I just think I feel lost, because we've got a situation and I think I don't know how to handle this... At times I just feel I just don't know where to turn and what to do... At times I feel as if I'm sinking...* [From interview with NAN2C6 in non-AN area 2]

This carer’s mother had regular (six-monthly) appointments with the memory service which both mother and daughter attended, and she also had contact with social services and her GP, but still felt she could not get satisfactory answers to her questions about how to handle her mother’s worsening symptoms. Primarily she felt this was because of a lack of continuity in the professionals she came into contact with, which meant that no-one with expertise in dementia had got to know her family or understood their needs:

*… it'd be nice for* [there to be] *somebody that, once you are diagnosed, they know you,* [and] *the person with it, and come and see you … and as the illness progresses and deteriorates, you have this support that “Have you tried this?” or “Have you tried that*?” [NAN2C6]

This was exactly the sort of ongoing, personalised support that carers who did sound confident in their ability to handle situations said they received. Primarily, it was carers in the Admiral Nursing group who said they received this sort of support and, indeed, some described a difference between the time before they had had an Admiral Nurse, when they were struggling, and the time after when they felt better equipped to cope:

*I was off work with stress because I just really did not know what to do… I contacted them* [Admiral Nurses] *and I have to say that my life changed the minute I spoke to them, and the minute they came through the door. They basically took me by the hand and said "Look, we need to do this, we need to do this...* [From Focus Group 1 in AN area 2]

*November and December were horrendous ...I don't think I could have done another 6 months of that without any help and support... Now, I do feel he's getting worse, but I do feel I can cope, and I now have a vision for the future that I know how it will go* [From Focus Group 2 in AN area 2]

Facing the future was a particularly important issue for the current carers of people with dementia in our sample, caring, as they were, for people with a deteriorating condition. Again, the division between those with Admiral Nurses, who could answer carers’ questions about how the illness might progress and, crucially, what was happening to their loved ones at the moment, was noticeable. Those with an Admiral Nurse had someone who could answer their questions [Item 5] whereas it was common for those without to feel lost at sea:

*...once the illness takes over ... the support isn't always there, I've been trying for long enough to have the psychiatrist check my wife's illness and tell me, because I, I actually don't really know what stage she's in and I seem to be having quite a bit of problem of getting the doctor to look at my wife, to be honest.* [From interview with NAN1C1 in non-AN area 1]

Some of the carers in the non-AN groups had accessed training and advice through third sector agencies, such as the Alzheimer's Society, who run a Caring and Coping course which can help prepare carers for the things to come. Some read books or used ‘Talking Point’, the Alzheimer’s Society online forum, to get advice from other carers. Indeed, peer support, whether elicited online or face-to-face, was a valued source of information that carers in both groups felt they could trust. However, there was agreement from those in the AN groups that the Admiral Nurse was their first port of call when a new situation arose or they were concerned about how things would progress [Item 2]:

*P1: The thing about the Admiral Nurses is … my mum would do something really random and I'd think "Is this part of it? Is this part of the disease, is this how it works?" They always, always had time to speak to me.*

*P2: They always know what to say.*

*P1: They just calm you down, and explain in a fashion that you understand.*[From Focus Group 1 in AN area 2]

Item 3 in Domain 1 of the SEMD asks carers about their confidence in their ability to deal with ‘the frustrations of caring’ they experience in caring for the person with dementia. This is an especially relevant outcome in areas, such as dementia care where some situations may not be resolvable (given current medical knowledge), but their impact on the carer could be altered. The outcome is therefore not derived by changing a situation but by learning to deal with its frustrations. Much of the training run by Admiral Nurses focusses on supporting carers to find ways to deal with the frustrations in their lives, which could involve reframing situations (helping carers to view the same situation differently) or making practical suggestions about how to handle or respond to situations. An example given was a carer facing a ‘battle’ every night with her mother over getting ready for bed. The Admiral Nurse reframed the situation, asking if it mattered whether her mum changed her clothes at night, as long as she was happy and healthy. As the carer explained, the Admiral Nurses taught her to '..*manage the things that you can, but if you can't, leave it*'. Another carer agreed: ‘…*it is acceptance, that what you're doing is ok*' [from Focus Group 1 in AN area 2].

The final item under Domain 1 is Item 4, which relates to carers’ confidence in their ability to do something to keep their relative as independent as possible. This was less of a prominent theme in our interviews and focus groups, possibly because our topic guides were designed to orientate participants to tell us about *their* needs and the outcomes for them, as carers, of receiving or not receiving support. As such we cannot speculate on the role or otherwise of Admiral Nurses or other support providers in influencing carers’ confidence in their ability to keep their relative independent.

Domain 2: Self-efficacy for community support service use

The first item under this second domain, Item 6, relates to carers’ confidence in their ability to care for their relative *without help* from organisations or agencies that provide services. This item sits awkwardly with our aim of understanding the impact of carer support services on carer outcomes, as a low score on this item would imply a greater need for support in situations where none was available, and a high score would indicate support possibly was not needed, but neither would tell us how well a service is meeting carers’ needs currently. Carers with an Admiral Nurse, for example, told us that without their Admiral Nurse they would be ‘struggling’, and some went as far as to say that they did not think they would have been able to carry on caring without his or her support:

…*I honestly don't believe that we would be able to manage them* [both parents need care] *in their own homes without that support. They would have definitely been in a nursing home by now, and neither of them want that...* [From Focus Group 2 in Admiral Nursing Area 2]

This participant was making a positive point here, saying that, because she received such good support, she was able to support her parents to stay at home, which was their wish. However, as Item 6 asks how certain she is that she could care for them *without* help, presumably she would enter a low score (indicating a poor outcome) here. Item 9 similarly asks about carers’ confidence in their ability to arrange for services themselves, implying they would be doing this without support, which does not fit neatly with a questionnaire evaluating support.

At first glance, Item 7 also seems a little circular, since it asks how confident carers are in their ability to access support. Participants in a study evaluating a service would, by virtue of them being in either the intervention or control group, already have access or otherwise to the service in question. However, if we take this question to refer to carers’ ability to access *other* or additional services, then it may indeed be relevant. One of the stated aims of Admiral Nursing is to ‘*join up different parts of the health and social care system*’23 and other professionals, such as Dementia Advisers and social workers, also aim to link carers up with the services they need. Participants felt that a good service would help them to access further support as and when they needed it and take the pressure off them to organise those services themselves. Certainly this was not always forthcoming, and simply being in contact with a professional in the system did not guarantee easy access to other services:

*… I've had four and a half years of looking after* [wife] *without one single day off not having to think about it... so I talked to* [CPN] *about doing this...a sanity break... she said "oh, I don't know much about that, it's social services".*   
[From Focus Group 1 in non-AN area 2]

This participant was eventually given the name of a respite provider and advised to look this up himself on the internet. His experience contrasted starkly with the intense support provided by an Admiral Nurse and social worker described below, where the carer needed support not only to access help, but also to accept it:

… [the AN] *was suggesting… a home visit so that I could get out of the house… not pushing but, you know, sort of encouraging me in the right direction and, …if only I’d taken that on board a little bit sooner, but again, he suggested day centres as well , and alongside the social worker; he knew* [my husband’s] *interests …and together they found this fantastic day centre for* [husband] *to attend... Again, I didn’t, I didn’t give in soon enough (laughs) not realising that it was not just for me ... but also for* [husband].[From interview with carer in AN area 2: AN2C1]

There was general agreement from the carers we spoke to that signposting alone was often not enough to help them access the help they needed. Indeed, knowing there were more agencies to contact, more numbers to look up and more forms to fill in, could add to the stresses they were experiencing. Not knowing the quality or track record of a service provider could similarly be a source of anxiety for carers, and where Admiral Nurses were able to vouch for the quality of a service, or look into it for the carer, this was highly valued. This ties in with Item 8 (Domain 2) which asks how confident the carer is that they will get answers to all their questions about the services they require. In the example given above, the Admiral Nurse actually visited the day centre when her husband was there and fed back to the carer on his progress, reassuring her that he was happy there, enabling her to relax.

The final item under Domain 2 of the self-efficacy scale relates to carers’ confidence in their ability to find ways to pay for services. In the UK, healthcare is delivered free at the point of use through the NHS. However, the majority of services required by carers of people with dementia are in fact classed as social care, the funding for which is subject to stringent means-testing. Many people with dementia and/or their carers contribute financially towards the services they receive, and carers’ confidence in their ability to find ways to pay for services may well be linked to the quality of the support they receive from those who are tasked with helping them. A number of participants reported receiving useful information about finances and support to access benefits from voluntary sector organisations, such as Age UK. The most significant role for Admiral Nurses in this respect appeared to be advocacy, particularly where carers were attempting to access continuing care funding. As this carer explained, in these negotiations Admiral Nurses are able to speak on behalf of families with some authority (which the families themselves felt they lacked) and without a vested interest in gatekeeping funds:

*…because social services and the CCG* [health service commissioners] *are trying to downplay it* [the person’s needs]*, whereas if they actually do it properly they're going to end up paying, so they're trying to avoid that, whereas the Admiral Nurses have got the authority to say "No, I have seen this, I know that this is happening." and they can support you*. [From Focus Group 1 in AN area 2]

Table 3 shows the degree of fit between the outcomes identified through our focus groups and interviews with carers, and the items on the Caregiver Self-Efficacy for Managing Dementia scale.47

Table 3: Degree of fit between outcomes identified by carers and the items on the Caregiver Self-Efficacy for Managing Dementia Scale

|  |  |  |
| --- | --- | --- |
| **Domain 1: Self-efficacy for symptom management** | | |
| **Item no.** | **Question:** How certain are you right now that you can: | **Degree of Fit** |
| **1.** | Handle any problems your relative has, like memory loss, wandering, or behaviour problems | Good |
| **2.** | Handle any problems that might come up in the future with your relative’s care? | Good |
| **3.** | Deal with the frustrations of caring for your relative? | Good |
| **4.** | Do something to keep your relative as independent as possible? | Unclear |
| **5.** | Get answers to all your questions about your relative’s problems? | Good |
| **Domain 2: Self-efficacy for community support service use** | | |
| **Item no.** | **Question:** How certain are you right now that you can: | **Degree of Fit** |
| **6.** | Care for your relative without help from organizations or agencies that provide services? | Poor |
| **7.** | Find organizations or agencies in the community that provide services to help you care for your relative? | Good |
| **8.** | Get answers to all of your questions about these services? | Good |
| **9.** | Arrange for these services yourself? | Poor |
| **10.** | Find ways to pay for these services? | Good |

While the self-efficacy measure was a good fit for much of the data on carer outcomes affected by support, it by no-means covered all of the identified themes. A considerable chunk of these fitted more squarely with quality of life, and it is this area of outcomes that we address next.

2. **The impact of carer support on quality of life:**

We mapped the outcomes identified by carers against a shortlist of six validated measures of quality of life:

* ASCOT-Carer46
* Carer Experience Scale (CES)59
* Carer-QoL 7D60
* ICEpop CAPability measures for Older people (ICECAP-O)61
* ICEpop CAPability measures for Adults (ICECAP-A)62
* ASCOT Quality of Life (QoL)63.

Table 4 shows how well the items in each of the shortlisted measures fit with the outcomes carers told us were influenced by support (or the absence of support).

Table 4: Degree of fit between outcomes identified by carers and the items on each of the shortlisted quality of life measures

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **ASCOT-Carer** | **CES** | **Carer-Qol 7D** | **ICECAP-O** | **ICECAP-A** | **ASCOT QoL** |
| Q1 Occupation (spending time as you want) – **good fit** | Q1 Activities outside caring - **good fit** | Q1 Fulfilment from caregiving - **not a prominent theme** | Q1 Love and friendship - **good fit** | Q1 Feeling settled and secure – **not a prominent theme** | Q1 Control over daily life - **partial fit** |
| Q2 Control over daily life - **partial fit** | Q2 Support from family and friends - **partial fit** | Q2 Relational problems with the person cared for – **not a prominent theme** | Q2 Thinking about future - **partial fit** | Q2 Love, friendship and support - **good fit** | Q2 Personal cleanliness and comfort – **not a prominent theme** |
| Q3 Self-care (looking after yourself) – **partial fit** | Q3 Assistance from organisations and the government - **partial fit** | Q3 Mental health problems - **good fit** | Q3 Doing things that make you feel valued (Q3) -**not a prominent theme** | Q3 Being independent - **not a prominent theme** | Q3 Food and drink – **partial fit** |
| Q4 Safety (how safe do you feel) - **partial fit** | Q4 Fulfilment from caring – **not a prominent theme** | Q4 Problems combining daily activities with care – **good fit** | Q4 Enjoyment and pleasure – **good fit** | Q4 Achievement and progress - **partial fit** | Q4 Personal safety **– partial fit** |
| Q5 Social participation (contact with people you like) – **good fit** | Q5 Control over the caring - **not a prominent theme** | Q5 Financial problems - **partial fit** | Q5 Independence - **not a prominent theme**  No more questions | Q5 Enjoyment and pleasure – **good fit**  No more questions | Q5 Social participation – **good fit** |
| Q6 Space and Time (to be yourself) – **good fit** | Q6 Getting on with the person you care for - **not a prominent theme**  No more questions | Q6 Support with lending care (from family and friends) –**partial fit** | Q6 Occupation (spending time as you want) - **good fit** |
| Q7 Encouragement and Support –**good fit**  No more questions | Q7 Physical health problems –**good fit**  No more questions | Q7 Accommodation cleanliness and comfort- **not a prominent theme** |
| Q8 Support (how getting support makes you feel about yourself) - **not a prominent theme** |
| Q9 Dignity (how the way you are treated makes you feel about yourself) - **not a prominent theme** |
| **ASCOT-Carer**  All 7 Qs relevant (4 fully, 3 partially) | **CES**  3/6 Qs relevant (1 fully, 2 partially) | **Carer-Qol 7D**  5/7 Qs relevant (3 fully, 2 partially) | **ICECAP-O**  3/5 Qs relevant (2 fully, 1 partially) | **ICECAP-A**  3/5 Qs relevant (2 fully, 1 partially) | **ASCOT QoL**  5/9 Qs relevant (2 fully, 3 partially) |

On the basis of this mapping, ASCOT Carer was selected as the quality of life measure for use in the survey of carers. The ASCOT measure was used in the study with permission from the University of Kent. A more detailed analysis of the relevance of this measure to the outcomes of support identified by carers is given below.

ASCOT Carer to measure impact of carer on quality of life:

The first question in ASCOT Carer asks to what degree carers are able to spend time doing things that they value or enjoy (including leisure activities, formal employment, voluntary or unpaid work, and caring for others). Question six follows this up, asking carers to think about the amount of space and time they have in their daily life ‘to be yourself’. These were key themes in our data, with most carers reporting that time for themselves was highly restricted. As one carer noted, when he was interrupted by his wife during our interview:

…*that’s what it’s like being a carer ... you know, it’s very difficult to get on with it, any, anything I want to do*… [From interview with AN2C2 in AN area 2]

As dementia progresses, the demands on carers’ time could become all consuming. Carers talked about their loved ones ‘*following me round the house*’ or not being able to leave their side for a minute for safety reasons ‘*for example, she’d take a boiling kettle and pour it over the cooker*…’ [AN1C5]. Under the Care Act (2014)19 social services departments have a responsibility to assess carers’ needs. Resultant care plans may, amongst other things, recommend that carers obtain some respite from caregiving. Options include a paid carer or ‘sitter’ coming into the home to look after the person, or the person with dementia attending a day centre or staying overnight (usually for a week) at a residential care home. However, a number of the carers we spoke to did not feel that the latter options, which required the person with dementia to go somewhere, offered a satisfactory solution, either because the person with dementia would be unsettled in another place, or because the carer did not trust that they would be well cared for there. While carers in both the Admiral Nursing and the non-Admiral Nursing groups expressed these concerns, we heard instances of Admiral Nurses helping to overcome these barriers, either by acclimatising people with dementia to settings and alternative care workers, or by checking in on people while they were at day centres or in care homes, enabling their family carers to relax and engage in some of the activities necessary to maintain their quality of life. These activities can be split into two broad categories, one being social and leisure activities, such as seeing friends or engaging in hobbies, the other being time to undertake ‘jobs’, such as shopping, cleaning and gardening, or even to continue in paid employment. Such time was highly valued. This participant, for example, was helped by two voluntary sector organisations, Age Concern and Crossroads, to have a few hours off a week and remarked:

*It was only two hours, but it's two hours that I had all to myself - yippee! I could go and get my hair cut, I could do anything I liked. It sounds small, but by God I looked forward to that.... You could just kick your heels! ...and it was very relieving.* [From Focus Group 2 in non-AN area 1]

As dementia symptoms progressed, carers’ time for themselves tended to be more and more limited. Some carers from both AN and non-AN areas paid an individual to come into the home regularly (or even to live-in) to provide some of the hands on care that they would otherwise be providing themselves, and this made a considerable difference to their quality of life. Access to funding to pay for replacement care may therefore be a key facilitator in quality of life:

*… none of these things are free... If you've got the money you've got far more choices and you can go “yeah well actually it is costing quite a bit having someone coming in so I can go and do that, but it means I can go and do something normal”, or I know that she's okay on a Tuesday afternoon because I know the befriender's coming round that day. So it's piece of mind. It all costs.* [From Focus Group 1 in non-AN area 1]

Arguably, carers’ time to themselves and ability to spend time as they want could be influenced more by their personal means, or those of the person they care for, than the quality of support they receive from services. However, some did receive benefits or funds through social services to help pay for replacement care, and support to access these funds varied greatly. Moreover, ability to pay for respite or a ‘sitter’ was not the only factor influencing whether a carer accessed replacement care; some described the practical help and encouragement that had helped them to find the right person or provider to deliver this. A service’s awareness of, and emphasis on, the needs of the carer in particular appeared to be important here. As the carers in one of our focus groups explained, the Admiral Nurse *'gives you permission*' to do something for yourself and to enjoy it. Guilt was a common emotion experienced by many of the carers trying to balance their needs with those of the person they cared for and without a service that saw them as the client some felt unable to take advantage of the limited replacement care, day care and respite available to them. Indeed, some former carers talked of still experiencing guilt long after their loved ones had passed away. Conversely, other carers described a process whereby, with the right support, they had been able to ‘step back’ and allow others to take on some of their caring responsibilities, for example, allowing them to go on holiday.

Two further items in ASCOT Carer are linked to the amount of time carers have for themselves: how much contact they have with people they like (Q.5); and how well they are able to look after themselves (Q.3). Unfortunately, instances where carers felt socially isolated were abundant in our data:

…*it’s like you’re in this little bubble that he doesn’t want anybody* [else] *to be in …* [and ] *I cannot make a choice to go out anywhere because I’ve got always* [husband] *to consider*...’ [From interview with NAN2C7 in non-AN area 2]

P1: …*you become isolated with that person you're looking after, being completely isolated …*

P2: *For me that's the biggest thing.*..

P3: *…that can lead to carer breakdown so quickly...* [From Focus Group 1 in non-AN area 2]

Some carers recounted experiences of friends, and even family, dropping away as the person’s symptoms grew more pronounced. Others said friends and family still called but carers did not want to burden them with the realities of their situation so had little to talk about. Still others said that the person with dementia found it hard to accept carers seeing friends, or behaved in other ways that made socialising difficult. Carers’ social groups and dementia specific activities, such as Singing for the Brain, were therefore highly valued as opportunities for social contact and peer support.

Similarly, a number of carers felt that their caregiving had impacted on their ability to look after themselves, either because they did not have the time (for example to exercise or cook healthy meals) or more directly because the necessities of caregiving directly affected their ability to sleep or protect their health:

… *I became a diabetic. And they said “you'd have always become one, but you're doing it seven years earlier because you're neglecting yourself”*… [From Focus Group 2 in non-AN area 1]

Some carers said they had been subject to violence, as the person they cared for could be aggressive, and others were concerned they might be injured in the course of caring, for example, when lifting the person with dementia in and out of the bath. Both of these latter concerns could be captured by Q.4 asking carers how safe they feel, and both could arguably be influenced by the support carers receive. A carer from Focus Group 1 in AN area 2, for example, talked about her husband being violent towards her and the Admiral Nurse supporting her through the process of realising that, for her safety, the situation could not go on as it had: *‘…she was there with me every step of the way, which nobody else would be*'.

Q.2 in ASCOT Carer asks how much control carers feel they have over their daily lives. In the main, the carers we spoke to felt as if they had very little control, in terms of either how they spent their time now, or how things might develop in the future. To some extent this may be the nature of caring for someone with a degenerative disease that can be unpredictable, but services did have a role in giving caregivers more or less control over their situations. Some of the participants with Admiral Nurses, for example, talked about being supported to take back some control, whether that be helping them to challenge the person’s medication regime, or looking into options for replacement care. By contrast, one participant without an Admiral Nurse felt social services were actively stopping her from taking control of her life:

*… when I was thinking about care, long-term care,* *I was probably thinking there’s a light at end of this tunnel for me, for my life... But then when they were telling me all this* [that he wasn’t ready to go into a care home] *and I, I just wanted to be able to put his name down because I liked the place and I thought he would be happy … I am a person that needs to plan … But I seem to be blocked that way*… [Interview with NAN2C7 in non-AN area 2]

Despite disclosing to social services that she sometimes felt suicidal, this carer did not feel that her husband’s social worker, or any other professional, was particularly interested in her needs as a carer. By contrast, one of the recurring themes from our interviews and focus groups with people with an Admiral Nurse was the feeling that they, as carers, had support from a professional whose job it was to focus on their needs. Partly this was an advocacy role (for example, supporting carers in meetings with hospital or care home staff and adding weight to their arguments) but often it was about helping them to recognise and meet their own needs.

*…you know you’re not on your own then … and she was one of the ones that said, “you know, you’ve really got to think of yourself too”…* [From interview with AN1C5 in AN area 1]

An important point made by carers was that Admiral Nurses are specialists in dementia care, with clinical expertise, and yet they make home visits and get to know the family, which other clinicians generally do not have the time to do. Indeed, some carers felt that their Admiral Nurse was the only professional who had truly got to know them and their situation, as was demonstrated by this example:

*… we both commented … you could see the difference between* [the AN’s] *report and the others; theirs is just sort of academic, but* [the AN’s] *report, you could see it was actually somebody who’s been in contact with us and there was exactly what’s going on... you could see it the way she’d written it.* [From joint interview with AN2C9 and AN2C10 in AN area 2]

A key difference between ASCOT Carer and the other quality of life measures in our shortlist was that ASCOT Carer has an item which specifically asks carers to what degree they feel supported and encouraged in their present situation. It was clear from our data that feeling supported was an important outcome for carers in and of itself. Whilst this question could pick up encouragement from family and friends, those well supported by a professional or service would presumably score higher than those who felt abandoned by the system or taken for granted. Carers in both AN and non-AN areas received emotional support informally through carers’ groups; and some had accessed more formal counselling, either while still caring, or after the person with dementia had passed away. Those with an Admiral Nurse consistently reported feeling relieved that they had someone to turn to who knew them and could respond quickly, and who would also check in on them proactively. Partly the reassurance came from someone taking the time to listen and provide emotional support as and when it was needed, but it was also important to carers that that person was a professional who was knowledgeable about dementia:

[the AN]… *takes a bit of the pressure away, you know. It's having somebody who's, who's knowledgeable in that field who can [say] “oh right, OK, you're going to need this, you're going to need that, and how's about the other”*...   
[Interview with AN1C1in AN area 1]

*…the emotional help is very valuable, but more than that she was able to, oh, comfort me, if you want, … for example* [wife] *was having a problem with her bowels, so we were able to talk about that, and the way things were going. Sleeping, we were able to talk about that…* [Interview with AN1C5 in AN area 1]

*Anyone who's dealt with dementia can give you practical tips, but the Admiral Nurses properly get to know you, care for you, and provide the essential emotional support...somebody understands, and that, I think, is more important than anything, somebody actually understands what you're going through.*[From Focus Group 1 in AN area 2]

3. **Carer health (mental and physical)**

A final theme from our interviews and focus groups with carers was the impact that caregiving could have on the mental and physical health of the caregiver and how support could alleviate this. It is well documented that caregiving is associated with poor health (particularly mental health) outcomes, and carers of people with dementia may have poorer health not only compared to the general population but also to carers of people with other diseases or impairments.3, 8, 9, 64, 11 Our data from carers with and without Admiral Nurses underlines the detrimental impact that caring can have on the caregiver’s mental health:

*…let down, frustrated, annoyed, upset, suicidal. (laughs)...I’m quite strong, but even I’ve thought about stepping off and going back to heaven…* [From interview with NAN1C2 in non-AN area 2]

*I don't like using the word depression, but that's how you feel.* [From Focus Group 1 in AN area 1]

*The impact mentally … I was just all over the place for huge amounts of time, mentally...* [From Focus Group 1 in non-AN area 2]

The impact of caring and support (or its absence) on physical health was less pronounced in our data, but is influence was there in examples where stress and sleep deprivation had manifested themselves as physical illness (headaches, shingles) or risk of injury.

The emotional support described above could arguably influence carers’ mental health, as could space and time ‘to be yourself’ and indeed any other of the quality of life themes covered by ASCOT Carer, and these may in turn influence physical health. However, ASCOT Carer does not ask directly about mental or physical health. For this we selected the health related quality of life measure known as EQ-5D.65 This is the standard measure preferred by NICE which is used to calculate quality-adjusted life years (QALYs) in health economics. The version we selected has five items covering mobility, self-care, usual activities, pain and discomfort and anxiety and depression. We would expect the final item, anxiety and depression, to be most relevant to carers of people with dementia.

Conclusion

The aim of this Work Package was to establish a data collection framework for the survey in the final stages of our proposed work (Objective 2). Through interviews and focus groups with 35 carers of people with dementia we identified three key outcome areas that are important to carers and appear to be influenced by carer support (and Admiral Nursing in particular) and three standardised instruments with which to measure these:

* Carer confidence, measured by the Caregiver Self-Efficacy for Managing Dementia scale47
* Carer quality of life, measured by ASCOT Carer46
* Carer mental and physical health, measured by EQ-5D-5L65.

Design of the final survey questionnaire:

The final (paper version of the) survey questionnaire is shown in full in Appendix 2. This included:

* Questions on the demographic and socioeconomic characteristics of the carer and of the person with dementia (age, gender, ethnicity, education and household resource level).
* The following Instruments to measure the outcomes important to carers:
* Caregiver Self-Efficacy for Managing Dementia scale47
* ASCOT Carer46
* EQ-5D-5L65.
  + Questions on the time and resource use associated with caring, including unpaid (informal) care time, out-of-pocket costs, health (hospital appointments, GP appointments) and social care (for example, home care) and non-statutory sector resources (for example, volunteer befriending service).

Exploration of acceptability and feasibility:

We carried out in-depth cognitive interviews with nine of the initial carer participants, using a ‘think aloud’ methodology66 to explore carers’ interpretations of each question in turn. This was only conducted for the electronic version of the questionnaire but demonstrated that the electronic version was easy to use and not off-putting to the carers in our sample. The data collected about the content and wording of the questions were very valuable, but we reached saturation more quickly than expected. Rather than conduct a full 20 cognitive interviews, we therefore decided to stop at nine and further ‘check’ the comprehensibility and feasibility of the questionnaire by sending it to our carer ‘virtual’ advisory group and steering group. Comments from these groups were fed into the questionnaire design at our second steering group meeting.

The final documents and processes for the survey were reviewed and approved by the HRA London - Chelsea Research Ethics Committee as a substantial amendment to our original application (IRAS ID 195413).

The following chapter sets out in detail our approach to administering the questionnaire, including the challenges we faced in recruiting to the non-AN comparison group, and also sets out the survey findings.

Chapter 5 Analysis of survey of carers of people   
with dementia

Constructing the sampling framework

Sample selection for the survey of AN services

Dementia UK provided us with a list of current AN services in the spring of 2016, from which we selected those that were providing the ‘standard model’ (see Chapter 2 for definition). We then matched the sites to local authority areas in order to facilitate matching of the non-AN areas, usually by contact with the services to establish what post-code areas they covered. We also examined current caseload sizes to ensure that over 16 sites we would be able to achieve our required sample size, and excluded those with fewer than 35 service users. Some services we subsequently contacted for inclusion did not feel able to participate at that point. By the end of this process we had 17 eligible services, one of which did not respond to our contacts.

The 16 services selected had, between them, around 3230 clients on their active caseloads, and we calculated that we needed to generate a sample of around 480 in order to achieve the desired number of returned surveys of around 160 (assuming a 30 per cent response rate). However, there was wide variation in the numbers of clients between the services – from 40 in the smallest to 974 in the largest. In order to create a representative sample of individuals from the totality of AN services selected, we therefore identified individuals using a sampling fraction of 1/6 (or around 15 per cent).

A random number between 1 and 6 was generated for each site using Stat Trek.67 Sites ordered their current caseload either by date of most recent contact or alphabetically by surname, depending on their current practice. We then instructed them to select the nth case (where n was the randomly generated number for that site) and every following 6th case, to the end of the caseload. Based on the caseload numbers the sites had given us we expected this to generate a sample of around 484 carers. Because of some increase in caseloads between issuing the sampling fractions and the services selecting carers, 497 carers were eventually identified and sent a paper questionnaire.

Comparison group sample

We identified 16 ‘broadly similar’ areas in terms of statistical neighbourhood, as defined by CIPFA’s statistical model (<http://www.cipfastats.net/default_view.asp?content_ref=18003>). Statistical neighbourhood is used by local authorities themselves, and across government, to allow comparisons between authorities that are similar in terms of population size and characteristics, such as age distribution, deprivation and ethnicity. The tool eventually used, which is based on the CIPFA model, was the Department of Health’s social care efficiency tool.

Learning from the challenges we faced recruiting carers to Work Package 2 (the qualitative interviews and focus groups with carers, see Chapter 4) we worked with Join Dementia Research (JDR) and a number of local voluntary sector organisations in the matched neighbourhoods, as well as TiDE, to identify and recruit current carers. Despite taking this multi-pronged approach, recruitment in these matched areas was labour intensive and very time consuming.

Over 500 paper questionnaire packs were posted out and over 400 emails with the link to the e-survey were distributed to non-AN areas. The link was also advertised online on multiple websites. Details of where the questionnaire packs and emails were sent are given below:

* Through JDR, 103 carers were emailed the questionnaire and a further nine people received a hard copy through the post.
* TiDE contacted 32 carers directly (28 by email, 3 by post) as well as publicising the survey more generally through email and social media.
* Fifteen local voluntary sector organisations (mainly local carers’ groups) were sent a total of 427 hard copy packs and six of these organisations also advertised the survey online or by email. One of these organisations emailed the link to 300 carers of people with dementia in their locality.
* Three local NHS partners were sent a total of 72 hard copy packs (but we know that at least ten of these were never distributed)
* Seven further organisations (local and national) advertised the survey online or by email.

Responses

Calculating an overall response rate for our survey is impossible because we can be sure about the number of questionnaires or links distributed only for the AN and the JDR groups. While we know how many paper questionnaires we sent to control area third sector organisations, we do not know how many they actually handed on. Further, while we know to which organisations we sent the electronic survey we do not know how many people received the link but chose not to open it.

After the survey was distributed we had ten responses from carers who told us that the person they had been caring for had died. We contacted this latter group to thank them for letting us know and to pass on our sympathy. A further six questionnaires were returned as undeliverable and two people contacted us to tell us that the person they had cared for was now in long-term care. Six paper questionnaires were returned blank, which we classed as refusals.

In total, we received 430 responses to the survey, whether by post or electronically, however not all 430 responses were usable or in scope. First, 22 electronic surveys, all from those contacted via the third sector, had been opened but no data had ever been entered. We classified these as refusals. Secondly, 37 carers told us that the person they cared for was living in long-term care and 25 that they were no longer caring for a person with dementia. Both these groups were out of scope for our survey which focussed exclusively on those currently caring for a person with dementia who was still living in the community.

*Table 36* in Appendix 1 summarises what we know about how many paper questionnaires or links to the electronic survey were distributed and the numbers of refusals or out of scope responses we had from each source. Twenty-six per cent of the paper questionnaires we distributed to the AN services and third sector organisations were returned to us and were in scope, but without knowing the total number actually passed on to carers, we cannot calculate an overall response rate. For the two organisations where we knew how many links were sent to carers, 25 and 43 per cent of carers provided in-scope responses.

In total, we received 346 completed questionnaires which were in scope, 158 (46 per cent) of which were from AN service users in our selected areas and 188 (54 per cent) of which were from carers in non-AN areas.

Description of whole sample

In describing the whole sample of carers we surveyed, we compared them with carers of people with dementia identified in the most recent nationally representative, detailed survey of carers - the Survey of Carers in Households (SCH).68 This comparison helps us to understand whether the group as a whole could be considered representative of all carers of people with dementia (see *Table 37* in Appendix 1 for full comparison).

Figure 3 shows that the our survey sample as a whole was broadly similar in respect of the sex of the carer, while a higher proportion of our survey carers were in the older age groups. Our survey carers were more likely to be caring for a man with dementia and somewhat less likely to be caring for someone over the age of 75 than were the SCH carers (Figure 4).

Figure 3: Sex and age of carers: SCH and our survey carers

Figure 4: Sex and age of person with dementia: SCH and our survey carers

Beyond this, however, our survey carers were very different from the SCH carers in that they were much more likely to be supporting a spouse or partner, much more likely to be heavily involved in caring (providing both personal and physical care) and much less likely to be in paid employment (Figure 5).

Figure 5: Relationship of person with dementia to carer, type of care provided and paid employment: SCH and our survey carers

Our survey sample was thus different in several important respects from carers of people with dementia included in the nationally representative sample of carers.

However, the SCH was a large survey of over 2000 adult carers of people with any condition, and only a single question differentiated between those caring for someone with dementia and other carers. Further, the SCH was carried out before the recent policy emphasis on the importance of diagnosis of dementia and the consequent increase in the numbers of people who know what their condition is. It is possible that a repeat of the SCH now would reveal both a higher proportion of carers reporting that they supported someone with dementia (11 per cent of the total in 2009/10) and, therefore, a different pattern of socio-economic characteristics. However, the differences between the carers in our survey and the SCH carers are so large that it seems unlikely that even this change would increase their comparability. The ways in which we recruited our carers – through service providers and third sector organisations – perhaps inevitably led us to the most heavily involved and vulnerable (by virtue of their age) carers who needed support and had started to access it.

Comparison of AN and non-AN area carers

Demographic and socio-economic status

By matching the AN and non-AN areas, using a statistical neighbourhood approach, we hoped to minimise differences between possible service outcomes for the two groups based on local characteristics, such as expenditure on older people’s services, proportion of older people living in the area, and so on. However, given that the AN carers were, by definition, all using at least one service we expected that our matching approach would not necessarily produce matching groups of carers in terms of their demographic and socio-economic status. Our analysis (*Table 38*) shows that the main difference between the two groups was age of the carer and variables related to that age difference.

AN respondents were more likely than non-AN area respondents to be: over the age of 75; caring for a spouse/partner; the main or sole carer; caring for someone with vascular dementia; without formal educational qualifications; and retired from paid work. As corollaries, non-AN respondents were more likely to be: caring for a parent/in-law, caring for someone with Alzheimer’s disease; aged between 45 and 54; educated to Master’s level or above; and in full-time work.

The difference in the carers’ age is obviously related to the differences in relationship (older carers being more likely to be spouses/partner and younger carers more likely to be children or children-in-law), and in educational and economic status. The difference in type of dementia is more difficult to explain, given that there was little difference in the ages or sex of the people with dementia in the two groups. The difference in main/sole carer status is perhaps explained by the natural history of caring in dementia: when people with dementia are married or in a partnership, the spouse takes on the main caring role until the point when she or he has become too old and frail to continue alone. At this point, the help of a daughter or son may enable the person with dementia to remain at home, and the spouse/partner is thus no longer the sole or main carer.

Caring activity

We summarised the information that carers provided about the caring tasks they carried out, using the typology developed by Parker and Lawton69 and used subsequently to analyse large national surveys of carers.7, 69, 70

The typology categorises six types of caring activity – personal and physical care; personal not physical care; physical not personal care; practical care without personal or physical care; practical help only; and other combinations not including personal, physical or practical care. These categories have been shown to distinguish between more and less heavily involved carers in terms of total hours of care, carer status, impact on employment and other carer characteristics.69

AN carers were more likely to be involved in the heaviest type of care (personal and physical care) than non-AN area carers (χ2=5.57, df=1, p=0.018).

The distribution of total hours for which carers said they provided care to the person with dementia was highly skewed, with 18 per cent of all respondents reporting that they had spent the maximum possible number of hours (24) caring the previous day. We therefore used non-parametric statistics to explore differences between the AN carers and non-AN area carers. This showed that AN carers reported significantly higher hours of care than non-AN area carers (Wilcoxon test, Z = - 2.599, p=0.009). Almost a third of AN carers (31 per cent) reported caring for 18 or more hours the day before the survey, compared with 19 per cent of non-AN area carers. *Table 39* shows the data recoded into quartiles. The largest difference lies in the 18 hours or more category.

Income

Given the differences between the two groups’ economic status, household incomes were more similar than expected at the lower end. Similar proportions (28 per cent and 27 per cent) had gross incomes of £15000 a year or less. At the higher end, however, 16 per cent of AN carers had gross household incomes of £35,000 and above, compared with 28 per cent of non-AN area carers. Fewer carers (243/346) chose to answer this question than any other, so these data need to be interpreted with care. The related question about how people felt they were managing financially, however, was answered by more people (310/346) and this showed a significant difference; in total 72 per cent of AN carers said that they had ‘some’ or ‘severe’ financial difficulties, compared to 50 per cent of non-AN area carers (χ2=13.62, df=5, p=0.018).

Outcome measures

Before we could examine the relationship between AN and non-AN area carers in terms of our chosen outcome measures (see Chapter 6), we needed to explore whether any of the variables on which the two groups varied significantly also varied significantly with these outcome measures, across the whole group. This analysis is reported in Appendix 3(and see *Tables 40-46* in Appendix 1).

The overall conclusion from this analysis was that age of the carer was a major driver of the other socio-economic differences we saw between AN carers and those from non-AN areas. However, the type of dementia that the person being supported had and, for ASCOT Carer only, the carer’s status and activity (sole/main carer or not, type of care provided and hours of care) may also be crucial areas to be controlled for when comparing the outcome measures.

Overall, we gained the sense that EQ-5D-5L worked as it should – reflecting carer’s underlying state of health, with some dimensions (mobility, usual activities and pain) affected by age, but not, by and large, by caring status and activity.

ASCOT Carer also seemed to work as it should – reflecting caring status and activity but not, by and large, the carer’s age. However, ASCOT Carer did seem to be sensitive to the nature of the relationship between the carer and the person being supported, with spouses/partners having poorer scores. There was also a relationship between type of dementia and ASCOT Carer scores (with those caring for people with Alzheimer’s disease seeming to fare better than those caring for people with vascular and ‘other’ dementias) that deserves future investigation.

The Caregivers’ Self-Efficacy Measure in Dementia (SEMD) showed relatively few differences related to carer characteristics, caring status and activity or type of dementia. However, we found higher levels of confidence about finding and arranging services among those caring for people with Alzheimer’s disease, and a non-linear relationship with hours of care, which could suggest that the SEMD is sensitive to service support.

The outcome measures for AN and non-AN area carers are compared in Chapter 6.

Carers’ use of services

We asked a range of questions about the health and social care services that carers and the person with dementia had ever used and were currently using.

AN service use

We started with a section about use of AN services and guided respondents either to an explanatory leaflet that came with the paper questionnaire or to a link to the AN website included with the electronic questionnaire. However, despite this and the fact that we had selected half of our sample via AN services, and half via organisations in areas where there were no AN services, some people in the former said that they had never used AN services and some in the latter said that they had. In both cases, evidence from answers to other questions suggested misunderstanding in both halves of the sample. AN service users who said that they had never used an AN service were mostly people who later reported that they attended carers’ groups; it may be that they did not know that the group they attended was run by an Admiral Nurse. Among non-AN area respondents there was again some misunderstanding, with some claiming to have used ‘other’ types of AN services, such as a sitting services, where no such services exist in reality. It is also possible that some carers in non-AN areas had used AN services that had subsequently closed, or had previously lived somewhere that did have AN services.

Because of this issue, the analysis in this sub-section, where we explored carers’ experiences of using AN services, is based on the 140 carers who were identified via AN services **and** who were aware that they had used an AN service.

More than half of the AN service users were recent - 54 per cent had first used an AN service in the past 12 months and only six per cent had been in contact for five or more years. The majority (90 per cent) had been in contact most recently in the previous six months. Face-to-face visits from Admiral Nurses were the most frequent type of contact reported (94 per cent), followed by telephone contact (54 per cent), AN group meetings (20 per cent), and email contact (ten per cent). As these figures suggest, most people had more than one type of contact with the service.

We then asked the two-thirds (n=89, 65 per cent) of carers who had been in any AN contact in the previous four weeks how many of what type of contacts there had been (see *Table 47*).

In total, 89 carers had had at least 193 contacts, of different types, with the AN service in the previous four weeks (an average of 2.2 each). Of these, face-to-face visits and telephone calls were the most frequent.

We asked those who had been in contact with AN in the past four weeks about a range of types of support they might have received. Providing emotional and social support to the carer (mentioned by 90 per cent) and providing information, advice and knowledge (92 per cent) were the most frequently reported, followed by practical help, including liaison with other services (75 per cent) and assessing the carer’s needs (72 per cent). Less often mentioned were attending support groups and carer training (26 per cent), and recommendations about medication for the person with dementia (21 per cent). Educating and supporting other professionals in touch with the carer (12 per cent) and clinical examination of the person with dementia (seven per cent) were reported less frequently. Two carers mentioned other types of support – one that the AN had facilitated a meeting with another carer and one that the AN spent time with the carer.

Other services intended for carers

There are other services specifically intended to support carers, although they may also help the person with dementia. We asked all carers whether they had ever used: short breaks/respite when the person with dementia is looked after away from home; services where someone sits with the person with dementia or takes them out during the day to give the carer time for themselves; night time sitting services to enable the carer to get a full night’s sleep; carers’ advice services; and support groups for carers.

It was clear from subsequent answers given about day care services (whose main purpose is to provide activity for the person with dementia during the day) that some carers had misinterpreted the short breaks/respite category (which we had intended to be understood as care away from home for more than a day to provide the carer with an extended break) *as* day care. This confusion had not been evident during the cognitive interviewing (see Chapter 4). Where it was clear that this misunderstanding had occurred, we recoded the data appropriately. Where it was not clear, we left the answers as originally given. It is therefore possible that this category of carer support service may be slightly over-represented and day care slightly under-represented. The totality of support to carers and the person with dementia, of course, remains the same.

Given the age and level of involvement of the carers in our survey, the proportions receiving any kind of support services that gave them some space for themselves was low: 15 per cent had ever used respite care, 26 per cent a sitting or ‘taking out’ service, and four per cent a night sitting service, Rather more had used a carers’ advice service (45 per cent) or had attended a carers’ support group (41 per cent), which is not surprising given how we identified carers.

There were some differences between AN carers and non-AN area carers: AN carers were significantly more likely ever to have used a respite service (20 per cent and 11 per cent respectively, χ2=4.32, df=1, p=0.038) and less likely to have used a carers’ advice service (39 per cent and 55 per cent respectively, χ2=8.49, df=1, p=0.004). Again, this last finding is not surprising given that we found many of our non-AN area carers via third sector organisations that run advice services. There were no other differences between AN carers and non-AN area carers in relation to ever having used services for carers.

We asked those who had *ever* used these services what type of support they felt they had received from them. As *Table 48* shows, this question distinguished well between the types of support that different services provided to carers. Thus, time for themselves or to allow them to do other things was mentioned by almost eight in ten of those who had used respite and day sitting/taking out services, while half of the small numbers who had used a night sitting service reported this as an outcome. By contrast, a half of those who used carers’ support groups reported receiving emotional or social support from them, while the most frequently mentioned type of support gained from carers’ advice services was information, advice and knowledge (mentioned by 76 per cent). Overall, these figures suggest that our sample found carers’ support groups less helpful than carers’ advice services.

A small number of carers who had used each of the services had found them no support at all.

Carers were much less likely to report recent use of all these services (*Table 49*), suggesting very low levels of ongoing support. For example, only 17 per cent of all carers reported having attended a carers’ support group in the previous four weeks. Recent use was different for AN carers and non-AN area carers only in relation to this type of support; as might be expected given how we recruited the non-AN area carers, AN carers were less likely to have attended a support group recently (32 per cent and 48 per cent respectively, χ2 = 3.84, df = 1, p = 0.05).

In terms of the perceived usefulness of the services used recently (see *Table 49*), we found lower levels of reporting of emotional and social support and receipt of information, advice and knowledge than we found among recent AN service users.

A small number of carers had used services frequently in the previous four weeks: five of the 21 who reported using respite had done so eight times, 12 of the 64 who had used day sitting/taking out services had used them ten or more times, and two of the seven who had used night sitting services had done so ten or more times. By contrast, most of those using advice services (33 out of 50) reported only a single use, as did 35 of the 57 who had been to a carers’ support group. Only one carer reported using a carers’ advice service and one a carers’ support group ten or more times in the previous four weeks.

In total, 60 per cent of all carers reported no use of a service for carers in the previous four weeks, 25 per cent had used one service, 11 per cent had used two services, and one person had used four services. There was no difference between AN carers and non-AN area carers in whether or not they had used a carer service recently. Neither was there any difference between older and younger carers or between those more or less involved, whether defined by hours of care, number of care tasks undertaken, main carer responsibility, or type of care provided.

On the face of it, this might suggest poor targeting of services for carers, that the services on offer are not reaching those in most need, or that the services on offer are not what carers want or need. We therefore looked at current carer service use by our outcome measures. This showed no relationship between any of the ASCOT Carer domains or on the total score and carer service use. One EQ-5D-5L domain – anxiety and depression – was significantly related to current carer service use, with service users more likely to report problems in this domain than those not using services (84 per cent and 74 per cent respectively, χ2 = 4.64, df = 1, p = 0.031). Those currently using carer services had a significantly *poorer* total SEMD scores on symptom management efficacy than those who were not (mean ranks 143.36 and 164.74 respectively, Wilcoxon W, Z score = -2.081, p = 0.037).

Looking at each type of service by each type of outcome measure showed few relationships. However, there were one or two that are worth mentioning. First, carers using day sitting/taking out services were more likely than those not to report problems in the EQ-5D-5L anxiety and depression domain (80 per cent and 58 per cent respectively, χ2 = 4.57, df = 1, p = 0.032). This was also the case with those using night sitting services (86 per cent and 63 per cent) but the numbers involved were small and the difference did not reach statistical significance. Those using carers’ advice services were also more likely to report problems in this domain (92 per cent and 77 per cent respectively, χ2 = 4.95, df = 1, p = 0.026).

*All* of those using respite services reported problems in the ASCOT Carer domain related to how they spent their time (100 per cent compared to 79 per cent of those not using respite, χ2 = 4.95, df = 1, p = 0.026). Carers using respite were also more likely to report problems in feeling that they had control over their lives (95 per cent and 74 per cent respectively, χ2 = 4.11, df = 1, p = 0.043). There was no other relationship between any ASCOT Carer domain and use of any carer service in the previous four weeks.

None of the SEMD individual questions, or the SSXEFF and SERVEFF scores (see Chapter 4) showed any relationship to recent use of any carers’ service.

Of course, different types of services may be related to different types of outcome measures in different ways. For example, one would hope that those using respite or sitting services would feel that they had more time to be themselves, while those using advice services would feel more confident about their knowledge about dementia and about services. However, given that we cannot distinguish cause from effect in this cross-sectional survey, we might find that carers using such services report more problems in these areas, because services have been targeted at their specific concerns.

Future multi-variate analysis to explore the relative contributions of carer characteristics, carer involvement and carer services to outcome assessment is clearly necessary.

Health service use by carers

In the four weeks before completing the questionnaire 45 per cent of carers had seen their GP and 16 per cent a practice or district nurse (see *Table 50*). In terms of hospital-based services, 23 per cent had had at least one out-patient appointment. *Table 50* also reports average contacts per carer and average contacts per carer using the service.

There was only one difference between AN carers and non-AN area carers in terms of hospital or primary care use: AN carers were significantly more likely to report having seen a nurse specialist of some type in the four previous weeks than were non-AN area carers (11 per cent and four per cent respectively, χ2=4.59, df=2, p=0.032). This question did make it clear that we did not want carers to include in their response any contact with an Admiral Nurse, so this may suggest that AN carers were more likely to be seeing other nurse specialists in addition to the AN service.

The lack of other differences in health service use is slightly surprising given that the AN carers were significantly older than the non-AN area carers, and that older people are usually seen as greater users of health care services.

Further analysis of health service use by age and level of involvement of the carer (main carer status, hours of care provided the previous 24 hours, and type of care provided) showed only one relationship: those caring for a relatively low number of hours (0-5) were more likely to report having seen a therapy health professional (21 per cent compared to 12 per cent of all carers, χ2 = 8.52, df = 3, p = 0.036).

Examining our outcome variables and health service use throws up some interesting and, in the case of ASCOT Carer some potentially disturbing, results (Table 5 below).

First, as one might expect, as a health status measure, problems in some domains of EQ-5D-5L - mobility, ability to carry out usual activities, and pain - were related to health service use in the past four weeks, in particular seeing a GP.

Analysis of ASCOT Carer data showed some relationships between needs and health service use, despite the fact that the ASCOT measures are not *designed* to be sensitive to health service use. In particular, having needs in the ‘feeling safe’ domain was related to more use by carers of outpatient and other hospital appointments, seeing the GP and seeing a practice or district nurse. While our data are cross-sectional, these relationships give pause for thought; are carers using more health services because not feeling safe affects their health indirectly or, more worryingly, directly through physical injury?

Some of these outcome domains were also related to overall health service use. So, with the EQ-5D-5L, 60 per cent of those who had used health services three or more times in the previous four weeks reported mobility problems while only 31 per cent of those who had not used health services had mobility problems (χ2 = 12.89, df = 3, p = 0.005). Similarly, 74 per cent of those using three or more services reported problems carrying out their usual activities compared to 46 per cent of those who used no health services. With ASCOT Carer, 23 per cent of those reporting three or more uses of health services had needs in relation to feeling safe, compared to six per cent of those reporting no use of health services (χ2 = 14.06, df = 3, p = 0.003).

As there was little relationship between carer age and use of individual or total health services, the EQ-5D-5L results shown in Table 5 presumably reflect differences in health unrelated to age. It is also possible that the ASCOT Carer relationships reflect physical injury sustained as a carer, but this remains to be explored in future research.

**Table 5: Relationships between carers’ use of health services by carer needs in outcome domains   
(statistically significant** relationships only)

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Outcome measure** | **Domain** | **Health service used** | **% of carers not using service who reported needs** | **% of carers using service who reported needs** | **χ2 and df** | **p=** | **N** |
| **EQ5D** | Mobility | Outpatient appointment | 37 | 58 | 9.45, 1 | 0.002\*\* | 317 |
|  |  | GP | 34 | 49 | 8.11, 1 | 0.004\*\* | 317 |
|  | Usual activities | Outpatient appointment | 53 | 71 | 7.41, 1 | 0.006\*\* | 317 |
|  |  | GP | 51 | 64 | 4.97, 1 | 0.026\* | 317 |
|  |  | Therapy professional | 56 | 74 | 4.74, 1 | 0.030\* | 314 |
|  | Pain | GP | 62 | 78 | 9.34, 1 | 0.002\*\* | 317 |
| **ASCOT Carer** | How spends time | Practice or district nurse | 85 | 71 | 5.54, 1 | 0.019\* | 314 |
|  | Looking after self | GP | 42 | 55 | 5.05, 1 | 0.025\* | 317 |
|  | Feeling safe | Outpatient appointment | 6 | 15 | 5.83, 1 | 0.016\* | 315 |
|  |  | Other hospital appointment | 7 | 23 | 6.42, 1 | 0.011\* | 312 |
|  |  | GP | 5 | 12 | 4.64, 1 | 0.031\* | 312 |
|  |  | Nurse specialist | 7 | 22 | 5.76, 1 | 0.016\* | 310 |
|  | Feeling supported | Nurse specialist | 57 | 78 | 4.00, 1 | 0.045\* | 306 |

\* significant difference at 0.05 level

\*\* significant difference at 0.01 level

\*\*\* significant difference at 0.001 level or beyond

Use of services by the person with dementia

Health services

We also asked carers who were completing the questionnaire how many times the person they supported had used health services in the past four weeks. Responses highlighted the importance of primary care – both GPs and practice and district nurses - in the lives of people with dementia (see *Table 51*). Over half had seen a GP in the previous four weeks and just under a third a nurse. However, there was also a relatively high use of outpatient appointments, with almost a third reporting this. For those who had used a service recently, average number of contacts was highest for practice or district nurses, therapy professionals and nurse specialists.

There were no significant differences in use of individual health services, or total number of services used in the past four weeks by the person with dementia between AN carers and non-AN area carers.

There were no obvious relationships between use of services and age of the person with dementia. The only statistically significant result here was non-linear; people aged 75-84 were less likely (23 per cent) and those aged 85-94 more likely (44 per cent) to have seen a practice or district nurse in the past four weeks than all people with dementia (30 per cent) (χ2=12.04, df=5, p=0.034) but there was nothing that suggested a clear relationship with increased age. These are surprising findings, given the relationship between age and health service use in the general population.

Carers who reported that the person they cared for had a type of dementia other than Alzheimer’s or vascular dementia were more likely to report that the person had had an outpatient appointment in the previous four weeks (25 per cent Alzheimer’s, 27 per cent vascular dementia, 46 per cent other type of dementia; χ2=7.11, df=2, p=0.029). There was also a tendency for men to be more likely to have had an outpatient appointment (34 per cent men, 24 per cent women) but this difference did not reach statistical significance. These differences are not explained by recentness of symptoms (where one might expect more contact with health services). Indeed, there was no relationship between any type of health service used in the past four weeks and how long carers reported being aware of the person’s symptoms. However, men were significantly more likely to have ‘other’ types of dementia, so there is clearly some clustering of difference here. Looking behind the ‘other’ classification, men in the survey were more likely than women to have Parkinson’s related dementia, Korsakoff’s/alcohol-related dementia or cortico-basal dementia. It may be that services for these conditions are more developed than for other types of dementia or perhaps that services stay in contact with these patients for longer after diagnosis.

People with vascular dementia were more likely than others to have had a planned overnight admission to hospital (zero per cent Alzheimer’s, five per cent vascular dementia, two per cent other, χ2=9.33, df=2, p=0.003), but numbers and thereby cell sizes were small here, so this difference needs to be interpreted with care. Men were also more likely to have used this type of service (three per cent men, zero per cent women, χ2=4.77, df=1, p=0.029) but there is the same proviso about small cell sizes.

There were no relationships between whether or not the person with dementia had a formal diagnosis of their condition and use of any health service.

Finally, we looked at health service use and the level of severity of dementia, as reported by the carer. There was a single statistically significant relationship here – those with dementia reported as ‘mild’ were more likely (25 per cent) and those reported as ‘moderate’ less likely (ten per cent) to have seen a therapy professional in the past four weeks than those with ‘severe’ dementia (17 per cent) (χ2=6.35, df=2, p=0.042).

Social care services

We asked carers whether the person with dementia had made any use of day care, home care, meals services, and memory cafés, or had an appointment with staff from social services in the previous four weeks.

Carers reported that the majority of people with dementia had not recently used any of the individual services we asked about (Table 6). However, counting-up use across all these services, 59 per cent of all carers reported some use in the previous weeks, with an average of at least nine contacts over that time. As this contrast suggests, some individuals used multiple social care services recently, and among those who had, some had many contacts. For example, those using home care had at least an average of 8.39 contacts in the previous four weeks.

Table 6: Use of social care services by person with dementia (reported by carer)

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Type of social care service** | **Not used: % of people with dementia** | **Used: % of people with dementia** | **Minimum total number of uses in the previous four weeks** | **N (100%)** | **Minimum average contacts per pwd (all pwd)** | **Minimum average contacts per pwd using services** |
| Day care centre | 72 | 27 | 4941 | 335 | 1.47 | 5.74 |
| Other type of day care provision | 89 | 10 | 1052 | 335 | 0.31 | 3.39 |
| Home care | 72 | 27 | 7053 | 335 | 2.10 | 8.39 |
| Meals service (at home or elsewhere) | 91 | 8 | 1574 | 335 | 0.47 | 6.54 |
| Memory café | 85 | 14 | 142 | 335 | 0.42 | 2.25 |
| Appointment with social services | 80 | 19 | 73 | 335 | 0.22 | 1.66 |
| Any social care service | 41 | 59 | 1711 | 336 | 5.09 | 8.77 |

1. Seventeen people used day care more than ten times.
2. Two people used other type of day care more than ten times.
3. Fifty-eight people used home care more than ten times.
4. Ten people used a meals service more than ten times.

In a few cases the carer did not know whether the person with dementia had used the service; this is why the row percentages do not always sum to 100 per cent.

There were differences between the AN carers and the others in terms of use of two individual services. Non-AN area carers were more likely to report use of ‘other’ types of day service (that is, not day care centres) - 14 per cent compared to six per cent of AN carers (χ2 = 5.54, df = 1, p = 0.019). Non-AN area carers were also more likely to report use of memory cafés (27 per cent compared to 11 per cent of AN carers, χ2 = 13.69, df = 1, p <0.001).

We also examined whether any characteristics of the person with dementia or the carer were related to individual service use. We examined sex and age of both the person with dementia and the carer, how long symptoms had been present, whether or not a formal diagnosis had been received, reported severity, relationship between the person with dementia and the carer, main carer status, and type and hours of care provided. Relatively few of these characteristics were statistically significantly related to service use (see *Table 52*).

Five services did show some relationship to characteristics of the person with dementia or the carer: day centres, other types of day care, home care, meals and attendance at a memory café.

Women with dementia were more likely to have used other types of day care and home care services in the past four weeks, while men were more likely to have attended a memory café. While people with Alzheimer’s disease were somewhat more likely to use a memory café than people with other forms of dementia (although this difference did not reach statistical significance), men were *less* likely than women to have Alzheimer’s disease, as we saw earlier. However, men with dementia in our survey were significantly less likely to be over the age of 85, so this may explain the difference.

Home care was more likely when the person with dementia was 85 years or over, but both day centre and memory café use were *less* likely for this age group. Those aged 65-74 were more likely than other people with dementia to have used a day centre. Day centre use and other day care were also related to reported severity of dementia, with those in the ‘severe’ category being more likely than others to have used these services recently. Where the carer reported having been aware of the symptoms of dementia for under a year, meals provision was more likely.

There were only two areas where the nature of the caring relationship was related to service use. Those caring for a parent/in-law were much more likely and those caring for a spouse/partner much less likely to report use of home care, while those caring for 6-11 hours were more likely to report meals provision.

Some of these differences make sense in terms of the progression of dementia (day care being more evident when dementia is severe, but with extreme age likely to depress its use) or what we know from other work on the services that are in place when a carer is also present (home care use is more often in place when the person with dementia is female and/or very old but less often when the carer is supporting a spouse or partner). One can also understand why very old people with dementia might not be using memory cafés, which in turn may explain the sex difference in use of this service.

Non-AN area carers were more likely to report use of any kind of social care service (63 per cent compared to 55 per cent of AN carers) but this difference was not large enough to reach statistical significance (χ2 = 2.11, df = 1, p = 0.146). Neither was there any difference between AN carers and non-AN area carers in the reported total number of contacts with social care services over the previous four weeks (Wilcoxon W test, Z = -1.029, p= 0.304).

We also explored any social care service use alongside the characteristics of the person with dementia and the carer.

Neither the sex of the person with dementia nor their age was related to total social care service use.

People with a formal diagnosis were more likely to be using any social care service (62 per cent than those without (46 per cent) or where the carer did not know if a diagnosis had been given (zero per cent) χ2=8.88, df=2, p=0.012). However, the type of dementia was not related to social care service use and neither was the length of time for which the carer reported that symptoms had been evident. By contrast, reported severity did play a part; 72 per cent of those whose carer reported that the dementia was ‘severe’ had used some form of social care service in the previous four weeks, compared with 58 per cent of those reported with ‘moderate’ and 46 per cent of those with ‘mild’ dementia (χ2=8.15, df=2, p=0.017).

The sex and age of the carer were not significantly related to use of any social care service; neither was the relationship of the carer to the person with dementia. However, there was a relationship with whether or not the carer had main or sole responsibility for caring. Those defined as a ‘joint main carer’ were less likely to report any use of social care services (29 per cent) compared to those who were main/sole carers (61 per cent) or who did not have main responsibility as a carer (67 per cent) and this difference was statistically significant (χ2 = 6.32, df = 2, p = 0.043). Despite this, there was no relationship between the intensity of the carers’ involvement, as defined by the type of care they were providing or by the total number of hours of care provided.

Unlike health services, social care services are not necessarily free at the point of use, as they are subject not only to assessment of need but also to means testing if the local authority social services department becomes involved. Further, as there is an active private market in social care, individuals with adequate resources can bypass the assessment of need and pay directly for services themselves. These issues make it difficult to know to what extent we see here services responding to need or individuals making their own judgements about what they require to help the person with dementia to continue to live in the community. We move on to these issues in the next section where we examine which services carers and the person with dementia paid for.

Paying for services

In terms of services intended for carers, four out of five who had used respite in the past four weeks said that they or the person with dementia or both had paid for the service. Half of those reporting using a day sitting service, two of the seven who had used a night sitting service, and one in ten of those attending a carers’ group also reported payment for the services. No one reported paying anything for using a carers’ advice service.

Payment was also common in relation to most social care services for the person with dementia: 78 per cent of those using the service paid for day centre care, 63 per cent paid for other types of day care, 74 per cent paid for home care, and 92 per cent paid something for meals provision. Payment was less common for memory cafés, but even here 46 per cent reported paying something for attendance.

We asked those who reported paying something for the service both how many times they had used it in the past week and what they had paid each time they had used it. This information is analysed fully in Chapter 6 where we explore the health economics aspects of our study. Here we simply report totals, where it is possible to calculate them, and analyse these alongside data on carers’ household financial situation.

Table 7: Range of cost per use, total cost and median cost in previous four weeks when services were paid for

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Type of service** | **Range per use (£)** | **Range of total cost in four weeks (£)** | **Median cost in past four weeks (£)** | **N of carers reporting cost per use/total N paying** |
| Respite | 8 – 850 | 18 - 850 | 252.00 | 14/15 |
| Day sitting  /taking out1 | 6 - 100 | 26 - 1000 | 120.00 | 28/30 |
| Night sitting | 100-140 | 1000-1400 | 1200.00 | 2/2 |
| Carers’ group1 | 3 – 8 | 3 - 24 | 8.00 | 5/5 |
| Day care1 | 5 – 130 | 5 - 950 | 156.00 | 65/66 |
| Other day care1 | 3 – 55 | 5 - 250 | 25.50 | 18/19 |
| Home care1 | 1-213 | 2 - 1917 | 150.00 | 56/57 |
| Meals1 | 3-40 | 5 - 400 | 49.50 | 20/23 |
| Memory café | 2-40 | 2 - 160 | 8.00 | 24/24 |
| All carers services | - | 3 - 2000 | 190.00 | 42 |
| All services for pwd | - | 2 - 1925 | 120.00 | 147 |
| Total social care service costs | - | 2 – 3008 | 120.00 | 164 |

1. In all these services some carers reported use ten or more times in the previous four weeks. These ranges and medians of total costs for the individual services and the totals are thus underestimates. Further work based on estimated usage of more than ten times in the previous four weeks is reported in Chapter 6.

Table 7 indicates the substantial financial burden that some carers and people with dementia were bearing in order to buy themselves or contribute towards the cost of services to support them. The wide range of costs per use – particularly in relation to respite, day and home care – is likely to reflect that some people were paying the full cost of these services while others were making means-tested contributions.

As indicated earlier, we asked whether it was the carer or the person with dementia or both who paid for the service. In this next section of analysis, where we look at costs alongside household finances, we confine the analysis to the 256 respondents who lived in the same household as the person with dementia. First we look at estimated gross annual income, for which 177 of these ‘same household’ respondents provided information, and then at how people felt they were ‘getting’ on financially, which 232 answered.

Over half (57 per cent) of the carers who provided information reported an annual household income of £25,000 or less; 23 per cent had an annual household income of £15,000 or less. At the other end of the income range, 14 per cent reported a household income of £40,000 or more per year. Over two-thirds of carers reported that they had some (34 per cent) or severe (35 per cent) financial difficulties.

It is not surprising, perhaps, to find those with the lowest incomes most likely to report severe financial difficulties: 75 per cent of those with incomes of £15,000 or less reported severe problems, as did 56 per cent of those with incomes between £15,001 and £19,999. At the other end of the income scale, 46 per cent of those with incomes between £35,000 and £39,999 and 41 per cent of those with incomes of £40,000 or over reported that they managed very or quite well. These differences were statistically significant (χ2 = 41.457, df = 12, p<.001).

One might have expected that household income and the costs of services would vary in a linear fashion, with those with the lowest incomes having the lowest costs (because they were accessing means-tested services and paying little) and those with the highest incomes having the highest costs (because they were paying the maximum towards means tested services or choosing to buy in the private market). There was, in fact, little evidence of this relationship in those households where the carer and person with dementia lived together. Non-parametric testing of the costs of carers’ services, services for the person with dementia and all social care services showed little relationship to household income.

Neither was there any significant relationship between the costs of services and how carers reported they were getting on financially. However, the median cost of both carers’ services and the total cost of social care services was higher for those reporting severe difficulties than for others (respectively £3302 and £1742 p.a. compared to £988 and £1560 p.a. for those reporting that they were managing quite or very well, and £2652 and £1248 p.a. for those reporting that they were getting by or had some difficulties). These figures suggest that the high costs of respite, day sitting and night sitting services could be driving some of these differences.

Future testing of the relationships between the costs of services, and the characteristics of the person with dementia and the carer is needed.

Conclusions

Overall, our total sample of carers was older and more heavily involved in caring activity than all carers of people with dementia. Further, the AN carers were older and more heavily involved than carers in non-AN areas. Both the general and the specific differences are likely to reflect the routes through which respondents were recruited. Carers who have started attending carers’ groups and who are known to statutory and third sector organisations are likely to be some way into the dementia caring journey, rather than at its beginning. Those known to AN services are likely to be even further into this journey and/or, as we see in Chapter 7, struggling with their caring responsibilities.

The other differences between our AN carers and non-AN area carers perhaps tell us something of the ‘natural history’ of caring for someone with dementia and the role that AN support might play in maintaining people in their own homes. Thus, the first port of call for support, when people are married or in long-term relationships is the partner, who acts as the main carer. If younger family members or friends are available, they may act as joint or non-main carers. If the main carer becomes frail or ill themselves or dies, or for other reasons the person with dementia needs more support than the main carer can provide alone, the younger generation takes over as the main carer, while the partner moves into the joint or non-main carer role. Alternatively, AN services may step in to support older or more heavily involved carers to continue.

Carers who had used AN services recently were more likely to report receiving emotional and social support and receipt of information, advice and knowledge from that source than were carers who had recently accessed other types of services for carers. This may reflect the personal and targeted nature of the relationship that ANs are able to develop with carers compared to that which is possible in, say, carers’ groups or advice services.

Given the heavy involvement of all our carers, in terms of their caring status and activity, their overall levels of use of and practical support from other health and social care services were surprisingly low. Moreover, those carers who were accessing services related to their caring activities, were often paying large amounts of money to do so and, for some perhaps, with consequent financial difficulties.

As other work shows,20, 27 and as participants in our stakeholder workshop pointed out (see Appendix 5), there is no single ‘silver bullet’ model of service that could possibly provide support for carers of people with dementia all the way from initial symptoms becoming evident, through the worsening of behaviour and physical health, to death. Carers’ needs across the dementia journey will vary substantially, both as symptoms and circumstances change and related to individual characteristics and the support networks they do or do not have around them. Our survey results show that AN services are supporting the very oldest and most burdened carers, many of whom may be very close to the end of that journey.

Chapter 6 Exploratory analysis of outcomes and costs of Admiral Nursing compared to usual care

This chapter reports Work Package 3 (WP3): the health economics component of the project. The overall aim of WP3 was to undertake exploratory analysis of outcomes and costs of AN compared to usual care.

Background

Carers of people with dementia provide an essential resource in supporting people with dementia to remain living in the community. Their support has implications for service use across the economy, including health and care services. In supporting carers of people with dementia, ANs may therefore also affect service use across the economy. It is important to quantify the impact of AN in terms of the cost of AN, the services used alongside AN but also the cost of alternative provision, namely usual care. If AN is not available, what other services are available and what are the associated costs? In embarking on this study, we defined usual care as outlined in Chapter 2, but our work also allowed us to identify in more detail and quantify what this involved.

AN and usual care might also have an impact in terms of benefits so these should also be considered. In offering any kind of support to carers, funders in health and social care services require information about the available options, what works (which service has a beneficial impact), what works best (of the alternative services compared, which one has the most beneficial impact), at what cost and for whom. This information can be used to inform decisions about which services it is most worthwhile to invest in. A key question then becomes, is AN associated with better outcomes and lower costs compared to usual care? This chapter explores this question.

Methods

As noted in Chapter 2, this WP explored the feasibility of undertaking a full economic evaluation of specialist nursing support for carers versus usual care, based on a cross-sectional survey of carers of people with dementia. To do this we examined the outcomes, resource use and cost associated with AN and non-AN including informal (unpaid) care time, out-of-pocket costs for carers, health (for example, hospital appointments, GP appointments), social care (for example, home care) and non-statutory sector resources, as described next.

Carer outcomes

At the project inception stage, we hypothesised that the AN service could have an impact on health-related quality of life (HRQoL), carer-related quality of life (CQoL), and general well-being, in addition to specific outcomes valuable to carers.

Health-related quality of life

In order to measure HRQoL, we selected EQ-5D-5L, given its common use in economic evaluation and NICE’s recommendation of its use to evaluate health and social care interventions.71 As the analysis progressed however, it became increasingly clear that AN was unlikely to have an impact on overall HRQoL. AN support is meant to help carers cope rather than improve their health or HRQoL. For this reason, we excluded HRQoL from the analysis of carers’ outcomes and instead used it as covariate in the econometric analyses to capture carers’ health. In our sensitivity analysis checks, however, we included the analysis of the EQ-5D-5L and EQ-5D-3L score when used as a dependent variable.

The EQ-5D-5L was selected as a generic measure of HRQoL.65 The measure consists of five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression.72 Each dimension is described on five levels: no problems, slight problems, moderate problems, severe problems and unable to/extreme problems. EQ-5D-5L thus describes 3,125 potential health states, including worst health to full health. These health states can be converted into a preference-based score anchored at nought for death to one for full health using a national tariff. The preference-based score reflects the preference for one health state over another. The national tariff reflects the preferences of 996 adults who were selected as a representative sample of the general public in England.72 The preference-based scores range from -0.281 (for extreme problems on all dimensions) to 1 (no problems on any dimensions).

NICE recently issued a position statement stating that it recommended the use of the van Hout *et al*. (2012)73 crosswalk tariff from EQ-5D-5L to EQ-5D-3L to ensure consistency between appraisals (NICE) rather than use of the Devlin *et al*. (2017) values.74 We used the Devlin *et al*. approach initially as the base-case and tested the impact of using the van Hout *et al*. approach in the sensitivity analysis.

Care related quality of life

There is currently no consensus on use of a CQoL measure in health economic evaluation. As described in Chapter 4, we carried out in-depth qualitative work with carers of people with dementia to inform the selection of outcomes that might be influenced by supporting carers and tools to measure these outcomes. The selection was made from a shortlist of validated QoL measures which have (or will have in the near future) a preference-based scoring system. This means that the scoring of the measure reflects people's preferences for one dimension over another. We selected ASCOT-Carer46 from this shortlist, as it was the measure that covered the most dimensions of CQoL that carers identified as important in the interviews and focus groups.

ASCOT-Carer measures social care related QoL in carers who care for adults with a variety of long-term conditions, impairments or problems related to old age. It includes seven questions/dimensions, with four levels each. Dimensions measure QoL related to spending time on valued or enjoyable activities, having control over daily life, looking after oneself, feeling safe, having social contact, having space and time to be oneself, and feeling encouraged and supported in the caring role. Preference weights for this instrument are currently in development and should be available soon.75 In the meantime, ASCOT-Carer can be presented as a summed score ranging from nought (lowest CQoL) to 21 (highest).46

Carer self-efficacy

The qualitative work with carers also found that self-efficacy (or confidence in caring) was an important outcome to carers that was not captured in ASCOT-Carer. There are very few tools that measure this outcome and only one that is both validated and developed specifically for carers of people with dementia. This is the Fortinsky *et al*. SEMD scale.47 This is a ten-item scale with two domains: domain 1 is about self-efficacy in relation to management of dementia (SXEFF) and domain 2 is about self-efficacy in relation to service use (SERVEFF).

The dementia management domain (SXEFF) includes five questions with answers on a ten-point scale on how certain carers are that they can manage problems related to dementia presentation. The items are: handling any problems the person with dementia currently has, handling any problems that might come up, dealing with the frustrations of caring for the person with dementia, doing something to keep the person with dementia as independent as possible, and getting answers to all their questions about the person with dementia’s problems. The scale runs from one, representing ‘not at all certain’ to ten representing ‘very certain’. A summed score can be derived by adding the question scores, with a possible range from five (least self-efficacy) to 50 (greatest self-efficacy).47

The items in the SXEFF domain cover: finding care for the person with dementia without help from organisations or agencies that provide services, finding organisations or agencies that provide services to help care for the person with dementia, getting answers to all questions about the services, and arranging for the services. A further question, about finding ways to pay for the services, does not load onto either domain. Thus, while the scaling of responses is the same as for domain 1, the summary scoring for domain 2 has a possible range of nought to 40.

Overall life satisfaction and happiness

To obtain a sense of carer well-being overall, carers were also asked how satisfied they were with their life nowadays, and were asked to rate this on a scale of nought to ten, with nought meaning not at all satisfied and ten meaning completely satisfied. This question is used in the Office of National Statistics (ONS) Annual Population Survey 76 and has previously been used to value informal care.77, 78

Carers were also asked how happy they felt yesterday using the same scaling. This question is also used in the Office for National Statistics (ONS) Annual Population Survey.76

Resource use and costs

One of the objectives of the survey was to understand the use of services by and costs for carers with and without AN services. The questionnaire included sections about service use by carers and the person with dementia, which covered specialist support services for carers (including AN), health care, social care, and voluntary sector services, as well as any out-of-pocket costs incurred in accessing or using associated services. This part of the questionnaire was developed by the whole research team, tested through cognitive interviewing, and then changed in response to this and to preliminary piloting.

We costed resource use using nationally available unit costs50, 79, 80 to aid transferability of results (see *Table 53*). Costs relate to the financial year 2015/16.

Measuring and costing informal care

We included questions about the time spent by carers in caring for the person with dementia in the 24 hours prior to answering the questionnaire.

First, we used the questions included in the most recent survey of carers in private households about the things that carers usually did for the person they cared for.6 These questions have been used in every official, representative survey of carers since the 1985 General Household Survey.41 We followed this with a question about how much time carers had spent on these tasks in the previous 24 hours. Where people had indicated that they were involved in three or more tasks, we asked them to provide the information about hours of care only for the three tasks that had taken up the most time. Finally, we asked carers to record how much time they had spent caring, *in total,* in the previous 24 hours.

We costed informal care time using two alternative methods, the opportunity cost method and the proxy good method.81 The opportunity cost method values informal care time as the income that would have been forgone by the carer due to the time spent caring had the carer been in active employment. We used the average gross hourly pay in the UK in 2016, at £15.72 per hour.82 The proxy good method values informal care time with the market price of a close substitute, which may be activity specific.

Cost of the AN service

In the survey, we asked carers if they had been in contact with the AN service in the past four weeks, and if so, what type of contact they had had (face-to-face visits, telephone contact, email contact, support group meetings, or other types of contacts specified by the carer) and how often. In our qualitative work, we understood that AN nurses can be employed at bands 5, 6 or 7; hence we assumed for the costing that, on average, an AN nurse is employed at Band 6 (£44 per working hour).50 We also assumed that the duration of face-to-face visits was two hours, including travel time, and that telephone contacts were one hour on average. We had no information on the resources involved in organising and facilitating support group meetings, and assumed that group meetings required one hour of AN time. We assumed that email contacts took 15 minutes. We have assumed that the cost of AN falls on the health and social care budget through commissioning, although this may not always be the case and varies across localities.

We have also calculated the cost of the AN service using information from Dementia UK. Dementia UK provided programme budgeting information on six AN services funded by charitable organisations. This was the only information available at the time of this research and may not be generalizable to all AN services. Dementia UK also provided the average number of carers served by one whole-time equivalent AN nurse. We averaged the costs of setting up and running a new AN service staffed with one nurse, and divided this by the average number of carers supported by a whole time equivalent nurse over one year. This assumes that the AN nurse dedicates all her/his time to supporting carers directly, although in actuality some time is also spent supporting commissioners and health care professionals in their services for people with dementia and their carers.

Exploratory analysis of outcomes and costs

To explore the effect on outcomes and costs of AN services compared to usual care we compared the differences in outcomes and costs in carers we recruited via AN with carers recruited in areas without AN (for simplicity, respectively, AN and non-AN carers from now on). We used an economic evaluation framework in order to draw learnings to inform future economic evaluations of interventions of specialist support services for carers. Economic evaluation is a systematic approach used to inform decision makers about the costs and effects of a range of mutually exclusive courses of action.83 In the UK health care setting, this has typically focused on analysing which option will maximise health outcomes subject to the health sector budget constraint. In the case of specialist support services for carers of people with dementia, such as AN services, a broader perspective may be appropriate and NICE guidance on the economic evaluation of interventions with a social care focus is likely to be more appropriate.49 For this reason, we considered health and social care outcomes, and included costs falling on a broad perspective, including resource and service use associated with AN in the NHS, social care sector, voluntary sector and services paid for out of pocket. We also costed informal care using the opportunity cost and the proxy good method. *Table 54* summarises the unit costs for the proxy good method.

The survey design was cross-sectional and went to a varied population of carers of people with dementia. While the sampling strategy was designed to minimise differences between AN carers and those from non-AN areas, there were important differences between respondents in the two groups (see *Chapter 5)*. Differences in the people with dementia that they cared for were much less marked.

While drawing inferences on the effect of receiving AN services on outcomes or costs was conditional on the carers recruited and the data collected, the data collected did provide an opportunity to explore whether using econometric methods could account for differences in the carers and still estimate the impact of AN services on outcomes and costs. We thus undertook an exploratory analysis, due both to the scope of the project and the limitations of the data.

In undertaking this evaluation, the aim was to compare the impact of intervention on carer outcomes. To do this in a scientifically robust way the two interventions (AN and usual care) should be given to two groups of carers which do not differ systematically, as such systematic differences between the two groups can bias the results. Random allocation is used to avoid bias but was not possible in this study. We hypothesised that non-AN carers were similar to AN carers once we had controlled for the observed carer characteristics that differed across the two groups. Under this assumption, we estimated the effect of AN services in the carers who used AN services, using linear regression analysis and propensity score matching (PSM).

The qualitative work suggested that AN services tend to target the carers with the highest need for support and, therefore, that AN carers would have higher needs than non-AN carers. Although the survey included several questions that indicate proxy need (for example, severity of dementia, informal care time, informal care activities), some dimensions of the carers’ needs are in all likelihood still unobserved. To address this issue we use an instrumental variables (IV) approach.

We employ complete case analysis in all our approaches. Cases that are missing variables in any proposed analysis are dropped from the analysis, leaving only complete cases. The analysis was in five stages, summarised below. Appendix 4details our approach in econometric terms.

Description of AN and non-AN carers

We described the outcomes, resource use and costs of AN and non-AN carers and assessed how comparable AN and non-AN carers were, based on their observed characteristics. A detailed comparison of AN and non-AN carer characteristics is in *Chapter 5* andAppendix 3.

Regression analysis

We used linear regression analysis to control for the observed differences between AN and non-AN carers, since differences between groups may bias the estimate of the average effect of the AN service on AN carers. There may be carer characteristics that have an influence on their costs and outcomes which vary depending on whether the carer has used the AN service or not. For example, AN carers may be older, and older people tend to have lower QoL.84 Therefore, in this example, a naïve comparison between the outcomes of AN and non-AN carers could underestimate the effect of the AN service QoL.

Regression analysis allows us to control for the effect of carer characteristics on the outcomes, such as CQoL, when those characteristics are not equally distributed between groups. Regression analysis provides unbiased estimates of the effect of the AN service on outcomes or costs under two key conditions. First, the regression needs to include all characteristics which affect outcomes and costs and can be confounded with the effect of AN. Second, the effect of AN and all characteristics on outcomes and costs is linear; that is, the effect of a variable on the outcome or cost is constant for any value of the variable.

Propensity score matching

We used PSM as an alternative to linear regression. PSM compares the average outcomes and costs between AN and non-AN carers after matching observations in the two groups of carers that are similar in their probability of having the AN service, given their observed characteristics (that is, their propensity score). Unlike regression analysis, PSM does not require linearity but it requires the matched AN and non-AN carers to have a similar propensity score distribution, that is a similar probability of being in the AN group, conditional on observed characteristics.

IV analysis

Regression, and matching analysis using PSM, control for observed differences. But there may be unobserved factors that determine whether carers receive AN and affect carers’ outcomes, such as their resilience and ability to care. IV analysis can deal with these unobserved factors through a variable, the instrument, that is correlated with having AN but has no direct effect on outcomes and costs and is not correlated with unobserved factors that affect costs and outcomes. Instead of computing the effect of AN on AN carers’ outcomes (as with regression analysis and PSM), IV estimates the effect of AN on those carers that are estimated to use AN because of the variable contained within the instrument. We decided that the travel time between the carer and the AN provider is a good instrument in the analysis of outcomes and costs. Carers living far from the AN provider may not be eligible because the service is delimited to a specific geographical area. Moreover, carers living at long travel distances from the AN provider may be less likely to be informed about AN compared to carers living close to AN teams. This implies that carers living nearby AN providers are more likely to be eligible for or to access the service. This condition does not exclude the possibility that carers living close to the AN provider are ineligible because of low needs. Similarly, it does not exclude the existence of carers that access the AN service even if living far from the provider.

The travel time distance to the closest AN provider is unlikely to be related to the carer’s outcomes, costs and needs because carers may live either close to or far from the AN provider regardless of their levels of needs or CQoL. Following Forder,85 we argue that the type of local authority is also a good instrument in the analysis of outcomes because it determines the local authority’s culture and, in turn, the local authority’s propensity to invest in services for carers. Some local authorities will therefore be more willing to fund AN than others, but the culture will not have a direct effect on carer’s outcomes. We tested the relevance of the instruments (that is, the strength of the relationship between the instrument and the AN dummy) through the Cragg-Donald F statistic.86 Thanks to the use of additional instruments, we also tested whether travel time was unrelated to outcomes.

Sensitivity analysis

We ran seven sensitivity analyses to test the robustness of our results. The findings from these analyses are provided in the technical Appendix 4.

Results

Outcomes of AN and non-AN carers

*Table 55* reports the descriptive statistics for the outcomes data. CQoL using ASCOT-Carer was 10.1 on average (minimum 0, maximum 21) and was statistically significantly lower (worse) for AN carers compared to non-AN carers (9.6 vs 10.6) at the 5% level. Similarly, HRQoL using EQ-5D-5L, was on average significantly lower for AN carers (0.744 vs 0.802). AN carers also reported significantly lower life satisfaction (4.3 vs 5). Self-efficacy on symptoms management was on average 27.4 and self-efficacy on service use 22.3 (minima and maxima of 5 to 50 and 4 to 40, respectively). AN and non-AN carers were statistically similar on both measures of self-efficacy. AN carers were also typically as happy as non-AN carers. Thus, on a straight comparison and without controlling for differences between them, AN carers had lower CQoL and HRQoL, but showed similar levels of self-efficacy and happiness.

Resource use and costs of AN and non-AN carers

*Table 56* summarises the use of services in the last four weeks. Typically, there was sporadic use of hospital services among both carers and people with dementia, but on average carers saw the GP just under once in the previous four weeks. However, there was variability in the use of resources amongst carers as the standard deviation was always greater than the mean. There were no substantial statistical differences in the amount of support, hospital, and community services used by AN and non-AN carers.

Costs to the public sector

*Table 57* reports descriptive statistics on health and social care costs in the last four weeks, These do not discount out-of-pocket costs, which in most cases were co-payments for social care services and, as we saw in Chapter 5, were substantial for some carers.

On average, the cost of using the AN service was £86 over the previous four weeks. As noted earlier, we have assumed that the AN services are funded by health and social care budgets.

Across all carers, the overall cost of health and social service use in the previous four weeks, including AN for those who used it, was around £1,000. Carers cost the NHS around £239 for their use of health care services, being costlier in terms of hospital costs (£309) compared to community services (£28). Such costs varied considerably across carers since the standard deviation was sometimes five times the mean (for example, for hospital costs). AN carers were less costly than non-AN carers for hospital services (£221 vs £391), but more costly for community health care services (£30 vs £26), although the differences were not statistically significant.

Overall, the costs of the health care services used by people with dementia followed a similar pattern, with the total costs equal to £324 and with larger hospital costs compared to community costs (£383 vs £40 respectively). Social care services costs were on average £627. People with dementia cared for by AN carers had lower hospital costs (£372 vs £393) but greater community health care services (£42 vs £37) and social care costs (£663 vs £594). The differences were not statistically significant.

Out-of-pocket costs

*Table 58* summarises the out-of-pocket costs for a single use of carer support services other than AN in the previous four weeks (total out-of-pocket costs of carer support services are described in *Chapter 5*). These out-of-pocket costs largely refer to payments for social care, since local authority (LA) social services are means tested or payment for services arranged privately. The out-of-pocket costs were asked in relation to the carer, the person with dementia or both, hence these related to the carer-person with dementia dyad. Fourteen of the 21 carers using short respite/break services reported paying on average £240 per use, 27 of the 64 carers using day sitting services paid £37 per use, and two of the seven carers using night sitting services paid £120 per use. No carers paid for advice services, while five of the 57 carers using support group services paid on average £6 per use.

*Table 59* summarises the out-of-pocket costs for a single use of social care services for the person with dementia in the previous four weeks (total out-of-pocket costs of social care services are described in *Chapter 5*). Sixty-five of the 86 carers who said that the person with dementia used a day care centre reported an average payment of £40 per use, with AN carers reporting payment of £13 less than non-AN carers. Nineteen out of the 27 carers who said that the person with dementia used other day care services paid an average of £15 per use. Of the 84 carers who reported the use of home care, 55 paid £29 per use, with AN carers paying £25 less than non-AN carers. Most (23/24) of those who said that they used meal services paid for them out of pocket, with an average payment of £10 per use, two of the 44 carers reporting a visit from someone from social services paid £30 per use. Finally, 24 out of the 63 carers who said that the person with dementia had visited a memory café paid £7 per use.

Informal care time and costs

*Table 60* shows the time spent and the value of the top three informal care tasks that carers carried out in the previous 24 hours, using the opportunity cost method and the proxy good method.

The informal care task which in our sample took the most time was keeping an eye on the person with dementia with, on average, carers spending 11 hours in the previous day on this. AN carers spent two hours per day more than non-AN carers on this task and the difference was statistically significant. Given that AN carers were more likely to live in the same household as the person with dementia than were non-AN carers, this difference is not surprising.

The second most important task in terms of hours spent in the previous 24 hours was on keeping company with the person with dementia. AN carers spent two hours per day more compared to non-AN carers and this result is also statistically significant. Again, the reasons for this are likely to do with household composition.

The care task among the ‘top three’ that took up the least amount of time was help with dealing with care services and benefits (for example, making appointments and calls, filling forms). On this task, AN and non-AN carers spent around two hours on the day previous to completing the questionnaire.

Using the opportunity cost method the total value of the top three informal care tasks in the previous day was £293 on average and £459 using the proxy good method. There was no statistically significant difference in these costs between AN and non-AN carers.

Use and costs of the AN service

*Table 61* shows the use of the AN service. In the previous four weeks, for all AN carers receiving an AN service, there was an average of 0.7 face-to-face visits, 0.3 telephone contacts, 0.2 emails and 0.2 support group meetings. Under the assumptions in the section on cost of the AN service (see p.101), AN services over the previous four weeks cost on average of £136 per AN carer.

*Table 62* summarises the information on the cost of AN services based on programme budget information from Dementia UK. In the six services we received information on, the AN service was staffed by one whole-time equivalent AN nurse. In addition to the employment costs, the host organisation bears the cost of recruitment, employment, training, travel, subscription and insurance, equipment, indirect costs and overheads. This amounts to £52,350 in year 1 and £50,034 in year 2. An ongoing study between Dementia UK and PSSRU/LSE shared some preliminary results regarding the caseload per whole time equivalent AN at 70.6 carers per year. Using this information, we calculated the cost of AN at £709-£742 per carer per year. This is, however, likely to be an overestimate of the true cost of AN per carer per year because the nurses carry out other activities in addition to carer support (for example, training health care professionals, advocacy), which we were unable to disentangle.

Regression analysis

We showed that AN and non-AN carers are different in their outcomes but similar in their costs. Such differences may be explained by differences in the characteristics of the carers, the people with dementia, and the caring experience reported in Chapter 5. Hence, in our exploratory analysis, we constructed a set of explanatory variables on the basis of the carer and care recipient characteristics described in *Table 63*. The objective was to use these explanatory variables to control for the differences between AN and non-AN carers and estimate the effect of AN on outcomes and costs.

*Table 64* reports the regression results for the outcome analysis. Being an AN carer is always associated with better outcomes, although the differences are not statistically significant (except for the self-efficacy measure on service use which is weakly significant at the ten per cent level). This suggests that AN carers have similar levels of CQoL, self-efficacy, and happiness as do non-AN carers.

*Table 64* also shows the effect of the covariates on the outcomes. In general, better outcomes were associated with higher HRQoL, while worse outcomes were associated with female gender, financial difficulties, the lack of a replacement for a break, and more severe dementia.

Having a job or being retired had a non-significant or weakly significant positive effect on the outcomes. Being the joint main carer or not the main carer (vs being the main carer) had no significant effect on any outcome. Caring for a parent or parent-in-law or any other relative/friend (vs being the spouse or partner) had no significant effect on outcomes.

The type and total hours of care had varying effects on outcomes. For example, an additional hour of care had a negative impact on ASCOT-Carer but a positive impact on self-efficacy in relation to symptom management. This suggests that the more intense caring role may have a negative impact on ASCOT-Carer but a positive impact on how confident carers feel in their caring role. Having been a carer for longer was significantly associated with greater self-efficacy in service use. Not having anyone to rely on to look after the person with dementia for a couple of days was negatively associated with all outcomes. There was no substantial effect of the age of the person with dementia on carer outcomes and no evidence of effect of the reported duration of the symptoms of dementia.

*Table 65* includes the regression results on health and social care costs. There was no statistically significant association between being an AN carer or not and costs. The covariates were statistically insignificant with a few exceptions. For example, care recipients with vascular dementia were associated with greater healthcare costs.

Propensity score matching

After assessing the validity of PSM in a number of ways, we argued that there was a satisfactory balance of the observed characteristics between AN and non-AN carers (Appendix 4, including *Table 66*, Figure 6, and *Figure 7*, provides more details on the statistical tests carried out). *Table 67* shows that the results of the PSM analysis on the outcome are mostly in line with the regression analysis, except for the effect of AN on the self-efficacy measure related to service use, which becomes statistically significant at the five per cent level. AN carers showed greater self-efficacy on service use of almost three points compared to non-AN carers. *Table 68* shows that PSM produces a statistically insignificant estimate of the effect of AN on costs, similar to the regression analysis.

These tables illustrate the estimated coefficients of the logit regression on the AN dummy used to calculated the propensity score. Carers taking care of a person with vascular dementia have twice the odds of being in the AN group compared to carers of people with Alzheimer’s disease. By contrast, carers with Master’s or higher degrees had between 15 per cent and 23 per cent lower odds of being in the AN group compared to carers with no university education. The longer the time since dementia diagnosis, the less likely carers were to be in the AN group.

Instrumental variable analysis results

As explained earlier, we considered travel time and type of local authority as instruments for this analysis. *Table 69* shows descriptive statistics for the instruments. Non-AN carers were 17 minutes (0.286 hours) on average away from AN services whilst AN carers were nine minutes away (0.151 hours), as would be expected given the way we identified carers. This difference is statistically significant at the 1 per cent level. There was also a significant difference in the distribution of carers by type of local authority: AN carers were most likely to reside in county local authorities whilst non-AN carers were most likely to reside in unitary local authorities.

*Tables 70 and 71* show the results of the IV approach for outcomes and costs, respectively, when travel time is used as an instrument. IV results are in line with those from the regression and PSM analysis. The coefficient on the AN dummy is not statistically significant for any outcome or cost measure except for ASCOT, which is weakly significant (at the ten per cent level). The effect of the covariates on outcomes is similar to what we observed in the regression analysis results.

Travel time is a strong instrument as the Cragg-Donald F statistic is between 41 and 56 (well above ten). As showed in the *Table 72* we cannot reject the hypothesis of no effect of travel time on outcomes when additional instruments are employed. In other words, this suggests that travel time has no relationship with the outcomes.

Discussion

In general, better outcomes were consistently associated with lower health needs as captured by higher HRQoL through the EQ-5D-5L score, while worse outcomes were consistently associated with financial difficulties, the lack of a replacement for a break, and more severe dementia. Similarly, financial difficulties may substantially decrease the carer’s self-efficacy and may preclude the purchasing of support services to complement statutory services. Moreover, AN carers were less likely to have a Master’s degree or higher education and report that the symptoms of dementia had been in existence for more than a year. Greater education might imply better caring skills (even when age is controlled for – for example, *Table 67*). AN carers are more likely to be caring for a person with vascular dementia, which might be associated with more severe cases.

There were differences between AN and non-AN carers as highlighted in *Chapter 5* and in *Tables 63 to 65*. AN carers were older, with lower education, more likely to be retired, and with more financial difficulties. AN carers were also more likely to care for their spouse/partner, to be the main carer, to carry out the heaviest tasks (for example, personal or physical care), to look after a person with Alzheimer’s or vascular dementia, but less likely to have someone who could replace them if in need of a break. This suggests that carers may be in receipt of AN on the basis of their greater needs when compared to carers with no AN support. A naïve comparison indicated that AN carers had worse outcomes than non-AN carers. Once we controlled for the different characteristics, however, AN carers were found to have better outcomes although these results were mostly not statistically significant. Similarly, we found little difference in costs between AN and non-AN carers or in the costs of the people with dementia they care for.

Strengths and limitations

To our knowledge this is the first time that costs and outcomes have been compared in users of AN vs non-AN.

Typically, within a standard economic evaluation framework, it is useful to collect data over multiple points in time. Although a cross-sectional study may provide a useful insight, it increases the uncertainty about the results because of a higher risk of selection bias (for example, due to unobserved needs). Even if the IV helps to address the selection bias, its estimate of the effect of AN refers to a sub-group of AN carers (that is, those carers that are estimated to use AN because of the variable contained within the instrument).

Other limitations are strictly related to the nature of AN. For instance, the effect on carers who received AN support in the past may be difficult to disentangle from other support services which may also have been utilised. Diversity in the referral process (in some cases carers are referred to AN after a triage assessment, in other cases they can self-refer) across AN providers may generate high heterogeneity within the group of AN carers, which may hamper us from identifying an effect. Finally, we are unable to estimate a summary indicator, such as an incremental cost-effectiveness ratio (ICER), to inform decision-making. Our CQoL measure, while generic to carers, is not generic to all members of the community. In addition, at the time of reporting no preference weights for ASCOT-Carer are available. We were unable to calculate a measure akin to a quality adjusted life year (QALY) given that currently we do not have information on time in state or a CQoL preference weight. In addition, based on this, there is no decision rule available to interpret an ICER and no empirical estimate of the cost-effectiveness threshold for decision making in social care to assist decision makers.

Chapter 7 Understanding the wider impact of specialist support for carers of people with dementia

Introduction

The effects of specialist dementia services may extend beyond individual outcomes and resource use, having effects also at a system level. In theory, for example, if services enable carers to care for longer, or help them to remain healthy they may reduce costs to both health and social care systems. In WP4 we explored with health and social care stakeholders what they perceived to be the system-wide effects of the services in their areas that were designed to support carers of people with dementia, with a specific emphasis on specialist nursing support of the type Admiral Nursing provides.

Methods

We selected two areas with Admiral Nursing services and two areas that did not have Admiral Nursing but that were broadly similar (in terms of ethnic diversity and urban/rural mix) to the Admiral Nursing areas. All four were areas that had also been selected for WP3 (the survey). However, it was not possible to triangulate the findings from the two WPs as we did not receive any eligible survey responses from two of the four case study areas. The case study findings set out below are therefore informed by qualitative interviews alone.

Within each area we identified the key health and social care stakeholders in relation to dementia care and support for carers from both the statutory and third sector. We began by inviting commissioners through the NHS research offices and then used snowballing techniques to identify other stakeholders. We expected to identify between 12 and 15 key stakeholders in each area to invite to take part.

Stakeholders were invited to take part in an in-depth, semi-structured telephone interview to explore the perceived system-wide impact of carer services, such as Admiral Nursing, as against ‘usual care’ (Objective 4). The interview aide memoire covered:

* Current provision for carers of people with dementia
* Commissioning arrangements and intentions
* Impact (if any) of Admiral Nursing and other relevant services on health and social care
* How services interact
* Views on the costs and benefits of Admiral Nursing and other relevant services
* Future plans for (further) developing support for carers of people with dementia.

We also asked stakeholders how they measured the impact of their services in order to explore the feasibility of implementing routine collection of outcome and resource use data in the future.

All interviews were digitally recorded and transcribed. Data from the transcripts were then ‘charted’ (summarised and organised in spreadsheets using the Framework Approach)43 and analysed thematically. All documents and processes were reviewed and approved by the HRA London - Chelsea Research Ethics Committee (IRAS ID 195413 see documentation here: [https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/1415407/#/](https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/1415407/%23/)).

Case study sites and participants

The four case study sites selected were:

* **Case study site 1:** a mixed rural/urban area with an Admiral Nursing service hosted by a dementia charity
* **Case study site 2:** a large, ethnically diverse city with an Admiral Nursing service hosted by the mental health trust
* **Case study site 3:** a mixed rural/urban county without an Admiral Nursing service
* **Case study site 4:** an ethnically diverse city without an Admiral Nursing service.

Across the four case study areas, 58 professional stakeholders in key positions were identified and invited to take part in a telephone interview. Of these, 20 eventually took part, the remaining 38 either actively declining to be interviewed or failing to respond after a reminder. Recruitment was very challenging in all areas, but particularly so in the areas without Admiral Nursing, where perhaps there was less motivation to learn about the impact of this model.

We were most successful in recruiting professionals in case study site 1, with seven professionals in total agreeing to be interviewed (out of a total of 14 invited). Recruitment in case study site 2 was more difficult, with only five of the 16 professionals invited agreeing to take part (less than a third). Recruitment in case study site 3 started well, with two commissioners and two front line nurses agreeing to be interviewed. However, it was not possible to interview anyone from the voluntary sector, and senior (strategic) staff from the mental health trust were also unavailable. We eventually spoke to just four of the ten professionals identified in this area. Two further stakeholders had initially agreed to take part, but when we contacted them to arrange the interview they did not respond, perhaps reflecting the time pressures facing professionals who in principle would like to contribute to research but in practice do not have the time.

Recruitment to case study site 4 was particularly challenging, and given what we now know about the potential decommissioning of key services and resultant instability in that area, this is perhaps not surprising. Recruitment was initially led by the local research office, who contacted commissioners but with no successes. The University of York research team then began contacting potential participants at all levels directly (via email). Of the 18 professionals contacted, only four agreed to be interviewed. Reasons for refusal ranged from not having the ‘level of detail’ the stakeholder thought would be useful to the research, to being in the process of being made redundant. This was clearly a difficult time for service providers, as is explained further in the findings section below.

*Table 73* in Appendix 1 shows the areas of responsibility of all professionals who took part in the case studies as well as those who were invited but did not participate. Box 2 (below) lists those who did take part.

Box 2: Professionals interviewed for case studies

|  |  |
| --- | --- |
| **Professionals interviewed from Site 1:**  (Mixed rural/urban area with Admiral Nursing)  WP4W1 - Dementia charity  WP4W2 - Commissioning  WP4W3 - Admiral Nursing  WP4W4 - Community organisation  WP4W5 - Palliative care  WP4W6 - Dementia charity  WP4W7 - Commissioning | **Professionals interviewed from Site 2:**  (City with Admiral Nursing)  WP4X1 - Admiral Nursing  WP4X2 - Occupational Therapy  WP4X3 - Carers’ charity  WP4X4 - Commissioner  WP4X5 - Dementia charity |
| **Professionals interviewed from Site 3:**  (Mixed rural/urban area without Admiral Nursing)  WP4Y1 - Commissioner  WP4Y2 - Commissioner  WP4Y3 - Nurse  WP4Y4 - Nurse | **Professionals interviewed from Site 4:**  (City without Admiral Nursing)  WP4Z1 - Commissioner  WP4Z2 - Nurse  WP4Z3 - Carers' charity  WP4Z4 - Dementia charity |

Results

**Case study 1:** A mixed rural/urban area with an Admiral Nursing service hosted by a dementia charity.

In this site the Admiral Nurses were hosted by a voluntary sector organisation jointly commissioned by three Clinical Commissioning Groups (CCGs) and an LA. The service provided a tiered dementia support service with a number of elements. It had two Admiral Nurses, each of whom worked with a team of dementia support advisors, enabling them to reach greater numbers of families than they could do alone, yet still provide continuity as people’s needs changed over time. A representative of the provider organisation explained:

*…the Admiral Nurse sits above a team of dementia support advisors…almost like a triaging system; so referrals come in, we support people from early diagnosis, or even pre-diagnosis, through to end of life, and at any given time if the support advisor sees fit, they can escalate it up to an Admiral Nurse. She does intensive input on what that particular problem is, with the family, the carers, and then when she feels things are stabilised, if they have, she will pass it back to the support advisors.* [WP4W1]

The service also ran two helplines and various group activities, and had been recently commissioned to pilot a practice-based dementia navigator, which was a non-clinical role that would be attached to a GP practice and mentored by an Admiral Nurse. The nurses also provided regular dementia training to palliative care staff, as well as to home care and voluntary sector organisations. From the perspective of the service, a core part of the Admiral Nursing role was to work alongside the memory clinic, adult social care and GPs. However, the Admiral Nurses themselves were not commissioned by the CCGs or the local authority, did not feature in the contract for the wider service that hosted them and, indeed, were funded entirely through voluntary donations. As one commissioner explained:

*…from* [my] *perspective having an Admiral Nurse that’s funded by* [the charity] *is really good because we couldn’t afford to employ her, I don’t think. So obviously we’re very grateful for, about that… we’ve got a several million pound deficit and we can’t invest in anything … that won't produce at least equivalent savings.* [WP4W2]

This commissioner had heard good things about the Admiral Nurses but had no actual evidence about their impact or the potential cost savings they could deliver. We do know that the Admiral Nurse took referrals from across the health, social care and voluntary sectors, particularly when other services were struggling with a complex situation or were unable to provide further help to a person or their family. They were thought by some to be used as an ‘overflow’ for NHS services. However, the cases they took on tended to be very complex and there did not appear to be any other professionals in the service system with the skills, capacity and remit to take to those cases. A (real) example was given of a person with dementia with multiple problems whose family were struggling to cope, but who had been told by the community mental health team that there was nothing they could do (no medication, no specific intervention) so the person and their family had been discharged. The LA adult social care services, then picked up the case, but called in the Admiral Nurse, who explained how she became involved:

WP4W3*:…because they* [adult social care] *also couldn't do anything, because although …* [there was a] *high state of self-neglect, some risky behaviours, family just on their knees, there's nothing they can do yet.*

Interviewer*: Right. So what can you do?*

WP4W3*: Just help reduce family stress and look at strategies to help to get through the, you know, the tricky times. So some of it is emotional, so listening to them and supporting them… and some of it is to try and find ways of problem solving and, you know, dealing with some of the risky behaviours… I rang them up and then went to the house and did a visit, and then actually there was some safeguarding stuff, so I ended up liaising with their care manager at adult community services, I've spoken to the GP; everybody's floundering and not knowing what to do… I've also maintained regular phone contact with the stressed* [family member so] *she feels like she's supported … and every time a little blip happens, something happens, I sort of steer her through that about what's appropriate to do…*

This was not an isolated case. Nevertheless, the view of another commissioner was that, while the Admiral Nurse was doing a valuable job, this might not be necessary if the statutory service system worked more effectively. The Admiral Nurse was, in effect, plugging the gaps in a system, which, with the right developments, should be able to meet the needs of its population without this expensive service:

*I think it* [the Admiral Nurse] *is having a value at this point in time. I do think though that Health could and should be better providing the dementia awareness support and education for their staff; I think that if that was in place … you can almost perceive that there would not need to be an Admiral Nurse* [WP4W7]

This commissioner argued that the key priorities for improvement locally were professional education, information and signposting. However, the carers interviewed for Work Package 2 (see Chapter 4) made a clear distinction between signposting, and the intensive support they received from Admiral Nurses to help them access services, and to encourage them and the people they cared for to accept help. A professional working in palliative care confirmed that such support could be very valuable for people with complex needs:

… [the Admiral Nurse would] *refer on to Adult Social Care but what they would do is they would support them in the meanwhile, and they would coordinate the referrals and liaise with them in terms of getting the support available. And also the person themselves, in accepting that help, can be very difficult; so they can be that person that helps them to come to terms with the fact that they need a referral. Because otherwise … say the GP saw them and just said, “oh can I refer you to Social Services”, and the person said “no”, pretty much that’d be it, whereas the Admiral Nurse would go in on a regular basis and … be a little bit more persuasive over a period of time, but they're, they’re able to do that because of the pre-existing relationship they’ve got …* [WP4W5]

This professional saw continuity as the key factor distinguishing the Admiral Nurses from other services. Yes, other professionals could (and should) be better trained and dementia aware, but she was doubtful that they would have the capacity to work with families affected by dementia in the intense, continuous way that the Admiral Nurse could. Crucially, the ongoing relationship afforded by the tiered approach (whereby support advisers engaged with people early on in their journey and retained contact) meant that if and when the Admiral Nurse became involved the family and their situation were already known. A representative from another community organisation working with older people similarly commented that it was the dementia charity as a whole, with its support advisers supervised by the Admiral Nurses, that was the valuable resource:

*… it’s not just the Admiral Nurse that we liaise with really, but, you know, in terms of the expertise of her training, that was really helpful, and also knowing that within* [the charity] *they do have that nursing expertise for people who really need it…* [WP4W4]

This account contrasted with that of another dementia charity, which provided a number of services locally (information and advice, social groups and training for carers) but had very little to do with the Admiral Nurse or the organisation that hosted it. Unlike the other organisations we spoke to, this charity did not often refer to the Admiral Nurses or access staff training from them. As they explained:

*…we generally are quite skilled at supporting people ourselves, we know who to refer to, you know, for financial advice and support like Age UK and other things, and also we know the need to refer back to the GPs occasionally or the mental health team,* [and] *we do do a lot of in-house training in our teams…* [WP4W6]

This organisation did not provide ongoing case management, except for a ‘*very small minority*’ [WP4W6] and did not have in house clinical expertise, but would refer on to other services if they felt this was required.

A final relevant service in the area was a dedicated carers’ service mentioned by several interviewees but which did not respond to our invitations to be interviewed. We know the support advisers liaised closely with this service and did joint home visits, but we do not know what the carers’ service thought about their impact or that of the Admiral Nurses.

It is clear that in this case study site not everyone had an Admiral Nurse, and indeed, one commissioner pointed out that there appeared to be very little awareness of the service amongst the general public. However, having this specialist resource locally and being able to draw on it was highly valued by services on the ground who came into contact with people with dementia and their carers but were not specialist dementia organisations themselves. The view from commissioners was ambivalent, recognising that having Admiral Nurses might add value to the system but not convinced that this would justify investment, particularly as there did not seem to be demand for Admiral Nursing from the general public. There was however strong demand for improved, more consistent services rather than the fragmented ‘postcode lottery’ currently experienced by many.

**Case study 2:** A large, ethnically diverse city with an Admiral Nursing hosted by the mental health trust.

This site was a large city with a small Admiral Nursing service based in community mental health services. The service was a small part of a large block contract, but was one of a handful of dementia services within that contract that came under a Section 75 pooled budget within the *Better Care Fund*.87 The aim of the service was to provide specialist support to carers with complex needs or co-morbidities, and referrals came primarily from the mental health trust itself. Interviewees explained that the service had to be quite selective and only take on carers with the highest needs as ‘*if everybody was referred, we wouldn’t be able to cope with the demand*…’ [WP4X1]. When fully staffed, the service should have had three full time and two part-time nurses, all band 6, but at the time of the interviews they were two nurses short. The service had responded to this restricted capacity by using their time more efficiently: running clinics and groups, being ‘*economical with home visits’*, and taking laptops when they did go out so that they could work anywhere rather than having to return to their office. Nevertheless, reduced capacity and tight referral criteria meant that their impact on, and integration with, the wider service system seemed limited. The service was not contracted to take referrals from primary care or social services, although if referrals came and they met the criteria they would not be turned away. The local carers’ service was aware of the Admiral Nurses but did not work closely with them. The memory service, whilst based in the same building, rarely referred to the Admiral Nursing service as they tended to see people with dementia at the start of their journey (that is, assessment and diagnosis) when carers’ needs were not generally so pronounced. Joint working was more likely between the Admiral Nurses and other elements of the community mental health team:

*…we’ll liaise with the community mental health teams and we work with them, such as reporting any concerns to psychiatrists, especially if someone’s suicidal or if they come out with any ideas, and also if we have any concerns such as if there’s changes in the caring role that’s going to impact on their mental health we’ll liaise with the mental health team as well. So that’s a good form of communication, we’re on the system, we can email, we can inform, we can find out what’s happening, we can enter things on their notes so that whoever comes in can see exactly what we’ve done.* [WP4X1].

Our interviewee from the Admiral Nurses did think that their work reduced pressure on primary and secondary care. Carers on the Admiral Nursing caseload could go to them rather than to a GP for advice, and those who attended their training would be able to spot signs of infection in the person with dementia and access treatment early, before a hospital admission was required. However, they knew of no way to measure this impact.

The commissioner leading on dementia and carers agreed that demonstrating the impact of dementia services was very difficult for two reasons: if you prevent an admission it does not take place so cannot be observed or measured, and any impact may take years to take effect. She also pointed out that the Admiral Nursing service was only a small part of the dementia service system and worked with only a few hundred carers per year. Where the model had strength, she argued, was as part of a tiered pathway: ‘…*it’s about having a menu of options*’ [WP4X4]. She explained that some people do not need much support (some people just want a few appointments with a dementia adviser, or to be signposted to dementia cafés or other services) whereas other people want longer-term support, and some people will have very complex needs that can be met only by the Admiral Nurses:

… *That’s what we’re paying them for, mental health expertise. So I would expect them to still link people in with dementia advisers as a long term thing, because they cannot case manage eight and a half thousand people with a diagnosis. … my expectation as a commissioner would be that they would hold onto the most complex ones, because we’re paying them for clinical expertise, they’re a much more expensive service in that way than if you go to the third sector. … if I found out that they were working with the same people, you know, they were doing a dementia adviser type role, I wouldn’t be very happy because you pay* [for a] *nurse*... [WP4X4].

The dementia advisers this interviewee referred to are part of a commissioned service provided locally by a dementia charity. The usual pathway for newly diagnosed people with dementia was to be referred from the memory service to a dementia adviser, who would work with the person for up to six months. If a person needed support more than six months after diagnosis, they would be referred to a dementia support worker (or in some areas a dementia navigator) and these workers would also support carers (something that was not an official part of the dementia adviser role). While a little disjointed, this model had far greater coverage than the Admiral Nursing service, reaching seven or eight hundred people per year. However, the service did not have the capacity to provide active case management to that many people in the long-term; rather, people were expected to move in and out of the service:

WP4X5: *We're not about creating a dependency, you know, we're about empowering people to...*

Interviewer: *So you do* [between] *one and three visits and then, what… do you close the case...?*

WP4X5: *It, yeah, yeah, the aim is, when we meet somebody, that we say we're here to help and support you, once we've met your needs we'll back off when, about you living your life and getting on with life, we'll back off and if you need us in the future you come back to us, we don't close people... until we've met the outcomes…*

Interviewer: *… and if they need support again, can they access the same adviser or worker?*

WP4X5: *We, we try as much as possible to, to keep that continuity, you know, it isn't always possible, but in the main we will try to keep that continuity going.*

The view from this interviewee, as well as the commissioner we spoke to, was that most people do not want a service involved all the time; the important thing is that they can access support when they need it. This contrasts somewhat with the findings of our interviews and focus groups with carers (see Chapter 4), who said that ongoing support from someone who knew them and their situation well was important and meant that, when crises did arise, a professional was already involved and so was better positioned to help them.

The tiered approach seen here has some similarities to the model described in case study site 1, and also some differences. While the Admiral Nurses in site 1 were employed by the same organisation as the support advisers and worked very closely with them (passing on expertise and escalating or de-escalating cases but not closing them), the relationship between the Admiral Nurses and the dementia advisers and support workers in site 2 was less developed. Each service would refer to the other, but there did not appear to be much joint working or formal professional education. While the Admiral Nurses did provide dementia training to local hospices, the dementia advisers and support workers accessed their own training in-house and from elsewhere. Nevertheless, they recognised the Admiral Nurses as a ‘*resource to tap into, in what feels, sometimes, like an ever decreasing resource pool*’ [WP4X5] and said ‘*the gift’* of the Admiral Nurses was their clinical expertise and dementia specialism.

One other significant resource for carers of people with dementia in this area was a consortium of 15 carers' organisations commissioned by the local authority. The service was described as ‘*diagnosis neutral*’ but all carers were welcomed and 18,000 people in total were registered with the service. The overall aim of the consortium was to help carers navigate an otherwise complicated service system but, rather than simply signpost, they assessed needs centrally and retained overall responsibility for the carer so that multiple and future needs could be met in a co-ordinated manner:

*…we will tap people into those services, as well as provide any additional wrap around services that we feel the carer might need around their own wellbeing … They stay on our books, so it’s not, “OK, we signpost you and we close the case” carers can come back whenever they want for that information* [and] *support … So we’ve got lots of carers that at any point in time are accessing services from more than one provider. That’s great …* [WP4X3]

While this consortium appeared to have overcome the challenge of co-ordinating support from a number of specialist services and maintaining continuity, it should be noted that none of the services signed up to the consortium were for carers of people with dementia in particular. Interviewees did tell us about one final service which had been commissioned specifically to provide information to carers of people with dementia. However, no-one from this service was available to be interviewed so our knowledge of it is limited.

On paper, the availability of the information service for carers of people with dementia, together with the larger consortium for carers, the routine care co-ordination for people with dementia and their carers available through the dementia advisers and support workers services and the more specialist support for carers with complex needs through Admiral Nursing, presents a picture of a well-designed tiered service system meeting the needs of carers and people with dementia across the city. However, the commissioner we interviewed explained that in practice there was not enough capacity in dementia services to reach the 11,500 people with dementia expected to reside in the city (8,500 currently diagnosed) and all their carers:

*I mean for* [thedementia carers’ information service] *there’s something like, I think it’s less than ten workers. So for a city the size of* [site 2], *eight and half thousand people with dementia, that’s not a huge service. … we’ve got dementia* cafés *and memory* cafés *as well, we’ve got probably thirteen of those, and then the dementia* café *only usually operates once a month sort of for half a day. So what I say to the GPs is, “well if all eight and a half thousand people with a diagnosis turn up to a dementia* café *on the same day it’s going be really, really difficult”…* [WP4X4]

Moreover, site 2 was a very diverse city with large numbers of people from different ethnic backgrounds, but it had very few dementia services or services for carers designed specifically to meet the needs of these different groups. As the commissioner explained:

*…the services that we’ve got are expected to cope with that, because there’s, whilst there’s no money to commission generic services, there’s no, there's totally no money to commission specialist ones…* [WP4X4]

When asked specifically about the Admiral Nursing service, the commissioner again felt that this small service, although highly targeted, did not have the capacity adequately to serve the city, citing the low prioritisation of dementia services, and the problems in demonstrating impact as reasons for this:

[It’s the] *tip of the iceberg… I mean what you’d ideally have is a bigger service that would offer more of what they’ve got, because I’m sure there’s lots of people that could benefit from the* [Admiral Nursing] *service but can’t actually access it. But it’s just about finding the funding, you know, funding for dementia services is usually the bottom of the pile and it’s just really difficult because there’s no evidence that the, these services make a difference to persuade the people that hold the money that they should invest.* [WP4X4]

**Case study site 3:** A mixed rural/urban county without an Admiral Nursing service.

This site was a large county with both rural and urban parts. The dementia strategy had been compiled jointly by the CCG and local authority and was jointly funded, partly through the *Better Care Fund*. The site did not have an Admiral Nursing service, but did have a voluntary sector dementia support worker service and a generic carers’ service, as well as acute based assistant practitioners and support workers assisting the memory service and home treatment teams. The latter received clinical supervision and dementia training via an innovative nurse practitioner position within the memory service, which appeared to fulfil a role that in other areas might have been undertaken by an Admiral Nurse:

*…this is clinical supervision, clinical education, doing it ‘on the job’… and doing it through experiences and reflection. But I’ve also just started … my Medical Educator Masters Degree as well so I’m bringing that education into the workplace.* [WP4Y3]

The home treatment team also delivered professional education, helping staff in care homes, for example, to recognise the underlying factors that might be causing distress for people with dementia and diffusing situations before they became acute. While this team also provided some follow-up to dementia patients in the community, and during inpatient stays, there was a view from some professionals that this was not enough. An interviewee working with young onset patients, for example, said he would keep patients with vascular dementia and frontotemporal lobe dementia on his caseload rather than transferring them to mainstream mental health services because he was concerned about lack of follow-up:

*…if I transferred them over to the memory service, because they don't need any medication reviewing they therefore aren't eligible to any reviews so they'd be discharged. If they needed home treatment, of course the teams would get involved, but, you know, I feel that they deserve more than that .*.. [WP4Y1]

This was also the view of one of the commissioners we interviewed, who was proposing to commission a new dementia companions service to ‘beef up’ the existing dementia support worker service. The dementia companions would be non-clinical workers supported by practice-based dementia specialist nurses, who themselves would primarily be focussed on diagnosis, but with availability to provide advice and support should that be required. Again, this proposed model does not sound dissimilar to the model described in case site 1, where teams of support workers worked under Admiral Nurses, although the proposed model here would be primary care - rather than voluntary sector-based.

Interestingly, in a neighbouring district there was an Admiral Nursing service that at least one of our interviewees could refer into for carers living within that boundary. This enabled a direct comparison between current support in the areas with and without Admiral Nursing, and this interviewee felt that support for carers in the area without this service was lacking:

Interviewer: *And what if someone has that kind of need that you've recognised, particularly the carer is not coping, needs help, but they're not in the area where they've got the Admiral Nurses?*

WP4Y1: *Well it's really difficult. So we refer most people to* [charity that provides dementia support workers].*.. but again* [they’re] *quite limited, they're unqualified staff; so, you know, although they're very good it's not quite to the level that the Admiral Nurses can give. So we just have to manage but it's not ideal; and I do struggle more with people in* [the area without the Admiral Nursing service] *than I do in* [the area with the Admiral Nursing service]*…*

No-one from the existing voluntary sector dementia support worker service in this area was available to be interviewed, but the commissioner explained that it did not currently provide continuous support to families affected by dementia and only had limited capacity. In contrast, the aim of the proposed service was to make available a ‘go-to person’ to people with dementia and their families, with whom they could develop an ongoing relationship. As the dementia progressed, the home treatment team might also become involved, but this would not replace the dementia companion:

*They’ll be with the person, very similar to how the Admiral Nurse works, throughout the entirety of the dementia journey… the dementia companion remains in contact, you know, they have a go-to person, if you like, for the person with dementia and their carer. Then as the journey progresses it may well be that the home treatment team is required in future*. *Now this home treatment team will be a team that responds to people with, with fairly moderate stage dementia, moderate to end-stage where the, the symptoms and behaviours become quite pronounced...* [WP4Y2]

The home treatment team did currently exist but the commissioner said that its role would be developed and standardised. In terms of services having an impact on acute admissions and reducing the need for residential care, the general view was that this was the role of the home treatment team. The commissioner explained that at present, there was no way of measuring this impact, but this was one of the developments being proposed. No-one from the home treatment team was available to be interviewed.

The service was envisaged to be for carers as well as people with dementia, and this would complement the existing generic carers’ service. It should be noted, however, that the dementia companion model, with its aspirations for continuity and joint working with primary and secondary care, had not yet been commissioned and it is impossible to say how it might work in practice.

**Case study site 4:** An ethnically diverse city without an Admiral Nursing service.

This site was a diverse city without an Admiral Nursing service. At the time of the interviews, both the city and county council, together with the three CCGs covering the area, were jointly undertaking ‘*a live procurement exercise around dementia support services*’ [WP4Z1] which made the recruitment of interview participants very challenging. A number of provider services faced uncertain futures and some of those in commissioning seemed reluctant to talk about current and future provision. The local authority dementia support service was one of the services currently out to tender and, as a result, no-one from this service was available to speak to us.

An interview was conducted with a lead commissioner for the city who set out the vision for support services for people with dementia and their carers going forward. The aim was to commission a service that would provide advice and information, one-to-one (short-term) support, training for carers, group support and advocacy. The commissioner explained: ‘…*the service will provide that consistent first point of contact for people, which is, I know that’s something that the Admiral Nurses do*…’ [WP4Z1]. However, the service would most likely be staffed by non-clinical support workers and provide time-limited support:

*…what we don’t want to do is, is obviously there’s the finite volume to this service, we don’t want it to get silted-up with people who require ongoing support necessarily; the idea being that the service will be a point of contact, a consistent point of contact for the person and their carer, and that they can zip in and out of the service as they require*. [WP4Z1]

It is impossible to know the potential impact of this service as it had not yet been commissioned, but interviewees were asked about their hopes for the service and how any impact would be measured. The commissioner explained that there would be a greater focus on measuring outcomes for service users than there had been in previous contracts. In terms of the wider impact, while it was envisaged that the service could reduce pressure on health services, this was not a primary aim and there were no plans to measure this:

*We do not expect the provider to answer for the NHS and for their targets. We do think there will be an impact, hopefully, if we get it right, because what the service will be doing when it links with people who are in hospital, they’ll be linking with the discharge teams as well. So there’ll be that sort of facilitating role between the discharge teams back into the community and, and maybe into Adult Social Care too. So I do think that we will, well I’m hoping that we will see improvements but we’re not expecting this service to be accountable for that*… [WP4Z1]

The existing LA support service was felt, at least by some stakeholders, already to provide continuity of care and to dovetail well with clinical services. When we asked a participant from memory services what she hoped the new service would achieve, she said she was mainly hoping there would be no deterioration in the high quality of care that people with dementia and their carers currently received from the existing LA service. She considered this service to be ‘invaluable’ because it was staffed by very experienced workers and provided continuity, which was something the memory service, with its focus on assessment and diagnosis, could not do:

*…one of the hardest things that I do and my colleagues do is actually say to someone “We’ve given you a diagnosis and treated your dementia, it’s stable at the moment but that won’t be that way forever, but we’re going to have, we’re going to discharge you.” What it can be reassuring is knowing, and saying to them, here is a contact number, here is someone that, who will actually help you; and if you’ve got confidence in that level of support that’s great.* [WP4Z2]

Moreover, in her view the involvement of these support workers did save the health service time and resources, as they would pick up problems in the community (such as, urine infections or constipation that could be affecting a person’s well-being and behaviour, and in turn the carer’s ability to manage) and act on these to prevent crisis. Unfortunately, she knew of no way to quantify this impact.

This nurse trusted the judgement of the support workers, despite their not having a clinical background, valuing their experience and commitment above qualifications. However, she was aware that these qualities were attributes of the individual workers and not necessarily of the support worker model in general, and she was concerned that a newly commissioned service, which on paper looked similar, might in practice not operate so effectively:

*I could put them alongside a new member of nursing staff and I, I think they’d give them a run for their money really. … but that’s what’s hard to replicate, experience and dedication, and that is a problem … you can have a model that works or you can* *have staff who are absolutely great. You could say, oh this works because that person’s done it for years and they know what they’re doing; but that’s not, that’s not replicable…* [WP4Z2]

No other health or social care services were identified which focussed primarily on support for carers of people with dementia in this case study site. Community psychiatric nurses (CPNs) and the unscheduled care service might get involved at crisis points, but they came under the umbrella of general mental health services, rather than targeting dementia in particular. We invited numerous managers covering these community mental health services to take part in an interview, as well as a senior mental health nurse, but all declined or did not respond.

Professionals working in the voluntary sector were more forthcoming. There were two main voluntary sector services providing support to carers of people with dementia: one a dementia charity that provided some services for carers, the other a generic carers’ service that worked with some carers of people with dementia. As such, neither service specialised in supporting carers of people with dementia and, as they were both non-clinical services, neither directly replicated Admiral Nursing. However, there were elements of both services that might be delivered by Admiral Nurses in other areas. The dementia charity, for example, ran an advocacy service for people with dementia and their carers, as well as peer support groups and carers' information and support programmes. Our interviewee from the memory service said she might refer someone with low level needs to these services instead of to the LA support workers, because the latter’s caseloads were often very high, but her service did not do this routinely. The interviewee from the dementia charity agreed that their services reduced the pressure on statutory services, in particular by taking on non-clinical support issues and advocacy so that GPs and CPNs could focus on medical issues. This impact was, to some extent, captured in case studies, but it was not recorded systematically and these case studies could be used selectively:

WP4Z4: …*we've got into the habit of writing case studies and keeping them on file … we send those with the monitoring, and I think they're often really good because, you know, they can actually see outcomes from that basically….*

Interviewer: *And so do you do that systematically, that for every case that comes through, or just for certain ones?*

WP4Z4*: Not for every case because otherwise we'd, well there'd be hundreds of case studies… we choose, actually, when the monitoring's due … which one is best to, you know, to fit with outcomes…*

The carers’ charity was a generic carers' organisation working with all adult carers including carers of people with dementia, but without any services or projects targeting specific conditions. They saw themselves as a prevention service, providing practical training and stress management for carers, as well as advocacy. This service argued that helping somebody to deal with stress might prevent illness, helping them to continue caring for longer and reducing pressure on other services. However, they did not feel that they were in a position to measure or demonstrate their impact on the statutory sector and felt this made services like theirs vulnerable to cuts:

Interviewer: *…. is there any way that the impact of that is measured … whether or not you're able to actually prevent admissions or prevent use of care home or homecare?*

WP4Z3: *This is the big problem, because generally you don't really see it (sighs), I don't know how they would measure it, we certainly are not in a position to measure it, and this is one of the problems with preventative approaches … it's one of the reasons why social care service* [commissioners], *when they're looking to make cuts, will not cut the emergency stuff, the crisis management stuff, they'll cut the prevention…*

There were contrasting views on the value of Admiral Nursing from the different professionals we interviewed. The commissioner felt there were advantages to the model but had always thought of Admiral Nursing as ‘*quite an expensive resource*’ [WP4Z1]. The interviewee from memory services described Admiral Nursing as ‘unmatched’ in the level of support and continuity they could provide. However, she too felt it was unrealistic to expect this service to be commissioned in this area:

Interviewer: *And what are you hoping for? What would be a good outcome from this* [re-tendering process]*?*

WP4Z2: *What would be a good outcome? Admiral Nursing across, across the city (laughs) but that’s never going to happen, is it? No, no.*

Interviewer: *Right, OK. So, and why do you say that?*

WP4Z2: *Um, because I, as much as I think it’s a wondrous, wonderful model, it’s an expensive model.*

Both voluntary sector organisations were asked whether they felt their services replicated Admiral Nursing or negated the need for it in their area, and both said “no”. The dementia charity pointed out that their staff were non-clinical and their role was primarily to provide a voice for people with dementia and their carers navigating the health and social care system. Similarly, the carer’s charity felt they did not have the expertise in dementia and could not offer the intensive case management that Admiral Nurses provide:

*…an Admiral Nurse can help the person to deal with the situation they're dealing with at home, and to understand what's going on with the person that they're looking after, which is a completely different thing. We can only do that up to a point, but we don't know the individual case, we don't know the specific diagnosis, bearing in mind how many different types of dementia there are and we do not know enough about it to go any further than the basics…* [WP4Z3]

Discussion

A key aim of this WP was to understand better the perceived system-wide impact of services, such as Admiral Nursing. What is immediately clear is that this impact is not well understood. While in the main Admiral Nursing and other dementia care co-ordination services, notably dementia advisers and support workers, undertake activity which in theory could reduce impact on acute health services (such as emergency admissions and hospital bed days) and adult social care (in particular the need for long-term care) this was rarely measured. Indeed, there was a suggestion that such effects were particularly difficult to capture, since prevented crises could not be observed. Nevertheless, the consensus was that these preventative services were valuable and did reduce pressure on statutory services.

In all four of the case study sites, the LAs and CCGs jointly commissioned the dementia services and so, in theory at least, the cost savings from both sectors would be reaped jointly and could be ploughed back into integrated preventative services. In practice, we heard that a large proportion of the funding for preventative services (including the Admiral Nurses themselves in case study site 1) came from donations or other charitable sources and statutory funding for prevention and continuity appeared to be reducing. A common theme across all sites was the significant financial pressure that commissioners and providers were under, exacerbated not only by funding cuts but by growing demand as the diagnoses of dementia increased. Admiral Nurses were valued, but seen as an expensive resource: a luxury that those with were grateful for, and those without thought they could not afford.

In both of the case study sites that had Admiral Nursing, the nurses were called upon only to work with carers with the most complex needs. Often this was when other services were struggling. Indeed, they appeared in these areas to be the only professionals with the skills, capacity and remit to take on some of these cases. In the areas without Admiral Nursing it was difficult to establish who was fulfilling this role. While there were non-clinical care-coordination services (and plans for these to be developed further in some areas) their staff were not qualified to work with the most complex cases, and the more specialised NHS services did not have the capacity to provide continuity under current working conditions. While commissioners stressed the importance of linking up services, carers told us (see *Chapter 4*) that information and signposting was not always sufficient; they wanted a relationship with a named professional they could turn to as things progressed.

Given the challenge of reaching, and providing continuity to, the growing numbers of people with a diagnosis of dementia and their carers across any given area, one solution does appear to be the tiered approach where specialist nurses, such as Admiral Nurses work with and mentor less qualified support workers and escalate/de-escalate cases as and when necessary, without discharging them. However, it remains to be seen whether the wider impact of such an approach can be demonstrated.

Chapter 8 Discussion and conclusions

Policy interest in dementia has continued since our project was funded,88 and with particular injunctions to the NHS to improve the quality of post-diagnostic support for people with dementia and their carers.89 A 2016 report, *Making a difference in dementia, nursing vision and strategy*, sets out how nurses can provide high quality compassionate care and support for people with dementia and their carers.90 The report sets out aspirations for how nurses can care for carers of people with dementia, in order to meet the aspirations of the Prime Minister’s Challenge,88 including offering the opportunity for respite, education, training, emotional and psychological support so that they feel able to cope with their caring responsibilities and to have a life alongside caring.

However, as a recent House of Commons Library briefing demonstrates, most progress in England seems to have been in relation to diagnosis, with little evidence about actual improved support for the specific needs of carers of people with dementia.91 This seems particularly the case in relation to support towards the end, rather than at the beginning, of the dementia journey.

Our report thus comes at an opportune moment, to explore how some of these policy aspirations are evidenced in the real lives of carers of people with dementia.

In this final chapter we discuss, first, the strengths and limitations of our complex, multi-method study. This provides the context within which the subsequent discussion of the results and our conclusions can be understood.

Strengths and limitations

Working with Dementia UK

We were lucky to work in partnership with Dementia UK, both in planning the project and throughout all its elements. They wanted to evaluate the Admiral Nursing service, which is a large part of what they do, and to have this evaluation carried out by independent researchers. In this, they demonstrated a wish to learn from impartial evaluators about what they currently do and to use this learning to improve what they do in the future. This openness to outside scrutiny is, perhaps, not as common among health and social care providers as it might be.

Officers at Dementia UK enabled access to their administrative database and answered very many questions from the research team to make it possible for us to carry out our analyses on it. They also provided a vital link between the research team and the AN services selected for the survey, ensuring that paper questionnaires and electronic links to the questionnaire were distributed in accordance with the research team’s sampling strategy. A senior member of the Dementia UK management team was an *ex officio* member of our project advisory group in order to facilitate all our links with the organisation, but did not have an advisory role in relation to the conduct of the research.

Despite all these facilitative links, for which we were very grateful, this was an independent evaluation, with the York researchers responsible for all aspects of the design and conduct of all the work packages, and analysis and interpretation of all the results.

Analysis of the administrative data set (WP1)

We experienced four main problems associated with using administrative data for research purposes – determining availability, receiving the data, merging multiple data sets and understanding what the data really meant. While these were largely overcome because we could work in partnership with Dementia UK, several challenges remained. These included only partial coverage of all AN services in the central database, the time-consuming nature of fully understanding and transforming those data into a format suitable for research purposes, and the lack of clarity about what triggered reassessment of carers’ needs.

We worked to address these challenges but some remained unresolvable, either completely or in part. So, for example, we could not detect any obvious differences in the types of services that did or did not use the central database, but without data from these services we could not formally test this. While we worked hard with Dementia UK to ensure that the data we received were as usable as possible, resolving issues around date fields and differing data formats took a long time and reduced the amount of analysis we could then carry out. Similarly, while we also worked hard to understand AN practice in relation to needs assessment, there were no data that explained why needs were reassessed (or not). Finally, the needs assessments did not use standardised tools, so relied on the nurses’, inevitably subjective, appraisal of the position of both the carer and the person with dementia.

By their nature, these types of administrative data reflect how a service works and so can limit the analysis that can be undertaken in a research project. Despite this, we were able to provide a summary of the type of clients that the AN service supported, an overview of the interventions that the nurses offered and an estimate of the changes in dyads’ needs over time. Further, we now have a prepared data set that offers opportunities for future multi-variate analysis that we had hoped to carry out as part of the project but which was constrained by the amount of time it took just to get the data into a usable form.

Qualitative work (WPs 2 and 4)

We experienced challenges in recruiting carers of people with dementia for WP2. Initially, we had intended to recruit 30 carers through TiDE and to conduct focus groups in York but we did not recruit the number of carers we needed via this route. In response, we engaged with local community organisations and we were able to identify several peer-support groups for carers of people with dementia from which we recruited participants. We had originally intended to conduct the bulk of our data collection for this WP through focus groups but, in response to carers' preferences, we adopted a more flexible approach to data collection depending on individual preferences. Although this responsive and flexible approach meant recruiting carers for WP2 took more time than had been anticipated, we recruited more carers than originally planned (n=35).

A strength of this study was that the survey design was informed by the priorities of carers and their views about which outcomes were likely to be influenced by the services they received. Analysis of the interviews and focus group data from carers fed directly into our choice of outcome measures. Moreover, we were able to test the full questionnaire with a sub-group of these carers ensuring that the final design was acceptable to them and that both carers and researchers had a shared understanding of the meanings of all questions.

We were unable to triangulate findings from the survey and the qualitative interviews with professional stakeholders in WP4 because there were insufficient survey responses from the case study areas. The numbers of stakeholders who agreed to participate was also lower than we had hoped. The pressures of reorganisation, responsibilities for areas other than dementia care, and time constraints all seemed to contribute to reluctance among some stakeholders to share their views with us. Despite this, however, we did feel that our material reached saturation in most areas.

The survey and health economics analysis (WP3)

The main challenge of this part of our work was identifying carers from non-AN areas. We had originally hoped to recruit people from our matched LA areas, using the third sector organisation TiDE. However, TiDE was at that point a relatively new organisation and had not yet been able to rebuild the cohort of carers that its predecessor organisation had access to. We then tried to find carers in our chosen areas via JDR; while this gave us a potentially larger number of carers, using the JDR system was time consuming. It also identified a fair proportion of carers who were no longer caring at home, because the person they cared for had entered long-term care or had died; in most cases this was not evident until carers returned the questionnaire.

We therefore spent much time contacting local organisations in our selected non-AN areas to identify carers’ groups and similar. We also put a link to the electronic questionnaire on some national organisations’ websites, including the Alzheimer’s Society’s Talking Point, and recruited some carers via statutory organisations who had approached us directly. Because of the complexity of the recruitment strategy and our lack of control over how many carers actually received the paper questionnaire or the link to the electronic questionnaire, we cannot calculate an overall response rate. A ‘guestimate’ of between 25 and 45 per cent is all that we can hazard.

We did finally manage to identify enough carers to have similar numbers of AN and non-AN carers, but the latter were different from the former in a number of important respects, which are discussed in Chapter 5. The variety of sources through which we recruited also made administration of the survey more complicated than we had originally planned for.

The survey itself worked well; most carers who responded answered most questions, demonstrating that our chosen outcome measures were, indeed, feasible to use in future evaluation and that carers were willing and able to provide useful information about services that they and the person with dementia used, and how much they paid for them.

We think the survey may be the largest, independent, detailed, and national survey of carers of people with dementia yet carried out in England. In purely descriptive terms, then, it has value that goes beyond its specific role in this project. The carers we surveyed were, on average, older and more heavily involved in care than those identified in the most recent national survey of carers,6 thus giving a unique insight into a potentially vulnerable group.

In terms of the health economics analysis and as far as we are aware, this is also the first time that costs and outcomes have been compared in users of specialist nursing services for carers and those receiving usual care.

Typically, within a standard economic evaluation framework, it is useful to collect data over multiple points in time. Although a cross-sectional study may provide a useful insight, it increases the uncertainty about the results because of a higher risk of selection bias (for example, due to unobserved needs). Even if the IV approach helps to address the selection bias, its estimate of the effect of AN refers to a sub-group of AN carers (that is, those carers that are estimated to use AN because of the variable contained within the instrument).

Other limitations are strictly related to the nature of AN. For instance, the effect on carers who received AN support in the past may be difficult to disentangle from other support services which may also have been used. Diversity in the referral process (in some cases carers are referred to AN after a triage assessment, in other cases they can self-refer) across AN providers may generate high heterogeneity within the group of AN carers, which may hamper us from identifying an effect. Finally, we are unable to estimate a summary indicator, such as an incremental cost-effectiveness ratio (ICER), to inform decision-making. Our CQoL measure, while generic to carers, is not generic to all members of the community. In addition, at the time of reporting no preference weights for ASCOT-Carer are available. We were unable to calculate a measure akin to a quality adjusted life year (QALY) given that currently we do not have information on time in state or a CQoL preference weight. In addition, based on this, there is no decision rule available to interpret an ICER and no empirical estimate of the cost-effectiveness threshold for decision making in social care to assist decision makers.

Informing future practice and evaluation (WP5)

The AN service we trained to use the chosen carer measures had not had time to implement these into their routine data collection systems before the project came to a close. However, Dementia UK as a whole is keen to integrate these measures into the data collection systems used by all services and we will continue to work with the charity to support this.

**Integrating the views of stakeholders to strengthen our findings (WP6)**

Work package six involved a workshop attended by 36 stakeholders, including carers, practitioners and commissioners. Participants discussed the research findings and fed back key messages and implications. These included overall messages from the research; messages relating to AN in particular, and messages relating to the future evaluation of services for carers of people with dementia. We also discussed the ways data are collected and used locally to inform and improve services. A full account of the messages from this workshop is given in Appendix 5 (see p.289).

The workshop gave us a valuable opportunity to discuss our initial interpretations of the study findings with professionals and carers with direct experience of the issues under consideration. An example would be the issue of balancing the intensive, specialist nature of AN support (which not everyone requires at all times) with the desire for continuity and full coverage for all carers and people with dementia. There were stakeholders at the workshop representing organisations that could provide greater coverage than most AN services, but not the intensive specialist support that AN offers, and there was a consensus in the room that these services should work together via a tiered model to ensure continuity and access to specialist support for all. This discussion added weight to our conclusion that, if embedded well into dementia services across a locality, AN could enable the system as a whole to offer appropriate ‘end-to-end’ care and support for all carers and people with dementia.

However, while the feedback from this workshop was useful, we did not feel that it provided a secure base for the production of best evidence guidelines. Instead, we have produced a short summary of findings which is now being widely disseminated and is available to download from the project webpage: <https://www.york.ac.uk/spru/projects/admiral-nursing/>

Discussion of results

Analysis of the Dementia UK database (WP1) showed that, on average, the needs of carers being supported by Admiral Nurses (ANs) reduced over time. However, as we were unable to link changes in carers’ needs to the input of the ANs, we cannot say what caused this reduction. The ANs do provide the types of support that are likely to help reduce carers’ level of need over time, or at least maintain these where situations become more complex, but to show a link between input and outcomes we would need additional information that the ANs do not currently collect.

The database confirmed that ANs are successfully targeting older carers, who are more likely to be affected by the demands of caring. The model employed typically involves triage, whereby those in most need receive greater levels of input, but those with lower levels of need can be escalated if/when their needs change.

Our qualitative research with carers for WP2 emphasised the value that carers place on continuity and ‘feeling supported’ as things progress. We identified three key outcome areas through this work package that are important to carers and appear to be influenced by carer support (and Admiral Nursing in particular). The first was confidence in caring, which carers said they gained when they were supported by a specialist in dementia who knew them and their situation well. Having an ongoing relationship with such a professional, who they could turn to as things progressed, could give them the confidence to continue caring in spite of the difficulties and uncertainty they faced. We chose to measure carer confidence using the Carergiver Self-Efficacy for Managing Dementia scale.47

The second outcome area identified by carers was their own quality of life, which we chose to measure using ASCOT Carer46 as this mapped most accurately onto our analysis of our qualitative data. In particular, ASCOT Carer was the only tool in our shortlist of validated quality of life measures with a specific question on ‘feeling supported and encouraged’.

Finally, and not surprisingly, carers told us that the level and quality of support they received could affect their physical and mental health. We chose to measure this using EQ-5D-5L65 because of its common use in economic evaluation and its relevance for NICE. However, subsequent work understanding the AN service convinced us that AN services are unlikely to have an effect on EQ-5D-5L, and therefore we used this variable in the economic analysis as an explanatory variable in our main analysis.

Feedback from testing suggested that our questionnaire was acceptable and comprehensible to carers. The acceptability of our chosen outcome measures was later confirmed by the high rates of completion of the outcome questions by survey participants. We thus feel that the questionnaire provides a useful evaluation framework for other dementia care services that might be expected to have an impact on carers.

Through the survey we identified a group of carers who were, as a group, older and more heavily involved in caring activity than found in nationally representative data about carers of people with dementia. Yet, within this, the AN carers were even older and more heavily involved in caring, echoing what we observed in the administrative data. These differences probably reflect our recruitment; carers who attend carers’ groups and who are known to statutory and third sector organisations are likely to be some way into the dementia caring journey, rather than at its beginning. Those known to AN services are likely to be even further into this journey and/or, as we saw in *Chapter 4*, struggling with caring.

AN carers were more likely to report receiving emotional and social support and information, advice and knowledge from ANs than were carers using other types of carer support services, perhaps reflecting the personal and targeted nature of the relationship that ANs are able to develop with carers.

We suspect that some differences between our AN and non-AN carers reflect the ‘natural history’ of caring for someone with dementia and the role that specialist support might play in maintaining people in the community. Spouses and partners were the largest group of main carers, both in the administrative data and among all carers in our survey. If the main carer is no longer able to provide the care that the person with dementia needs, younger family members may take over as the main carer, while the partner moves into a less involved role. The administrative data showed that increasing the amount of informal support that carers could access was a key part of what the ANs were doing. Alternatively, AN services may step in to support older or more heavily involved carers who have no other source of informal support, to continue by improving their coping strategies and enabling them to take time for themselves. This, we conjecture, may thus prevent or delay admission to long-term care.

Given the heavy involvement of all our carers, in terms of their caring status and activity, their overall levels of use of and practical support from other health and social care services were surprisingly low. Moreover, those carers who were accessing services related to their caring activities, were often paying large amounts of money to do so and, for some perhaps, with consequent financial difficulties.

The health economics work, based on data collected through the survey, explored outcomes in the group of carers as a whole, and compared AN and non-AN carers, in both cases controlling for other variables that might affect these outcomes.

Better health was associated with better carer outcomes, while worse carer outcomes were consistently associated with financial difficulties, the lack of anyone to stand in for the carer if they needed a short break, and reported severity of dementia.

The older age and heavier involvement of carers using AN services suggests that they may be receiving appropriately targeted support through AN, on the basis of their greater needs when compared to carers with no AN support. While initial analysis showed that AN carers had worse outcomes than non-AN carers, once the differences between the two groups were controlled for in the analysis, this difference disappeared. Indeed, AN carers had better outcomes although these results were mostly not statistically significant. Similarly, there was little difference in health and social care costs between AN and non-AN carers or in the costs of the people with dementia they cared for.

A key aim of WP4 was to understand stakeholders’ views on the system-wide impact of services, such as AN, but it was clear that this impact was not well understood. While support for carers might be able to reduce impact on acute health and adult social care (in particular the need for long-term care) this was rarely measured. Nevertheless, participants in this part of the study did feel that preventative services were valuable and were likely to reduce pressure on statutory services.

With increasing use of joint commissioning for dementia services, cost savings from services that had a preventative role could accrue to both health and social care services. In fact, a large proportion of preventative services funding (including the ANs themselves in one site) came from donations or other charitable sources, and as statutory funding grew scarcer prevention and continuity seemed to be suffering.

ANs were seen as a valuable, but expensive resource. This was despite the fact that, in both the sites that had Admiral Nursing, the nurses worked only with carers with the most complex needs and often when other services were struggling. The difficulty of the cases they worked with was such that ANs seemed to be the only professionals with the skills, capacity and remit to take them on. In the areas without Admiral Nursing it was difficult to know who would deal with similar complexity. Other staff in dedicated dementia services were generally not qualified to work with the most complex cases, and the more specialised NHS services did not have the capacity to provide continuity. While commissioners stress the importance of linking up services, information and signposting are not always sufficient for carers; they want and need a relationship with a named professional they can turn to as dementia progresses and its demands increase.

Given the challenge of reaching, and providing continuity to, growing numbers of people with dementia and their carers, the tiered approach where specialist nurses work with and mentor less qualified support workers and escalate/de-escalate cases as and when necessary, without discharging them seems promising.

The routine evaluation of services to support carers of people with dementia (or indeed any carers) is still not in place. Ouroutcome measurementtools and data collection system were acceptable to carers and seen as relevant and useful to the ANs we trained to use them. However, when it came to incorporating them into routine data collection systems of one service for our pilot, the service could not find the capacity to try them out. In a climate of increased demand and reduced resources, improving data collection and evaluation systems is rarely prioritised. Yet, it is just such evaluative data that can prove the value of services to commissioners.

Dementia UK have agreed to incorporate the selected outcome measures into their new AN national data collection system, as hoped for as an outcome of our work. However, services and professionals need protected time to apply these and use the data collected to evaluate their services and demonstrate impact.

As other work shows20, 27 and as participants in our stakeholder workshop pointed out (see Appendix 5), there is no single model of service that could possibly provide support for carers of people with dementia all the way from initial symptoms becoming evident, through the worsening of behaviour and physical health, to death. Carers’ needs across the dementia journey will vary substantially, both as symptoms and circumstances change and related to their characteristics and the support networks they do or do not have around them. Overall, our results show that specialist nursing services can support the very oldest and most burdened carers, many of whom may be very close to the end of that journey. They can also act as resources for non-clinical dementia support workers, and indeed other clinicians, and if embedded well into dementia services across a locality, enable the system as a whole to offer appropriate ‘end-to-end’ care and support.

Areas for future research

**1.** Findings from across our work packages underline the role of specialist nursing support with carers who are under considerable stress, whether by virtue of their age, their caring activity, or their coping skills. This raises the inevitable research question of whether support of this type, for carers at this stage, delays or prevents admission of the person with dementia to long-term care.

**2.** Analysis of the textual data in the administrative data set showed that carers and people with dementia could be at risk of problems related to their health (for example, falls), as well as physical and verbal assault and other forms of abuse. These data would benefit from further analysis, alongside professional and carer accounts, to explore this issue in greater detail. This material also highlighted the role of the police service in dealing with risk in dementia. We feel this would benefit from further exploration in research specifically designed to focus on this under-researched (in relation to dementia care) service.

**3.** Our work has demonstrated the use of econometric analysis for economic evaluation in analysing observational, cross-sectional data. This is particularly relevant in the context of social care where it is not always possible to implement randomised controlled trials and the use of quasi-experimental datasets is more common. The high response rates in the survey suggest that routine collection of these data is possible and can be used to examine the impact of the service on individuals over time. Future research may use routinely collected data in the same individuals over time to explore whether econometric methods that take time into account (for example, difference-in-difference) may help to reduce uncertainty of the results and further address potential selection bias.

**4.** In-depth, qualitative analysis of the remainder of the daily activity data in the AN administrative data set, in addition to the 200 cases we thematically reviewed for this study, might shed more light on the day-to-day work of ANs and how this affects carers’ lives and their capacity to continue to support people with dementia.

**5.** The AN administrative data sets are now fully prepared for multi-variate analysis that would allow us to understand other factors that might affect change in carers’ needs over time.

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Statement on data sharing

Due to the nature of this study and the type of data collected, there are no data available for wider use. Some raw data were supplied from the Dementia UK AN administrative datasets, and these remain their property and cannot be shared further due to conditions attached. Any requests relating to the Dementia UK database in particular should be directed to the Dementia UK database helpdesk administrator: [Wandahelpdesk@dementiauk.org](mailto:Wandahelpdesk@dementiauk.org). All other queries should be submitted to the corresponding author in the first instance.

Contributions of authors

**Kate Gridley** (Research Fellow, SPRU) was project manager. She led WPs 2, 4, 5 and 6 (the qualitative research and implementation work) and wrote Chapters 4, 7 and elements of Chapter 8 of the final report. She also contributed to WPs 1 and 3, including recruitment for the survey.

**Professor Gillian Parker** (Professor of Social Policy Research, SPRU), was principal investigator. She designed the study, led the design of the survey, analysed and wrote up all the material included in Chapter 5, contributed to the writing of Chapters 1, 2, 3, and 8 and was responsible for editing the final report. She also contributed to WPs 1, 2, 4, 5 and 6.

**Dr Fiona Aspinal** (Research Fellow, SPRU) led the analysis of the administrative dataset for WP 1, wrote Chapter 3 of the final report and contributed to Chapter 8. She also contributed to WPs 2, 3 and 6.

**Dr Helen Weatherly** (Senior Research Fellow, CHE) led on the health economic design for WP3. She worked with RF and jointly supervised FL and co-wrote Chapter 6 (economic evaluation). She also contributed to WP6.

**Rita Faria** (Research Fellow, CHE) developed the health economic design, and worked alongside KG, GP and FA on WP2 in developing the data collection processes for WP3 and selecting the study sites. She jointly supervised FL with HW and co-wrote Chapter 6 (economic evaluation). She also contributed to WP6.

**Francesco Longo** (Research Fellow, CHE) was the lead quantitative analyst for the economic evaluation and co-wrote Chapter 6 (WP3). He also contributed to WP6.

**Professor Bernard Van Den Berg** (Professor of Health Economics, CHE)provided high level advice to support the health economic design, regression analysis and write-up for WP3 (Chapter 6).

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Appendix 1 Tables and figures

Table 8: List of datasets provided by Dementia UK

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Data set | N of cases | N of variables | Information held | Data analysed |
| CADI1 | 57 | 38 | Needs assessments (based on published assessment tools) for carers focusing on stress, coping and rewards. Only one time-point and too few cases to analyse. | No |
| CASI2 | 51 | 36 |
| CAMI3 | 45 | 44 |
| Agency | 3543 | 24 | Agencies ‘involved’ in the case. | Yes |
| Other family members | 2342 | 12 | Other family members involved in the case but who are not clients of the AN service in their own right. | Yes |
| Work | 24825 | 5 | Client’s status – also reported in Cases data set so no additional relevant data. | No |
| Cases | 24825 | 51 | The latest core descriptive information held on each current or previous client. | Yes |
| Current needs assessment | 2541 | 24 (covering 18 areas of need) | Needs assessment using latest version of in-house needs assessment tool. | Yes |
| Daily activity log | 17362 | 1 | Details of actual input ANs have provided to clients over time. Sample of 200 cases analysed. | Yes - qualitatively |
| Legacy needs assessment | 2074 | 25 (19 needs) | Needs assessment using previous version of in-house needs assessment tool. | Yes |
| PWD status | 6609 | 3 | Living circumstances of the person with dementia. Information already available in Cases data set. | No |
| Referral | 24088 | 4 | Services and professionals who referred the carer to the AN service and services referred to. | Yes |
| Review proforma | 2276 | 4 | Discretionary field that ANs can use to make additional notes. No data. | No |
| Risk screening tool | 1091 | 24 | Risk assessment based on in-house screening tool. Summarised a 5% sample of data. | Yes - qualitatively |
| Triage assessment | 2517 | 4 | System generated output. Does not link to other data. | No useful data |

1. Carer’s Assessment of Difficulties Index 92

2. Carer’s Assessment of Satisfactions Index 92

3. Carer’s Assessment of Managing Index 92

Table 9: Results of calculation of survey sample size under different assumptions

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Assumptions** | **Assumed response rate** | **Total achieved sample size required and original sample size to ensure this** | **N of independent variables in regression using more and less conservative inflators (10 observations or 5 observations per variable)** |
| Population survey sample calculation | 66% of people with dementia live in the community with support of a carer (population size c. 528000)  30 clusters  Design effect of 1 (random sampling) | 60% | 384 (640) | Achieved sample size would allow for 38 independent variables using conservative ratio, 76 using less conservative ratio. |
| Comparative research sample calculation | Mean difference of -5.0 points on GHQ, with 5% confidence level and 80% power | 60% | 16 (26) | Achieved sample size would allow one independent variable using conservative ratio and three using less conservative ratio. |

Table 10: Questions on legacy and current needs assessments forms

|  |  |  |
| --- | --- | --- |
| **Question topics** | **Legacy needs assessment** | **Current needs assessment** |
| Physical health - person with dementia | q1 | q1 |
| Mental health - person with dementia | q2 | q2 |
| Physical health - carer | q3 | q3 |
| Mental health - carer | q4 | q4 |
| Medication management | q5 | q5 |
| Insight into dementia | q6 | q6 |
| Dementia symptom | q7 | - |
| Coping with behaviour/symptoms | q8 | q7 |
| Communication – professionals and carer | q9 | q8 |
| Environment/accommodation | q10 | q9 |
| Financial issues | q11 | q10 |
| Practical aids | q12 | q11 |
| Practical support | q13 | q12 |
| Informal support | q17 | q13 |
| Adjustment to loss | q16 | q14 |
| Balancing needs | q18 | q15 |
| Time for self | q14 | q16 |
| Time for self – longer respite | q15 | - |
| Looking to the future | q19 | q17 |
| Risk | - | q18 |

Table 11: Number of times needs assessments were repeated

|  |  |  |
| --- | --- | --- |
|  | Legacy needs Assessment | Current needs Assessment |
| N of assessments completed | Number of carers | Number of carers |
| 1 | 1628 | 1987 |
| 2 | 281 | 343 |
| 3 | 105 | 134 |
| 4 | 33 | 40 |
| 5 | 20 | 23 |
| 6 | 5 | 6 |
| 7 | 1 | 6 |
| 8 | 1 | - |
| 9 | - | 2 |
| Total | 2074 | 2541 |
| Eligible cases for analysis | 165 | 554 |

Table 12: Number of cases able to be analysed (legacy and current needs assessment)

|  |  |  |
| --- | --- | --- |
| Eligibility for analysis | Legacy needs assessment | Current needs assessment |
| Eligible cases (>3 assessments) | 165 | 211 |
| Excluded – no dates | 8 | 1 |
| Excluded – duplicate from legacy needs assessment | - | 9 |
| Total | 157 | 201 |

Table 13: Case status of carer

|  |  |  |
| --- | --- | --- |
| **Case status in date set** | **N** | **%** |
| Closed case (previous) | 21073 | 85 |
| Open case (current) | 3510 | 14 |
| Waiting (future) | 242 | 1 |
| Total | 24825 | 100 |

Table 14: Proportions of carers defined as main or secondary carer

|  |  |  |
| --- | --- | --- |
| **Type of carer** | **N** | **%** |
| Main | 17557 | 71 |
| Secondary | 1641 | 7 |
| Not yet set | 5604 | 23 |
| Total | 24802 | 100 |
| Missing cases | 23 |  |

Table 15: Living circumstances of person with dementia

|  |  |  |
| --- | --- | --- |
| **Living circumstances of person with dementia** | **N** | **%** |
| Living with AN carer | 3704 | 57 |
| Living with another carer | 453 | 7 |
| Living alone | 916 | 14 |
| Residential care/nursing home | 425 | 7 |
| Deceased | 660 | 10 |
| In hospital | 243 | 4 |
| Supported living | 62 | 1 |
| Other | 37 | 1 |
| Total | 6500 | 100 |
| Missing | 18325 |  |

Table 16: Gender of carer and person with dementia

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Carer** | | **Person with dementia** | |
| Gender | N | % | N | % |
| Female | 14647 | 70 | 10774 | 53 |
| Male | 6258 | 30 | 9452 | 47 |
| Total | 20905 | 100 | 20226 | 100 |
| Missing | 3920 |  | 4599 |  |

Table 17: Employment status of carer and person with dementia

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Carer** | | **Person with dementia** | |
| Employment status | N | % | N | % |
| Employed full-time | 2114 | 15.3 | 20 | 0.3 |
| Employed part-time | 1240 | 9.0 | 11 | 0.1 |
| Self-employed | 331 | 2.4 | 15 | 0.2 |
| Retired | 8682 | 62.7 | 7238 | 98.1 |
| Unemployed | 783 | 5.7 | 84 | 1.1 |
| Left work to become carer | 695 | 5.0 | 9 | 0.1 |
| Total | 13845 | 100.0 | 7377 | 100 |
| Missing | 10980 |  | 17448 |  |

Table 18: Ethnic group of carers and people with dementia

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Carer** | | **Person with dementia** | |
| Ethnic group | N | % | N | % |
| White | 13899 | 90.8 | 12668 | 90.7 |
| Mixed | 63 | 0.4 | 40 | 0.3 |
| Asian/Asian British | 517 | 3.4 | 498 | 3.6 |
| Black African/Caribbean/British | 580 | 3.8 | 549 | 3.9 |
| Other | 253 | 1.7 | 218 | 1.6 |
| Total | 15312 | 100.0 | 13973 | 100.0 |
| Missing | 9513 |  | 10852 |  |

Table 19: Age of carers and people with dementia

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Carer** | | **Person with dementia** | |
| Age group | N | % | N | % |
| <161 | 99 | .8 | 169 | .8 |
| 16-24 | 43 | .4 | 3 | .4 |
| 25-34 | 143 | 1.2 | 6 | 1.2 |
| 35-44 | 595 | 4.9 | 14 | 4.9 |
| 45-54 | 1860 | 15.3 | 113 | 15.3 |
| 55-64 | 2425 | 20.0 | 696 | 20.0 |
| 64-69 | 1265 | 10.4 | 1068 | 10.4 |
| 70-74 | 1430 | 11.8 | 2107 | 11.8 |
| 75+ | 4261 | 35.2 | 13855 | 35.2 |
| Total | 12121 | 100.0 | 18031 | 100.0 |
| Missing | 12704 |  | 6794 |  |

1. Possible database entry errors.

Table 20: Relationship between age of carer and age of person with dementia

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | PWD age groups | | | | | | | | | |
| <16 | 16-24 | 25-34 | 35-44 | 45-54 | 55-64 | 64-69 | 70-74 | 75+ | Total |
| Carer age groups | <161 | 16 | 0 | 1 | 0 | 0 | 2 | 1 | 8 | 52 | 80 |
| 16-24 | 1 | 0 | 0 | 1 | 3 | 5 | 5 | 5 | 18 | 38 |
| 25-34 | 1 | 0 | 1 | 1 | 5 | 24 | 17 | 17 | 64 | 130 |
| 35-44 | 5 | 0 | 0 | 2 | 5 | 32 | 47 | 95 | 316 | 502 |
| 45-54 | 12 | 0 | 0 | 1 | 26 | 65 | 43 | 147 | 1303 | 1597 |
| 55-64 | 15 | 0 | 0 | 2 | 12 | 215 | 172 | 129 | 1596 | 2141 |
| 64-69 | 7 | 0 | 0 | 0 | 3 | 56 | 230 | 266 | 578 | 1140 |
| 70-74 | 7 | 0 | 0 | 1 | 1 | 19 | 89 | 387 | 782 | 1286 |
| 75+ | 24 | 1 | 0 | 1 | 8 | 6 | 29 | 192 | 3505 | 3766 |
| Total | | 88 | 1 | 2 | 9 | 63 | 424 | 633 | 1246 | 8214 | 10680 |

Missing cases: 141451. Possible database entry errors.

Table 21: Marital status of carers and people with dementia

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Carer** | | **Person with dementia** | |
| Marital status | N | % | N | % |
| Married | 14429 | 84.5 | 10481 | 69.5 |
| Widowed | 315 | 1.8 | 3648 | 24.2 |
| Divorced | 387 | 2.3 | 265 | 1.8 |
| Separated | 107 | 0.6 | 87 | 0.6 |
| Single | 1242 | 7.3 | 316 | 2.1 |
| Living in partnership | 604 | 3.5 | 287 | 1.9 |
| Total | 17084 | 100.0 | 15084 | 100.0 |
| Missing | 7741 |  | 9741 |  |

Table 22: Marital status and carer’s relationship to person with dementia

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Carer marital status | **Carer's relationship to person with dementia** | | | | | | |
| Spouse1 | Child (adult) | Sibling | Neighbour/friend | Grandchild (adult) | Other | Total |
| Married | 10327 | 3562 | 118 | 24 | 33 | 129 | 14193 |
| 72.8% | 25.1% | 0.8% | 0.2% | 0.2% | 0.9% | 100.0% |
| Widowed | 87 | 134 | 40 | 20 | 0 | 15 | 296 |
| 29.4% | 45.3% | 13.5% | 6.8% | 0.0% | 5.1% | 100.0% |
| Divorced | 35 | 305 | 10 | 16 | 0 | 8 | 374 |
| 9.4% | 81.6% | 2.7% | 4.3% | 0.0% | 2.1% | 100.0% |
| Separated | 20 | 72 | 0 | 5 | 0 | 4 | 101 |
| 19.8% | 71.3% | 0.0% | 5.0% | 0.0% | 4.0% | 100.0% |
| Single | 13 | 1025 | 49 | 48 | 43 | 29 | 1207 |
| 1.1% | 84.9% | 4.1% | 4.0% | 3.6% | 2.4% | 100.0% |
| Living in partnership | 287 | 253 | 5 | 9 | 18 | 10 | 582 |
| 49.3% | 43.5% | 0.9% | 1.5% | 3.1% | 1.7% | 100.0% |
| Not entered | 80 | 806 | 37 | 25 | 20 | 31 | 999 |
| 8.0% | 80.7% | 3.7% | 2.5% | 2.0% | 3.1% | 100.0% |
| Total | 10849 | 6157 | 259 | 147 | 114 | 226 | 17752 |
| 61.1% | 34.7% | 1.5% | 0.8% | 0.6% | 1.3% | 100.0% |

Missing cases: 7073

1. Spouse includes all spousal relationships, including partners and ex-spouses.

Table 23: Dementia type by current case status

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Current case status | | | |
| Dementia Type | Closed N (%) | Open N (%) | Waiting list N (%) | Total N (%) |
| Alzheimer's | 4124 (19.6) | 642 (18.3) | 48 (19.8) | 4814 (19.4) |
| Vascular dementia | 3194 (15.2) | 434 (12.4) | 41 (16.9) | 3669 (14.8) |
| Dementia non-specific | 574 (2.7) | 105 (3.0) | 25 (10.3) | 704 (2.8) |
| Mixed vascular and Alzheimer's | 1441 (6.8) | 219 (6.2) | 16 (6.6) | 1676 (6.8) |
| Lewy body disease | 329 (1.6) | 44 (1.3) | 5 (2.1) | 378 (1.5) |
| Oher forms of dementia | 255 (1.2) | 46 (1.3) | 8 (3.3) | 309 (1.2) |
| Frontal temporal lobe dementia | 268 (1.3) | 45 (1.3) | 2 (0.8) | 315 (1.3) |
| Parkinson's Disease | 260 (1.2) | 34 (1.0) | 3 (1.2) | 297 (1.2) |
| Alcohol-related dementia | 60 (0.3) | 7 (0.2) | 1 (0.4) | 68 (0.3) |
| Not entered | 3032 (14.4) | 144 (4.1) | 22 (9.1) | 3198 (12.9) |
| Blank | 7539(35.8) | 1790(51) | 71(29.3) | 9397(37.9) |
| Total | 13537 (100) | 1720 (100) | 171 (100) | 24825(100) |

Table 24: Intensity of input for current clients (n=3510)

|  |  |  |
| --- | --- | --- |
| **Intensity of input** | **N** | **%** |
| Maintaining | 1093 | 31 |
| Holding pool | 434 | 13 |
| Not yet set | 1591 | 45 |
| Intensive | 392 | 11 |
| Total | 3510 | 100 |

Table 25: Services referring carers into the AN service

|  |  |  |
| --- | --- | --- |
| **Service referring carer to AN** | **N** | **%** |
| Mental health professional/service | 5925 | 24.9 |
| Psychiatrist (inc. consultant) | 3275 | 13.6 |
| Self | 4362 | 18.3 |
| Other health care professional | 2719 | 11.4 |
| Social services (inc. day care) | 2081 | 8.7 |
| Other | 1869 | 7.9 |
| GP | 1355 | 5.7 |
| Relative | 613 | 2.6 |
| Voluntary agency/third sector | 539 | 2.3 |
| Carer support worker | 470 | 2.0 |
| Community health | 465 | 2.0 |
| Other carer | 89 | 0.4 |
| Friend/Neighbour | 57 | 0.2 |
| Not clear | 3 | 0.0 |
| Total | 23822 | 100.0 |
| Missing | 1003 |  |

Table 26: Number of services involved with the dyads

|  |  |  |
| --- | --- | --- |
| **Number of services involved** | **N of dyads** | **%** |
| 0 | 77 | 2 |
| 1 | 2268 | 64 |
| 2 | 777 | 22 |
| 3 | 281 | 8 |
| 4 | 93 | 3 |
| 5 or more | 47 | 1 |
| Total | 3543 | 100 |

Table 27: The number of dyads receiving each type of service

|  |  |
| --- | --- |
| **Type of service** | **N of dyads receiving service** |
| Adult Mental Health Services | 218 |
| Alzheimer's Society | 98 |
| Carer Dementia Support Service | 3 |
| Carer's Group | 43 |
| Community Mental Health Team | 503 |
| Day Care | 329 |
| Day Centre | 18 |
| District Nursing | 8 |
| Elderly Mental Health Services | 652 |
| General Medical Services | 222 |
| Home Care | 15 |
| Independent Sector | 331 |
| Hospital-based MDT | 1 |
| National Hospital | 2 |
| Primary Care | 355 |
| Social Services | 1818 |
| Voluntary Organisation | 217 |

Table 28: Services received by dyads who were only receiving one service

|  |  |  |
| --- | --- | --- |
| **Type of service** | **N of dyads using only this one service** | **%** |
| Adult Mental Health Services | 110 | 5 |
| Alzheimer's Society | 44 | 2 |
| Carer's Group | 20 | 1 |
| Community Mental Health Team | 262 | 12 |
| Day Care | 87 | 4 |
| Day Centre | 5 | 0 |
| District Nursing | 2 | 0 |
| Elderly Mental Health Services | 349 | 15 |
| General Medical Services | 93 | 4 |
| Independent Sector | 117 | 5 |
| Primary Care | 124 | 5 |
| Social Services | 977 | 43 |
| Voluntary Organisation | 78 | 3 |
| Total | 2268 | 100 |

Table 29: Number of other people ‘involved’ per dyad

|  |  |  |
| --- | --- | --- |
| **Number of other people** | **N of dyads reporting this number of other people** | **%** |
| 0 | 25 | 1.1 |
| 1 | 1926 | 82.2 |
| 2 | 303 | 12.9 |
| 3 | 72 | 3.1 |
| 4 | 11 | 0.5 |
| 5 | 3 | 0.1 |
| 6 | 2 | 0.1 |
| Total | 2342 | 100 |

Table 30: Other involved person’s relationship to the person with dementia (all other involved people)

|  |  |  |
| --- | --- | --- |
| **Relationship family member to person with dementia (all other family members)** | **N of dyads reporting this relationship** | **%** |
| Spouse/partner | 120 | 5 |
| Adult child/child-in-law | 2012 | 84 |
| Sibling | 60 | 3 |
| Grandchild | 81 | 3 |
| Neighbour/Friend | 38 | 2 |
| Other | 81 | 3 |
| Total | 2392 | 100 |

Table 31: Other involved person’s relationship to the person with dementia when there was only one other person reported as ‘involved’

|  |  |  |
| --- | --- | --- |
| **Relationship of family member to person with dementia (cases where only one other person involved)** | **N of dyads reporting this relationship** | **%** |
| Spouse | 101 | 5 |
| Adult child | 1646 | 85 |
| Sibling | 44 | 2 |
| Grandchild | 54 | 3 |
| Neighbour/Friend | 25 | 1 |
| Other | 56 | 3 |
| Total | 1926 | 100 |

Table 32: Descriptive results from legacy needs assessment

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | | **Responses – level of intervention needed (%)** | | | | |  | |
| Question number\_  Time | n | None  (0) | Minimal  (1) | Some  (2) | Considerable  (3) | Urgent  (4) | Total % | Median |
| 1\_1 | 154 | 63 | 31 | 5 | 0 | 1 | 100 | 0 |
| 1\_2 | 154 | 75 | 20 | 3 | 1 | 1 | 100 | 0 |
| 1\_3 | 147 | 73 | 22 | 3 | 1 | 1 | 100 | 0 |
| 2\_1 | 155 | 43 | 31 | 17 | 7 | 2 | 100 | 1 |
| 2\_2 | 154 | 69 | 21 | 7 | 2 | 1 | 100 | 0 |
| 2\_3 | 147 | 71 | 19 | 8 | 2 | 0 | 100 | 0 |
| 3\_1 | 155 | 67 | 22 | 8 | 3 | 0 | 100 | 0 |
| 3\_2 | 157 | 67 | 27 | 4 | 2 | 0 | 100 | 0 |
| 3\_3 | 157 | 64 | 27 | 7 | 1 | 1 | 100 | 0 |
| 4\_1 | 154 | 39 | 32 | 24 | 5 | 0 | 100 | 1 |
| 4\_2 | 157 | 41 | 34 | 24 | 1 | 0 | 100 | 1 |
| 4\_3 | 157 | 40 | 42 | 15 | 3 | 0 | 100 | 1 |
| 5\_1 | 152 | 78 | 10 | 8 | 3 | 1 | 100 | 0 |
| 5\_2 | 154 | 78 | 17 | 3 | 1 | 1 | 100 | 0 |
| 5\_3 | 145 | 89 | 9 | 1 | 1 | 0 | 100 | 0 |
| 6\_1 | 154 | 25 | 27 | 24 | 16 | 8 | 100 | 1 |
| 6\_2 | 155 | 54 | 32 | 13 | 0 | 1 | 100 | 0 |
| 6\_3 | 147 | 78 | 15 | 5 | 1 | 1 | 100 | 0 |
| 7\_1 | 156 | 22 | 29 | 29 | 16 | 4 | 100 | 1 |
| 7\_2 | 155 | 46 | 36 | 16 | 1 | 1 | 100 | 1 |
| 7\_3 | 147 | 66 | 26 | 5 | 1 | 2 | 100 | 0 |
| 8\_1 | 153 | 21 | 33 | 30 | 13 | 3 | 100 | 1 |
| 8\_2 | 155 | 35 | 43 | 18 | 4 | 0 | 100 | 1 |
| 8\_3 | 148 | 53 | 37 | 6 | 2 | 2 | 100 | 0 |
| 9\_1 | 156 | 69 | 18 | 8 | 4 | 1 | 100 | 0 |
| 9\_2 | 156 | 74 | 17 | 8 | 1 | 0 | 100 | 0 |
| 9\_3 | 151 | 71 | 20 | 6 | 3 | 0 | 100 | 0 |
| 10\_1 | 154 | 88 | 6 | 2 | 3 | 1 | 100 | 0 |
| 10\_2 | 154 | 88 | 10 | 1 | 1 | 0 | 100 | 0 |
| 10\_3 | 149 | 90 | 8 | 1 | 1 | 0 | 100 | 0 |
| 11\_1 | 154 | 54 | 30 | 12 | 4 | 0 | 100 | 0 |
| 11\_2 | 156 | 73 | 24 | 3 | 0 | 0 | 100 | 0 |
| 11\_3 | 153 | 87 | 10 | 2 | 1 | 0 | 100 | 0 |
| 12\_1 | 146 | 86 | 10 | 3 | 1 | 0 | 100 | 0 |
| 12\_2 | 151 | 93 | 4 | 3 | 0 | 0 | 100 | 0 |
| 12\_3 | 143 | 91 | 6 | 2 | 1 | 0 | 100 | 0 |
| 13\_1 | 155 | 70 | 21 | 8 | 1 | 0 | 100 | 0 |
| 13\_2 | 153 | 83 | 14 | 2 | 1 | 0 | 100 | 0 |
| 13\_3 | 145 | 85 | 10 | 3 | 1 | 1 | 100 | 0 |
| 14\_1 | 155 | 45 | 28 | 17 | 8 | 2 | 100 | 1 |
| 14\_2 | 151 | 60 | 26 | 11 | 1 | 2 | 100 | 0 |
| 14\_3 | 143 | 69 | 24 | 5 | 1 | 1 | 100 | 0 |
| 15\_1 | 140 | 70 | 17 | 8 | 4 | 1 | 100 | 0 |
| 15\_2 | 143 | 70 | 18 | 8 | 3 | 1 | 100 | 0 |
| 15\_3 | 139 | 73 | 17 | 7 | 2 | 1 | 100 | 0 |
| 16\_1 | 141 | 48 | 25 | 16 | 10 | 1 | 100 | 1 |
| 16\_2 | 151 | 44 | 30 | 18 | 7 | 1 | 100 | 1 |
| 16\_3 | 155 | 53 | 27 | 12 | 8 | 0 | 100 | 0 |
| 17\_1 | 157 | 81 | 13 | 4 | 1 | 1 | 100 | 0 |
| 17\_2 | 155 | 83 | 14 | 1 | 1 | 1 | 100 | 0 |
| 17\_3 | 151 | 90 | 7 | 2 | 0 | 1 | 100 | 0 |
| 18\_1 | 155 | 50 | 29 | 13 | 8 | 0 | 100 | 1 |
| 18\_2 | 154 | 60 | 26 | 11 | 3 | 0 | 100 | 0 |
| 18\_3 | 149 | 69 | 22 | 7 | 2 | 0 | 100 | 0 |
| 19\_1 | 137 | 73 | 20 | 6 | 1 | 0 | 100 | 0 |
| 19\_2 | 142 | 66 | 20 | 8 | 6 | 0 | 100 | 0 |
| 19\_3 | 138 | 59 | 25 | 9 | 5 | 2 | 100 | 0 |

Table 33: Descriptive results from current needs assessment

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | | **Responses – level of needed (%)\*** | | |  | |
| Question\_  Time | n | No need  (0) | Needs currently met (1) | Unmet need (2) | Total (%) | Median |
| 1\_1 | 188 | 26 | 62 | 12 | 100 | 1 |
| 1\_2 | 172 | 29 | 66 | 5 | 100 | 1 |
| 1\_3 | 175 | 29 | 68 | 3 | 100 | 1 |
| 2\_1 | 189 | 16 | 65 | 19 | 100 | 1 |
| 2\_2 | 175 | 22 | 65 | 13 | 100 | 1 |
| 2\_3 | 175 | 22 | 67 | 11 | 100 | 1 |
| 3\_1 | 186 | 35 | 51 | 14 | 100 | 1 |
| 3\_2 | 177 | 41 | 52 | 7 | 100 | 1 |
| 3\_3 | 179 | 40 | 53 | 7 | 100 | 1 |
| 4\_1 | 190 | 26 | 24 | 50 | 100 | 1.5 |
| 4\_2 | 178 | 33 | 37 | 30 | 100 | 1 |
| 4\_3 | 176 | 35 | 35 | 30 | 100 | 1 |
| 5\_1 | 187 | 47 | 44 | 9 | 100 | 1 |
| 5\_2 | 171 | 47 | 48 | 5 | 100 | 1 |
| 5\_3 | 171 | 52 | 46 | 2 | 100 | 0 |
| 6\_1 | 187 | 17 | 22 | 61 | 100 | 2 |
| 6\_2 | 177 | 22 | 29 | 49 | 100 | 1 |
| 6\_3 | 175 | 29 | 34 | 37 | 100 | 1 |
| 7\_1 | 186 | 16 | 19 | 65 | 100 | 2 |
| 7\_2 | 180 | 22 | 24 | 54 | 100 | 2 |
| 7\_3 | 178 | 30 | 25 | 45 | 100 | 1 |
| 8\_1 | 185 | 64 | 24 | 12 | 100 | 0 |
| 8\_2 | 168 | 66 | 25 | 9 | 100 | 0 |
| 8\_3 | 169 | 70 | 21 | 9 | 100 | 0 |
| 9\_1 | 173 | 62 | 32 | 6 | 100 | 0 |
| 9\_2 | 159 | 65 | 32 | 3 | 100 | 0 |
| 9\_3 | 163 | 70 | 29 | 1 | 100 | 0 |
| 10\_1 | 180 | 36 | 48 | 16 | 100 | 1 |
| 10\_2 | 167 | 42 | 52 | 6 | 100 | 1 |
| 10\_3 | 168 | 45 | 50 | 5 | 100 | 1 |
| 11\_1 | 176 | 61 | 34 | 5 | 100 | 0 |
| 11\_2 | 167 | 62 | 33 | 5 | 100 | 0 |
| 11\_3 | 168 | 68 | 29 | 3 | 100 | 0 |
| 12\_1 | 180 | 40 | 42 | 18 | 100 | 1 |
| 12\_2 | 173 | 43 | 46 | 11 | 100 | 1 |
| 12\_3 | 169 | 48 | 44 | 8 | 100 | 1 |
| 13\_1 | 181 | 35 | 47 | 18 | 100 | 1 |
| 13\_2 | 172 | 39 | 53 | 8 | 100 | 1 |
| 13\_3 | 170 | 42 | 53 | 5 | 100 | 1 |
| 14\_1 | 171 | 30 | 24 | 46 | 100 | 1 |
| 14\_2 | 169 | 36 | 24 | 40 | 100 | 1 |
| 14\_3 | 171 | 39 | 30 | 31 | 100 | 1 |
| 15\_1 | 178 | 22 | 30 | 48 | 100 | 1 |
| 15\_2 | 175 | 31 | 35 | 34 | 100 | 1 |
| 15\_3 | 172 | 36 | 44 | 20 | 100 | 1 |
| 16\_1 | 183 | 25 | 38 | 37 | 100 | 1 |
| 16\_2 | 181 | 31 | 37 | 32 | 100 | 1 |
| 16\_3 | 176 | 35 | 41 | 24 | 100 | 1 |
| 17\_1 | 159 | 28 | 27 | 45 | 100 | 1 |
| 17\_2 | 163 | 29 | 29 | 42 | 100 | 1 |
| 17\_3 | 174 | 31 | 31 | 38 | 100 | 1 |
| 18\_1 | 24 | 71 | 25 | 4 | 100 | 0 |
| 18\_2 | 63 | 56 | 30 | 14 | 100 | 0 |
| 18\_3 | 86 | 62 | 22 | 16 | 100 | 0 |

\*Option 4 – ‘not known’ excluded from report

Table 34: Legacy needs assessment – Friedman test (with post hoc analysis) results

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Question\_Time | n | Mean rank | χ2 (df=2) | p (Friedman) | Pairs being tested | Z | p (Wilcoxon) |
| 1\_1 | 144 | 2.1 | 4.895 | 0.087 |  |  |  |
| 1\_2 | 1.93 |  |  |  |
| 1\_3 | 1.97 |  |  |  |
| 2\_1 | 145 | 2.28 | 28.848 | 0.000 | 1to2 | -4.354 | 0.000 |
| 2\_2 | 1.85 | 1to3 | -4.725 | 0.000 |
| 2\_3 | 1.87 | 2to3 | -0.093 | 0.926 |
| 3\_1 | 155 | 2.02 | 0.589 | 0.745 |  |  |  |
| 3\_2 | 1.97 |  |  |  |
| 3\_3 | 2.01 |  |  |  |
| 4\_1 | 154 | 2.04 | 1.574 | 0.455 |  |  |  |
| 4\_2 | 2.02 |  |  |  |
| 4\_3 | 1.94 |  |  |  |
| 5\_1 | 141 | 2.09 | 11.253 | 0.004 | 1to2 | -1.609 | 0.108 |
| 5\_2 | 2.03 | 1to3 | -3.478 | 0.001 |
| 5\_3 | 1.88 | 2to3 | -2.399 | 0.016 |
| 6\_1 | 143 | 2.58 | 132.991 | 0.000 | 1to2 | -7.928 | 0.000 |
| 6\_2 | 1.88 | 1to3 | -8.271 | 0.000 |
| 6\_3 | 1.55 | 2to3 | -4.314 | 0.000 |
| 7\_1 | 145 | 2.51 | 104.739 | 0.000 | 1to2 | -7.418 | 0.000 |
| 7\_2 | 1.9 | 1to3 | -7.917 | 0.000 |
| 7\_3 | 1.59 | 2to3 | -4.002 | 0.000 |
| 8\_1 | 143 | 2.4 | 65.49 | 0.000 | 1to2 | -5.833 | 0.000 |
| 8\_2 | 1.94 | 1to3 | -6.756 | 0.000 |
| 8\_3 | 1.66 | 2to3 | -3.442 | 0.001 |
| 9\_1 | 150 | 2.06 | 3.619 | 0.164 |  |  |  |
| 9\_2 | 1.93 |  |  |  |
| 9\_3 | 2.01 |  |  |  |
| 10\_1 | 147 | 2.02 | 1.326 | 0.515 |  |  |  |
| 10\_2 | 2.01 |  |  |  |
| 10\_3 | 1.97 |  |  |  |
| 11\_1 | 150 | 2.29 | 49.805 | 0.000 | 1to2 | -4.719 | 0.000 |
| 11\_2 | 1.95 | 1to3 | -5.752 | 0.000 |
| 11\_3 | 1.76 | 2to3 | -3.244 | 0.001 |
| 12\_1 | 133 | 2.07 | 5.396 | 0.067 |  |  |  |
| 12\_2 | 1.95 |  |  |  |
| 12\_3 | 1.98 |  |  |  |
| 13\_1 | 141 | 2.13 | 12.339 | 0.002 | 1to2 | -2.906 | 0.004 |
| 13\_2 | 1.94 | 1to3 | -2.221 | 0.026 |
| 13\_3 | 1.92 | 2to3 | -0.328 | 0.743 |
| 14\_1 | 138 | 2.22 | 22.302 | 0.000 | 1to2 | -3.281 | 0.001 |
| 14\_2 | 1.96 | 1to3 | -4.385 | 0.000 |
| 14\_3 | 1.82 | 2to3 | -2.076 | 0.038 |
| 15\_1 | 122 | 2.07 | 2.197 | 0.333 |  |  |  |
| 15\_2 | 1.95 |  |  |  |
| 15\_3 | 1.98 |  |  |  |
| 16\_1 | 140 | 2.06 | 4.502 | 0.105 |  |  |  |
| 16\_2 | 2.04 |  |  |  |
| 16\_3 | 1.9 |  |  |  |
| 17\_1 | 151 | 2.07 | 8.845 | 0.012 | 1to2 | -1.333 | 0.182 |
| 17\_2 | 2.01 | 1to3 | -2.921 | 0.003 |
| 17\_3 | 1.92 | 2to3 | -2.065 | 0.039 |
| 18\_1 | 145 | 2.21 | 27.992 | 0.000 | 1to2 | -2.563 | 0.010 |
| 18\_2 | 1.99 | 1to3 | -3.907 | 0.000 |
| 18\_3 | 1.8 | 2to3 | -2.434 | 0.015 |
| 19\_1 | 118 | 1.87 | 9.869 | 0.007 | 1to2 | -2.761 | 0.006 |
| 19\_2 | 2.01 | 1to3 | -3.456 | 0.001 |
| 19\_3 | 2.12 | 2to3 | -1.500 | 0.134 |

Friedman significance level – 0.05; Wilcoxon significance level (after Bonferroni adjustment) – 0.017

Table 35: Current needs assessment - Friedman test (with post hoc analysis) results

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Question\_Time | n | Mean rank | χ2 (df=2) | p (Friedman) | Pairs being tested | Z | p (Wilcoxon) |
| 1\_1 | 158 | 2.08 | 6.721 | 0.035 | 1to2 | -2.351 | 0.019 |
| 1\_2 | 1.98 | 1to3 | -2.592 | 0.010 |
| 1\_3 | 1.95 | 2to3 | -.192 | 0.847 |
| 2\_1 | 158 | 2.11 | 10.685 | 0.005 | 1to2 | -2.370 | 0.018 |
| 2\_2 | 1.98 | 1to3 | -2.408 | 0.016 |
| 2\_3 | 1.91 | 2to3 | -1.766 | 0.077 |
| 3\_1 | 160 | 2.09 | 7.597 | 0.022 | 1to2 | -2.448 | 0.014 |
| 3\_2 | 1.97 | 1to3 | -2.498 | 0.012 |
| 3\_3 | 1.94 | 2to3 | -.010 | 0.992 |
| 4\_1 | 161 | 2.21 | 29.779 | 0.000 | 1to2 | -4.380 | 0.000 |
| 4\_2 | 1.93 | 1to3 | -3.719 | 0.000 |
| 4\_3 | 1.86 | 2to3 | -.592 | 0.554 |
| 5\_1 | 155 | 2.08 | 11.176 | 0.004 | 1to2 | -1.422 | 0.155 |
| 5\_2 | 2.01 | 1to3 | -3.064 | 0.002 |
| 5\_3 | 1.91 | 2to3 | -2.353 | 0.019 |
| 6\_1 | 160 | 2.23 | 47.722 | 0.000 | 1to2 | -3.505 | 0.000 |
| 6\_2 | 2.01 | 1to3 | -5.497 | 0.000 |
| 6\_3 | 1.76 | 2to3 | -3.959 | 0.000 |
| 7\_1 | 158 | 2.19 | 38.273 | 0.000 | 1to2 | -3.250 | 0.001 |
| 7\_2 | 2.01 | 1to3 | -4.995 | 0.000 |
| 7\_3 | 1.8 | 2to3 | -3.737 | 0.000 |
| 8\_1 | 152 | 2.07 | 4.762 | 0.092 |  |  |  |
| 8\_2 | 2.00 |  |  |  |
| 8\_3 | 1.93 |  |  |  |
| 9\_1 | 139 | 2.10 | 13.850 | 0.001 | 1to2 | -2.172 | 0.030 |
| 9\_2 | 1.99 | 1to3 | -3.535 | 0.000 |
| 9\_3 | 1.91 | 2to3 | -1.831 | 0.067 |
| 10\_1 | 147 | 2.08 | 4.908 | 0.086 |  |  |  |
| 10\_2 | 1.98 |  |  |  |
| 10\_3 | 1.94 |  |  |  |
| 11\_1 | 147 | 2.02 | 5.150 | 0.076 |  |  |  |
| 11\_2 | 2.04 |  |  |  |
| 11\_3 | 1.93 |  |  |  |
| 12\_1 | 150 | 2.11 | 10.953 | 0.004 | 1to2 | -1.933 | 0.053 |
| 12\_2 | 2 | 1to3 | -2.465 | 0.014 |
| 12\_3 | 1.89 | 2to3 | -1.559 | 0.119 |
| 13\_1 | 148 | 2.12 | 12.457 | 0.002 | 1to2 | -2.687 | 0.007 |
| 13\_2 | 1.97 | 1to3 | -3.073 | 0.002 |
| 13\_3 | 1.91 | 2to3 | -.878 | 0.380 |
| 14\_1 | 145 | 2.09 | 10.307 | 0.006 | 1to2 | -.473 | 0.636 |
| 14\_2 | 2.02 | 1to3 | -2.359 | 0.018 |
| 14\_3 | 1.89 | 2to3 | -1.835 | 0.066 |
| 15\_1 | 151 | 2.24 | 42.306 | 0.000 | 1to2 | -3.144 | 0.002 |
| 15\_2 | 2 | 1to3 | -5.377 | 0.000 |
| 15\_3 | 1.77 | 2to3 | -3.173 | 0.002 |
| 16\_1 | 155 | 2.10 | 14.304 | 0.001 | 1to2 | -1.525 | 0.127 |
| 16\_2 | 2.04 | 1to3 | -3.162 | 0.002 |
| 16\_3 | 1.86 | 2to3 | -1.726 | 0.084 |
| 17\_1 | 129 | 2.05 | 2.651 | 0.266 |  |  |  |
| 17\_2 | 2.01 |  |  |  |
| 17\_3 | 1.94 |  |  |  |
| 18\_1 | 22 | 2.05 | 0.667 | 0.717 |  |  |  |
| 18\_2 | 1.98 |  |  |  |
| 18\_3 | 1.98 |  |  |  |

Friedman significance level – 0.05; Wilcoxon significance level (after Bonferroni adjustment) – 0.017

Table 36: Source of carers for survey and response rates

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Source of carers identified for survey** | | | |  |
|  | **Admiral Nursing services** | **Join Dementia Research (JDR)** | **Third sector organisations** | **TiDE** | **Totals** |
| Number of paper questionnaires distributed (excluding reminder packs) | 497 | 9 | 501 | 3 | 1010 |
| Paper questionnaires returned | 194 | 4 | 108 | 0 | 304 |
| Paper questionnaire refusals | 1 | 2 | 3 | - | 6 |
| **Paper questionnaires attempted and in scope** | **158** | **2** | **98** | **0** | **258** |
| Response rate (% returned and in scope) | 32 | 22 | 20 | 0 | 26 |
| Number of organisations sent anonymous electronic link for distribution | n/a | n/a | 6 | n/a | n/a |
| Number of individual links sent via organisations | n/a | 103 | At least 300 | 28 | n/a |
| Electronic survey returns | 0 | 35 | 76 | 15 | 126 |
| Refusals via electronic survey | 0 | 2 | 20 | 2 | 24 |
| **Electronic surveys in scope** | **0** | **26** | **50** | **12** | **88** |
| % response rate | n/a | 25 | n/a | 43 | n/a |
| **Total returned and in scope** | **158** | **37** | **139** | **12** | **346** |

Table 37: Comparison of survey carers with carers of people with dementia in the Survey of Carers in Households 2009/10

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  |  | ***% of AN carers*** | ***% of non-AN area carers*** | **% of all survey carers** | **% of SCH carers of people with dementia** |
| **Sex of carer** | Male | *36* | *26* | 31 | 35 |
|  | Female | *64* | *74* | 69 | 65 |
|  |  |  |  |  |  |
| **Age of carer** | <55 | *10* | *25* | 18 | 42 |
|  | 55-64 | *20* | *29* | 25 | 27 |
|  | 65-74 | *30* | *19* | 24 | 19 |
|  | 75+ | *40* | *26* | 32 | 11 |
|  |  |  |  |  |  |
| **Sex of person with dementia** | Male | *51* | *45* | 48 | 37 |
|  | Female | *49* | *55* | 52 | 63 |
|  |  |  |  |  |  |
| **Age of person with dementia** | <65 | *7* | *12* | 9 | 9 |
|  | 65-74 | *21* | *18* | 20 | 11 |
|  | 75+ | *72* | *69* | 71 | 80 |
|  |  |  |  |  |  |
|  |  |  |  |  |  |
| **Relationship of pwd to carer** | Spouse or partner | *76* | *58* | 66 | 22 |
|  | Parent/in-law | *22* | *37* | 30 | 57 |
|  | Other | *3* | *5* | 4 | 21 |
|  |  |  |  |  |  |
| **Type of care provided** | Personal and physical | *49* | *36* | 42 | 22 |
|  | Other | *51* | *64* | 58 | 78 |
|  |  |  |  |  |  |
| **Economic activity** | In paid employment | *15* | *29* | 23 | 49 |
|  | Not in paid employment | *85* | *77* | 77 | 51 |
| **Maximum N** |  | *158* | *188* | 346 | 249 |

Table 38: Differences between AN carers and non-AN area carers in a range of socio-economic characteristics

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Characteristic** | **Key categories** | **% of AN carers** | **% of non-AN area carers** | **χ2 value and degrees of freedom1** | **Statistical significance (two-sided)**  **P=** | **N =** |
| **Person with dementia** | |  |  |  |  |  |
| Where person with dementia lives: | living at home with carer | 81 | 68 | 9.404, df=4 | 0.052 | 346 |
| Relationship of person with dementia to carer: | spouse/partner | 76 | 58 |  |  | 332 |
|  | parent/in-law | 22 | 37 | 11.095, df=2 | 0.004\*\* | 332 |
| Sex of person with dementia: | Male | 51 | 45 | 1.058, df=1 | 0.304 | 332 |
| Age of person with dementia: | aged 75-84 | 43 | 39 | 3.758, df=5 | 0.585 | 331 |
| Self-reported ethnicity of person with dementia: | ‘white’ | 96 | 95 | 5.47, df=4 | 0.140 | 338 |
| How long dementia symptoms present: | 1-5 years | 60 | 59 | 1.119, df=3 | 0.773 | 339 |
| Whether has formal diagnosis of dementia: | yes | 95 | 96 | 0.391, df=2 | 0.822 | 340 |
| Diagnosis of: | Alzheimer’s Disease | 52 | 66 | 7.043, df=1 | 0.008\*\* | 346 |
|  | Vascular dementia | 39 | 27 | 5.727, df=1 | 0.017\* | 346 |
| Carer-reported severity of dementia | moderate | 65 | 62 | 3.412, df=2 | 0.182 | 339 |
| **Carer** | |  |  |  |  |  |
| Sex of carer: | female | 64 | 74 | 3.546, df=1 | 0.060 | 340 |
| Age of carer: | aged 45-54 | 9 | 18 |  |  |  |
|  | aged 75 or over | 40 | 26 | 23.202, df=7 | 0.002\*\* | 340 |
| Self-reported ethnicity of carer: | ‘white’ | 96 | 97 | 6.444, df=5 | 0.265 | 340 |
| Highest level of qualification of carers: | Master’s level or above | 3 | 14 |  |  |  |
|  | none | 24 | 13 | 23.902, df=6 | 0.001\*\*\* | 339 |
| Economic status of carer: | in full-time work | 2 | 12 | 13.195, df=1 | <0.001\*\*\* | 346 |
|  | retired from paid work | 63 | 50 | 5.577, df=1 | 0.018\* | 346 |
| Carer status | Is sole or main carer | 97 | 84 | 15.662df=2 | <0.001\*\*\* | 336 |
| How long has been caring for person with dementia: | 1-3 years | 35 | 30 | 4.854, df=6 | 0.563 | 339 |

\* significant difference at 0.05 level

\*\* significant difference at 0.01 level

\*\*\* significant difference at 0.001 level or beyond

1. The χ2 value is for the total distribution of the variable, so degrees of freedom reflect the numbers of categories in each variable. The % values in the table have been chosen to represent the category or categories that had the largest adjusted standardised residuals (>±1.96) when χ2 values suggested significant differences, or the largest categories where there was little difference between the two groups.

Table 39: Hours of care provided the previous day by AN carers and non-An area carers

|  |  |  |  |
| --- | --- | --- | --- |
| **Hours of care provided on previous day** | **% of AN carers** | **% of Non-AN area carers** | **All** |
| **0-5** | 19 | 26 | 23 |
| **6-11** | 22 | 27 | 25 |
| **12-17** | 28 | 27 | 27 |
| **18 or more** | 31 | 19 | 25 |
| **N (100%)** | 153 | 175 | 328 |

χ2 = 7.98, df = 3, p = 0.046

Table 40: Percentage of carers reporting problems on EQ-5D dimension by age group of carer

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **EQ-5D Dimension** | | **Age group of carer  (all carers)** | | | | | **χ2 value and degrees of freedom** | **Statistical significance (two-sided) p=** | **N** |
| <55 | 55-64 | 65-74 | 75 and over | Total |
| Mobility | No problems | 76 | 71 | 67 | 32 | 59 |  |  |  |
|  | Problems | 24 | 29 | 33 | 63 | 41 | 45.53, df=3 | <.001\*\* | 330 |
| Self-care | No problems | 95 | 96 | 93 | 87 | 92 |  |  |  |
|  | Problems | 5 | 4 | 7 | 13 | 8 | 7.03, df=3 | 0.071 | 329 |
| Usual activity | No problems | 53 | 51 | 45 | 30 | 43 |  |  |  |
|  | Problems | 48 | 49 | 55 | 71 | 57 | 12.42, df=3 | 0.006\*\* | 330 |
| Pain/discomfort | No problems | 48 | 33 | 32 | 20 | 31 |  |  |  |
|  | Problems | 53 | 67 | 68 | 80 | 69 | 13.59, df=3 | 0.004\*\* | 330 |
| Anxiety and depression | No problems | 27 | 14 | 20 | 28 | 22 |  |  |  |
|  | Problems | 73 | 86 | 81 | 72 | 78 | 6.02, df=3 | 0.111 | 330 |

\* significant difference at 0.05 level

\*\* significant difference at 0.01 level

\*\*\* significant difference at 0.001 level or beyond

Table 41: Proportion of carers with needs and no needs in each ASCOT Carer domain by age of carer

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **ASCOT Carer domain** | | **% of carers in each age group (all carers)** | | | | | **Χ2 value and degrees of freedom** | **Statistical significance (two-sided) p=** | **N** |
| <55 | 55-64 | 65-74 | 75 and over | Total |
| How spend time | No needs | 24 | 19 | 13 | 16 | 18 |  |  |  |
|  | Needs | 76 | 81 | 87 | 84 | 82 | 2.79, df=3 | 0.426 | 330 |
| Control over daily life | No needs | 46 | 29 | 22 | 23 | 28 |  |  |  |
|  | Needs | 54 | 71 | 78 | 77 | 72 | 12.22, df=3 | 0.007\*\* | 331 |
| Look after self | No needs | 58 | 46 | 50 | 57 | 53 |  |  |  |
|  | Needs | 42 | 54 | 50 | 43 | 47 | 2.82, df=3 | 0.421 | 329 |
| Feel safe | No needs | 93 | 94 | 88 | 91 | 91 |  |  |  |
|  | Needs | 7 | 6 | 12 | 9 | 9 | 2.27, df=3 | 0.518 | 327 |
| Social contact | No needs | 48 | 36 | 29 | 32 | 35 |  |  |  |
|  | Needs | 52 | 64 | 71 | 68 | 65 | 5.72, df=3 | 0.126 | 329 |
| Space and time to be self | No needs | 32 | 27 | 24 | 21 | 25 |  |  |  |
|  | Needs | 68 | 73 | 76 | 79 | 75 | 2.43, df=3 | 0.489 | 327 |
| Feeling supported and encouraged | No needs | 38 | 31 | 48 | 49 | 42 |  |  |  |
|  | Needs | 62 | 69 | 52 | 51 | 58 | 7.915, df=3 | 0.048\* | 322 |

\* significant difference at 0.05 level

\*\* significant difference at 0.01 level

\*\*\* significant difference at 0.001 level or beyond

Table 42: ASCOT Carer total score by age of carer

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **% of carers in each age group (all carers)** | | | | |
| **ASCOT Carer score** | **<55** | **55-64** | **65-74** | **75 and over** | **Total** |
| 0-7 | 19 | 29 | 30 | 24 | 26 |
| 8-9 | 14 | 23 | 20 | 24 | 21 |
| 10-12 | 37 | 25 | 28 | 28 | 29 |
| 13 or more | 30 | 24 | 23 | 23 | 24 |
| N (100%) | 57 | 80 | 80 | 99 | 316 |

Missing cases = 30

Table 43: Proportion of carers with and without needs in each ASCOT Carer domain by nature of relationship to the person with dementia

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **ASCOT Carer domain** | | **% of carers in each relationship to person with dementia  (all carers)** | | | |  |  |  |
| **Spouse or partner** | **Parent or parent in-law** | **Other** | **Total** | **Χ2 value and degrees of freedom** | **Statistical significance (two-sided) p =** | **N** |
| How spend time | No needs | 15 | 27 | 8 | 18 |  |  |  |
|  | Needs | 86 | 73 | 92 | 82 | 7.66, df = 2 | 0.022\* | 323 |
| Control over daily life | No needs | 24 | 39 | 17 | 28 |  |  |  |
|  | Needs | 76 | 61 | 83 | 72 | 8.71, df =2 | 0.013\* | 324 |
| Look after self | No needs | 51 | 57 | 50 | 53 |  |  |  |
|  | Needs | 49 | 43 | 50 | 47 | 0.925, df = 2 | 0.630 | 323 |
| Feel safe | No needs | 91 | 94 | 92 | 92 |  |  |  |
|  | Needs | 9 | 6 | 8 | 8 | 0.635, df = 2 | 0.728 | 321 |
| Social contact | No needs | 31 | 43 | 33 | 35 |  |  |  |
|  | Needs | 69 | 57 | 67 | 65 | 4.47, df = 2 | 0.107 | 322 |
| Space and time to be self | No needs | 21 | 35 | 17 | 25 |  |  |  |
|  | Needs | 79 | 65 | 83 | 75 | 7.53, df = 2 | 0.023\* | 320 |
| Feeling supported and encouraged | No needs | 44 | 39 | 25 | 42 |  |  |  |
|  | Needs | 56 | 61 | 75 | 58 | 2.10, df = 2 | 0.349 | 315 |

\* significant difference at 0.05 level

\*\* significant difference at 0.01 level

\*\*\* significant difference at 0.001 level or beyond

Table 44: Proportion of carers with and without needs in each ASCOT Carer domain by carer status

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **ASCOT Carer domain** | | **% of carers in each carer category (all carers)** | | | |  |  |  |
| **Sole/main carer** | **Joint main carer** | **Not main carer** | **Total** | **Χ2 value and degrees of freedom** | **Statistical significance (two-sided) p =** | **N** |
| How spend time | No needs | 15 | 15 | 53 | 17 |  |  |  |
|  | Needs | 85 | 85 | 47 | 83 | 17.46, df = 2 | <0.001\*\*\* | 328 |
| Control over daily life | No needs | 25 | 54 | 58 | 28 |  |  |  |
|  | Needs | 75 | 46 | 42 | 72 | 14.44, df = 2 | 0.001\*\*\* | 328 |
| Look after self | No needs | 50 | 85 | 58 | 52 |  |  |  |
|  | Needs | 50 | 15 | 42 | 48 | 6.27, df = 2 | 0.043\* | 326 |
| Feel safe | No needs | 91 | 92 | 100 | 91 |  |  |  |
|  | Needs | 9 | 8 | 0 | 9 | 1.95, df = 2 | 0.378 | 324 |
| Social contact | No needs | 31 | 62 | 68 | 34 |  |  |  |
|  | Needs | 69 | 38 | 32 | 66 | 15.55, df = 2 | <.001\*\*\* | 326 |
| Space and time to be self | No needs | 23 | 31 | 56 | 25 |  |  |  |
|  | Needs | 77 | 69 | 44 | 75 | 10.22, df = 2 | 0.006\*\* | 324 |
| Feeling supported and encouraged | No needs | 41 | 33 | 59 | 41 |  |  |  |
|  | Needs | 59 | 67 | 41 | 59 | 2.55, df = 2 | 0.280 | 318 |

\* significant difference at 0.05 level

\*\* significant difference at 0.01 level

\*\*\* significant difference at 0.001 level or beyond

Table 45: Proportion of carers with and without needs in each ASCOT Carer domain by hours of care

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **ASCOT Carer domain** | | **% of carers in each category of hours of care provided in previous 24 hours(all carers)** | | | | |  |  |  |
| **0-5 hours** | **6-11 hours** | **12-17 hours** | **18 or more hours** | **Total** | **Χ2 value and degrees of freedom** | **Statistical significance (two-sided) p =** | **N** |
| How spend time | No needs | 31 | 20 | 7 | 13 | 17 |  |  |  |
|  | Needs | 69 | 80 | 93 | 87 | 83 | 17.87, de = 3 | <0.001\*\*\* | 324 |
| Control over daily life | No needs | 43 | 31 | 22 | 17 | 28 |  |  |  |
|  | Needs | 57 | 69 | 78 | 83 | 72 | 14.82, df = 3 | 0.002\*\* | 325 |
| Look after self | No needs | 71 | 57 | 43 | 42 | 53 |  |  |  |
|  | Needs | 29 | 43 | 57 | 58 | 47 | 17.19, df = 3 | .001\*\*\* | 325 |
| Feel safe | No needs | 96 | 93 | 93 | 85 | 92 |  |  |  |
|  | Needs | 4 | 7 | 7 | 15 | 8 | 6.50, df = 3 | .090 | 322 |
| Social contact | No needs | 55 | 34 | 26 | 27 | 35 |  |  |  |
|  | Needs | 45 | 66 | 74 | 73 | 65 | 18.06, df = 3 | <.001\*\*\* | 324 |
| Space and time to be self | No needs | 42 | 28 | 13 | 19 | 25 |  |  |  |
|  | Needs | 58 | 72 | 87 | 82 | 75 | 20.93, df = 3 | <.001\*\*\* | 323 |
| Feeling supported and encouraged | No needs | 53 | 46 | 35 | 32 | 41 |  |  |  |
|  | Needs | 47 | 54 | 65 | 68 | 59 | 9.73, df = 3 | .021\* | 318 |

\* significant difference at 0.05 level

\*\* significant difference at 0.01 level

\*\*\* significant difference at 0.001 level or beyond

Table 46: Proportion of carers with and without needs in each ASCOT Carer domain by type of dementia of person being supported

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **ASCOT Carer domain** | | **% of carers supporting someone with this type of dementia (all carers)** | | | | **χ2 and degrees of freedom** | **Statistical significance (two-sided) p=** | **N** |
|  |  | **Alzheimer’s Disease** | **Vascular dementia** | **Other type of dementia** | **Total** |  |  |  |
| How spend time | No needs | 21 | 14 | 4 | 17 |  |  |  |
|  | Needs | 79 | 86 | 96 | 83 | 7.65, df=2 | 0.022\* | 303 |
| Control over daily life | No needs | 32 | 21 | 17 | 28 |  |  |  |
|  | Needs | 68 | 79 | 83 | 72 | 6.04, df=2 | 0.049\* | 305 |
| Look after self | No needs | 57 | 48 | 31 | 52 |  |  |  |
|  | Needs | 43 | 52 | 69 | 48 | 10.79, df=2 | 0.005\*\* | 303 |
| Feel safe | No needs | 92 | 89 | 89 | 91 |  |  |  |
|  | Needs | 8 | 11 | 11 | 9 | 0.624, df=2 | 0.732 | 301 |
| Social contact | No needs | 40 | 27 | 23 | 35 |  |  |  |
|  | Needs | 60 | 73 | 77 | 65 | 6.23, df=2 | 0.044\* | 303 |
| Space and time to be self | No needs | 28 | 16 | 17 | 24 |  |  |  |
|  | Needs | 72 | 84 | 83 | 76 | 4.47, df=2 | 0.107 | 301 |
| Feeling supported and encouraged | No needs | 49 | 37 | 28 | 43 |  |  |  |
|  | Needs | 51 | 63 | 72 | 57 | 7.88, df=2 | 0.019\* | 296 |
|  |  |  |  |  |  |  |  |  |

\* significant difference at 0.05 level

\*\* significant difference at 0.01 level

\*\*\* significant difference at 0.001 level or beyond

Table 47: Type and number of contacts with AN service in previous four weeks

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Number of carers reporting specified frequency of contact** | | | | | | |  |  |
| **Type of contact** | None | 1 | 2 | 3 | 4 | 5 | 6 | Number not reported | Minimum number of individual contacts |
| **Face-to-face visit** | 3 | 56 | 15 | 3 | 0 | 0 | 0 | 2 | 97 |
| **Telephone contact** | 12 | 20 | 7 | 1 | 2 | 0 | 0 | 1 | 46 |
| **AN group meeting** | 3 | 12 | 1 | 1 | 1 | 0 | 0 | - | 21 |
| **Email** | 1 | 5 | 0 | 1 | 2 | 1 | 1 | - | 27 |
| **Other** | 1 | 2 | 0 | 0 | 0 | 0 | 0 | - | 2 |
| **Total number of contacts** | - | 95 | 46 | 18 | 20 | 5 | 6 | 3 | 193 |

Table 48: Type of support carers felt they received from a range of carer support services

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Carer support services ever used: *n* or % reporting type of support received from service** | | | | |
| **Type of support received** | Respite (n) | Day sitting/taking out (%) | Night sitting (n) | Carers’ advice service (%) | Carers’ support group (%) |
| **Emotional and social support** | *7* | 16 | *2* | 39 | 50 |
| **Information, advice or knowledge** | *7* | 12 | *1* | 76 | 17 |
| **Practical help** | *12* | 10 | *1* | 40 | 26 |
| **Time for self** | *40* | 75 | *6* | 6 | 11 |
| **Assessment of carer’s needs** | *5* | 4 | *2* | 27 | 9 |
| **Other type of support** | *2* | 3 | *2* | 7 | 9 |
| **No support** | *5* | 8 | *1* | 3 | 4 |
| **N of carers ever used this service** | 53 | 91 | 13 | 157 | 138 |

Table 49: Type of support received from carer service used in the previous four weeks

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Carer support services used in the previous four weeks: number reporting type of support received from service** | | | | |
| **Type of support received** | Respite (n) | Day sitting/taking out (n) | Night sitting (n) | Carers’ advice service (n) | Carers’ support group (n) |
| **Emotional and social support** | 2 | 13 | 2 | 26 | 37 |
| **Information, advice or knowledge** | 3 | 10 | 1 | 42 | 41 |
| **Practical help** | 4 | 7 | 1 | 25 | 20 |
| **Time for self** | 18 | 52 | 4 | 4 | 9 |
| **Assessment of carer’s needs** | 2 | 3 | 2 | 19 | 7 |
| **Other type of support** | 1 | 1 | 1 | 3 | 5 |
| **No support** | 1 | 3 | 0 | 1 | 0 |
| **N (%) of all carers who had used this service in previous four weeks** | 21 (6%) | 65 (19%) | 7 (2%) | 51 (15%) | 58 (17%) |

Table 50: Carers’ use of health services for themselves in the past four weeks

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Type of health service use** | **Not used: % of carers** | **Used: % and (n) of carers** | **Total number of events** | **N (100%)** | **Average contacts per carer (all carers)** | **Average contact per carer using services** |
| **Elective overnight admission** | 99 | 1 (2) | 4 | 318 | 0.012 | 2.000 |
| **Elective day admission** | 96 | 4 (14) | 23 | 318 | 0.072 | 1.643 |
| **Out-patient appointment** | 77 | 23 (74) | 113 | 320 | 0.353 | 1.486 |
| **Emergency admission** | 99 | 1 (4) | 4 | 318 | 0.012 | 1.000 |
| **Other hospital appointment** | 93 | 7 (23) | 30 | 318 | 0.094 | 1.304 |
| **GP contact** | 55 | 45 (145) | 211 | 320 | 0.659 | 1.455 |
| **Practice or district nurse** | 84 | 16 (52) | 76 | 317 | 0.240 | 1.461 |
| **Nurse specialist** | 93 | 7 (23) | 26 | 314 | 0.082 | 1.130 |
| **Therapy professional (incl. OT, physiotherapist, speech therapist)** | 88 | 12 (39) | 80 | 317 | 0.252 | 2.051 |

Table 51: Use of health services by person with dementia in previous four weeks (reported by carers)

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Type of health service use** | **Not used: % of people with dementia** | **Used: % and (n) of people with dementia** | **Total number of events** | **N (100%)** | **Average contacts per pwd (all pwd)** | **Average contact per pwd using services** |
| **Elective overnight admission** | 98 | 2 (4) | 4 | 313 | 0.013 | 1.00 |
| **Elective day admission** | 96 | 4 (12) | 13 | 313 | 0.041 | 1.083 |
| **Out-patient appointment** | 71 | 29 (92) | 152 | 320 | 0.474 | 1.652 |
| **Emergency admission** | 90 | 10 (31) | 47 | 315 | 0.149 | 1.516 |
| **Other hospital appointment** | 88 | 12 (36) | 43 | 315 | 0.137 | 1.194 |
| **GP contact** | 47 | 53 (168) | 275 | 322 | 0.854 | 1.637 |
| **Practice or district nurse** | 69 | 31 (95) | 204 | 314 | 0.650 | 2.147 |
| **Nurse specialist1** | 86 | 14 (40) | 73 | 311 | 0.235 | 1.825 |
| **Therapy professional (incl. OT, physiotherapist, speech therapist)1** | 87 | 12 (39) | 82 | 313 | 0.262 | 2.103 |

1. Two carers reported that the person they cared for had seen a nurse specialist ten or more times and two that they had seen a therapist ten or more times in the previous four weeks. The total number of events and the averages for these two categories are thus underestimates.

Table 52: Characteristics of person with dementia and carer related to social care service use in the previous four weeks

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Sex of person with dementia (% used service)** | **Age of person with dementia (% used service)** | **Severity of dementia (% used service)** | **How long aware of symptoms (% used service)** | **Relationship of person with dementia to carer (% used service)** | **Hours of care provided (% used service)** |
| **Day centre use** |  | 65-74: 37%  ***85+: 18%***  *χ2*=7.99, df =2, p=0.046 | Severe: 43%  *χ2* = 15.74, df = 2, p<.001 |  |  |  |
| **Other day care** | Female: 14%  *χ2*=5.86, df=1, p=0.015 |  | Severe: 19%  *χ2*=10.129, df=2, p=0.006 |  |  |  |
| **Home care** | Female: 36%  *χ2*=11.97, df=1, p=0.001 | 85+: 39%  *χ2*=9.17, df=3, p=0.027 |  |  | Parent/in-law: 40%  ***Spouse/partner: 21%***  *χ2*=13.35, df=2, p=0.001 |  |
| **Meals** |  |  |  | Under 1 yr: 31%  *χ2*=15.59, df=3, p=0.001 |  | 6-11 hrs: 16%  *χ2*=9.61, df=3, p=0.022 |
| **Memory café** | Male: 25%  *χ2*=4.73, df=1, p=0.030 | ***85+: 10%***  *χ2*=10.04, df=3, p=0.018 |  |  |  |  |

Bold and italicised figures indicate a **negative** adjusted standardised residual of 1.96 or greater

Table 53: Unit costs of health and social care resources

| **Item** | **Unit cost, £** | **Source** | **Notes** |
| --- | --- | --- | --- |
| **Hospital services** | | | |
| Hospital outpatient appointment | 120 | NHS reference costs 2016 | Average consultant led, non-consultant led and outpatient procedures. |
| Planned hospital admission without staying overnight | 733 | NHS reference costs 2016 | Average day case |
| Planned hospital admission with an overnight stay | 3750 | NHS reference costs 2016 | Average elective inpatient |
| Unplanned hospital admission | 1609 | NHS reference costs 2016 | Trim point=  Average non-elective inpatient, including short stay |
| Other hospital admissions | 389 | NHS reference costs 2016 | Regular day or night admissions |
| **Other health care services (rounded to units)** | | | |
| GP appointment | 36 | PSSRU 2016 p.154 | Per surgery consultation of 9.22 minutes including direct care staff costs and qualification costs |
| Nurse appointment | 11 | PSSRU 2016 p.152  PSSRU 2015 p.183 | Nurse based at GP practice including qualification costs: £44 per hour  Average contact duration is 15.5 minutes (PSSRU 2015) |
| Nurse specialist appointment | 13 | PSSRU 2016 p.151  PSSRU 2015 p.184 | Nurse Band 7 including qualification costs: £52 per hour  Assumes Average contact duration is 15.5 minutes (PSSRU 2015) as per nurse based at GP practice. |
| Therapist appointment: occupational therapist, physiotherapist, speech therapist, chiropodist, podiatrist | 9 | PSSRU 2016 p.194 | Allied health professionals Band 5: £34 per hour  Assumes Average contact duration is 15.5 minutes (PSSRU 2015) as per nurse based at GP practice. |
| **Social care services** | | | |
| Home care, per appointment | 12 | PSSRU 2016 p.169 | Face-to-face weekday: £24 per hour  Assume 30 minutes per session (ref UKHCA 2016 report) |
| Day care, per hour | 61 | PSSRU 2016 p.37 | £61 per client attendance |
| Meals, per meal | 4 | Glendenning *et al.* p.201; inflated to 2015-16 |  |
| Social service appointment: social worker | 20 | PSSRU 2016 p.165 | Per hour of client-related work including qualifications=£79  Assumes Average contact duration is 15.5 minutes (PSSRU 2015) as per nurse based at GP practice. |
| Memory café, per session | 14 | Rotary club 2015 | Based on example of memory café, at £138.33/monthly session. Assumes 10 carer-dementia pairs per session. |

Table 54: Unit costs used for costing informal care with proxy good method

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Item** | **Unit cost, £** | **Source** | **Notes** | **Informal care activity** |
| Paid carer, per hour | 24.6 | PSSRU 2016 p.169 | Weighted average of weekday, night and weekend hours. | Personal care, physical help, keeping company, transport, keeping an eye |
| Citizen Advice Bureau adviser, per hour | 52 | PSSRU 2016 p.171 | Knapp *et al*., 2013 used the cost of a family support worker to reflect the cost of an adviser. | Dealing with care services and benefits |
| Finance administrator, per hour | 25 | PSSRU 2016 p.146; NHS Agenda for change | Finance officer is at Agenda for change Band 3 ([here](https://www.healthcareers.nhs.uk/explore-roles/corporate-services/finance-staff)). | Dealing with other paperwork and financial matters |
| Cleaner/handy person, per hour | 21 | PSSRU 2016 p.146 | Housekeeping assistant is at Agenda for change Band 1. Mid-point Band 1 is £15,500/year. See [here](https://www.healthcareers.nhs.uk/about/careers-nhs/nhs-pay-and-benefits/agenda-change-pay-rates). Calculated from the ratio wages/hourly cost Band 2. | Practical help |

Table 55: Descriptive statistics of outcomes

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Outcome measure** | **All carers** | | | | |  | **AN** | | **Non-AN** | | **Δ** |
| Obs | Mean | SD | Min | Max |  | Obs | Mean | Obs | Mean |
| ASCOT score | 317 | 10.1 | 4.0 | 0 | 21 |  | 147 | 9.6 | 170 | 10.6 | 0.019 |
| Self-efficacy on symptoms management | 310 | 27.4 | 10.5 | 5 | 50 |  | 142 | 26.6 | 168 | 28.0 | 0.238 |
| Self-efficacy on service use | 302 | 22.3 | 9.3 | 4 | 40 |  | 137 | 22.5 | 165 | 22.0 | 0.654 |
| Overall life satisfaction | 330 | 4.7 | 2.3 | 0 | 10 |  | 153 | 4.3 | 177 | 5.0 | 0.008 |
| Happiness yesterday | 328 | 5.0 | 2.5 | 0 | 10 |  | 154 | 4.8 | 174 | 5.1 | 0.278 |
| EQ-5D-5L score | 330 | 0.775 | 0.181 | 0 | 1 |  | 153 | 0.744 | 177 | 0.802 | 0.004 |
| SD=standard deviation; Δ=p-value of the t-test (bootstrapped with 1,000 replications) comparing the mean between AN and non-AN carers. | | | | | | | | | | | |

Table 56: Descriptive statistics of resource use

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Variable** | **All carers** | | | | |  | **AN** | | **Non-AN** | | **Δ** |
| Obs | Mean | SD | Min | Max |  | Obs | Mean | Obs | Mean |
| **Carer** | | | | | | | | | | | |
| **No. of hospital services used in the last four weeks** | | | | | | | | | | | |
| elective overnight | 318 | 0.013 | 0.158 | 0 | 2 |  | 153 | 0.000 | 165 | 0.024 | 0.172 |
| elective day | 318 | 0.072 | 0.425 | 0 | 5 |  | 153 | 0.065 | 165 | 0.079 | 0.778 |
| out patient | 320 | 0.366 | 0.784 | 0 | 4 |  | 153 | 0.399 | 167 | 0.335 | 0.477 |
| emergency | 318 | 0.013 | 0.112 | 0 | 1 |  | 153 | 0.013 | 165 | 0.012 | 0.941 |
| other | 318 | 0.126 | 0.518 | 0 | 4 |  | 153 | 0.144 | 165 | 0.109 | 0.554 |
| **No. of community services used in the last four weeks** | | | | | | | | | | | |
| GP | 320 | 0.659 | 0.937 | 0 | 6 |  | 153 | 0.686 | 167 | 0.635 | 0.628 |
| practice nurse | 317 | 0.240 | 0.724 | 0 | 8 |  | 152 | 0.276 | 165 | 0.206 | 0.390 |
| nurse specialist | 314 | 0.083 | 0.309 | 0 | 2 |  | 151 | 0.113 | 163 | 0.055 | 0.097 |
| other therapist | 317 | 0.252 | 0.783 | 0 | 5 |  | 152 | 0.276 | 165 | 0.230 | 0.609 |
| **Care recipient** | | | | | | | | | | | |
| **No. of hospital services used in the last four weeks** | | | | | | | | | | | |
| elective overnight | 313 | 0.013 | 0.113 | 0 | 1 |  | 152 | 0.020 | 161 | 0.006 | 0.300 |
| elective day | 313 | 0.042 | 0.230 | 0 | 2 |  | 152 | 0.053 | 161 | 0.031 | 0.403 |
| outpatient | 320 | 0.475 | 0.892 | 0 | 6 |  | 154 | 0.461 | 166 | 0.488 | 0.788 |
| emergency | 315 | 0.149 | 0.633 | 0 | 8 |  | 151 | 0.073 | 164 | 0.220 | 0.033 |
| other | 315 | 0.137 | 0.404 | 0 | 2 |  | 153 | 0.098 | 162 | 0.173 | 0.099 |
| **No. of community services used in the last four weeks** | | | | | | | | | | | |
| GP | 322 | 0.854 | 1.065 | 0 | 6 |  | 153 | 0.824 | 169 | 0.882 | 0.619 |
| district nurse | 314 | 0.650 | 1.434 | 0 | 8 |  | 152 | 0.763 | 162 | 0.543 | 0.167 |
| nurse specialist | 311 | 0.235 | 0.947 | 0 | 10 |  | 152 | 0.276 | 159 | 0.195 | 0.451 |
| therapist | 313 | 0.262 | 1.048 | 0 | 10 |  | 152 | 0.296 | 161 | 0.230 | 0.579 |
| **No. of social care services used in the last four weeks** | | | | | | | | | | | |
| Day care centre | 327 | 1.830 | 4.141 | 0 | 28 |  | 152 | 2.277 | 175 | 1.442 | 0.077 |
| Other day care service | 324 | 0.262 | 0.996 | 0 | 8 |  | 152 | 0.118 | 172 | 0.390 | 0.008 |
| Home care | 325 | 8.657 | 20.2 | 0 | 112 |  | 151 | 7.278 | 174 | 9.853 | 0.253 |
| Meals | 329 | 0.829 | 3.887 | 0 | 28 |  | 154 | 1.160 | 175 | 0.538 | 0.152 |
| Social services | 327 | 0.223 | 0.745 | 0 | 9 |  | 154 | 0.182 | 173 | 0.260 | 0.335 |
| Memory café | 330 | 0.430 | 1.062 | 0 | 6 |  | 153 | 0.242 | 177 | 0.593 | 0.002 |
| SD=standard deviation; Δ=p-value of the t-test (bootstrapped with 1,000 replications) comparing the mean between AN and non-AN carers. | | | | | | | | | | | |

Table 57: Descriptive statistics of costs

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Variable** | **All carers** | | | | |  | **AN** | | **Non-AN** | | **Δ** |
| Obs | Mean | SD | Min | Max |  | Obs | Mean | Obs | Mean |
| **Overall costs** | 260 | 999 | 1,327 | 0 | 7,000 |  | 121 | 1,047 | 139 | 958 | 0.567 |
| **Carer** |  |  |  |  |  |  |  |  |  |  |  |
| Cost of AN | 323 | 36 | 72 | 0 | 440 |  | 135 | 86 | 188 | 0 | 0.000 |
| Total healthcare costs | 306 | 239 | 841 | 0 | 9,110 |  | 150 | 198 | 156 | 277 | 0.393 |
| Hospital costs | 317 | 309 | 1,506 | 0 | 17,932 |  | 153 | 221 | 164 | 391 | 0.304 |
| Community costs | 310 | 28 | 37 | 0 | 238 |  | 151 | 30 | 159 | 26 | 0.338 |
| **Care recipient** |  |  |  |  |  |  |  |  |  |  |  |
| Total healthcare costs | 297 | 324 | 837 | 0 | 6,940 |  | 148 | 290 | 149 | 358 | 0.483 |
| Hospital costs | 308 | 383 | 1,071 | 0 | 9,206 |  | 151 | 372 | 157 | 393 | 0.857 |
| Community costs | 305 | 40 | 47 | 0 | 273 |  | 150 | 42 | 155 | 37 | 0.419 |
| Total social care costs | 307 | 627 | 1,096 | 0 | 6,928 |  | 144 | 663 | 163 | 594 | 0.588 |
| SD=standard deviation; Δ=p-value of the t-test (bootstrapped with 1,000 replications) comparing the mean between AN and non-AN carers. All costs refer to the last four weeks. | | | | | | | | | | | |

Table 58: Descriptive statistics of out-of-pocket costs for carer support services

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Variable** | **All carers** | | | | |  | **AN** | | **Non-AN** | | **Δ** |
| Obs | Mean | SD | Min | Max |  | Obs | Mean | Obs | Mean |
| **Short respite/break** |  |  |  |  |  |  |  |  |  |  |  |
| Ever used (p) | 334 | 0.159 | 0.366 | 0 | 1 |  | 158 | 0.203 | 176 | 0.119 | 0.051 |
| Used in last 4 weeks (p) | 53 | 0.396 | 0.494 | 0 | 1 |  | 32 | 0.406 | 21 | 0.381 | 1.000 |
| Used in last 4 weeks (n) | 21 | 3.048 | 3.057 | 1 | 8 |  | 13 | 2.308 | 8 | 4.250 | 0.154 |
| Who pays |  |  |  |  |  |  |  |  |  |  |  |
| Carer (p) | 19 | 0.421 | 0.507 | 0 | 1 |  | 11 | 0.455 | 8 | 0.375 | 0.036 |
| Care recipient (p) | 19 | 0.211 | 0.419 | 0 | 1 |  | 11 | 0.364 | 8 | 0.000 |
| Both (p) | 19 | 0.158 | 0.375 | 0 | 1 |  | 11 | 0.182 | 8 | 0.125 |
| Neither (p) | 19 | 0.211 | 0.419 | 0 | 1 |  | 11 | 0.000 | 8 | 0.500 |
| Cost per single use (£) | 14 | 240 | 305 | 8 | 850 |  | 10 | 297 | 4 | 97 | 0.101 |
| **Day sitting** |  |  |  |  |  |  |  |  |  |  |  |
| Ever used (p) | 334 | 0.272 | 0.446 | 0 | 1 |  | 158 | 0.291 | 176 | 0.256 | 0.538 |
| Used in last 4 weeks (p) | 91 | 0.714 | 0.454 | 0 | 1 |  | 46 | 0.674 | 45 | 0.756 | 0.488 |
| Used in last 4 weeks (n) | 64 | 6.522 | 7.144 | 1 | 28 |  | 30 | 5.510 | 34 | 7.416 | 0.266 |
| Who pays |  |  |  |  |  |  |  |  |  |  |  |
| Carer (p) | 61 | 0.213 | 0.413 | 0 | 1 |  | 27 | 0.222 | 34 | 0.206 | 0.556 |
| Care recipient (p) | 61 | 0.230 | 0.424 | 0 | 1 |  | 27 | 0.222 | 34 | 0.235 |
| Both (p) | 61 | 0.049 | 0.218 | 0 | 1 |  | 27 | 0.000 | 34 | 0.088 |
| Neither (p) | 61 | 0.508 | 0.504 | 0 | 1 |  | 27 | 0.556 | 34 | 0.471 |
| Cost per single use (£) | 27 | 37 | 21 | 6 | 100 |  | 12 | 31 | 15 | 41 | 0.222 |
| **Night sitting** |  |  |  |  |  |  |  |  |  |  |  |
| Ever used (p) | 334 | 0.039 | 0.194 | 0 | 1 |  | 158 | 0.032 | 176 | 0.046 | 0.581 |
| Used in last 4 weeks (p) | 13 | 0.538 | 0.519 | 0 | 1 |  | 5 | 0.600 | 8 | 0.500 | 1.000 |
| Used in last 4 weeks (n) | 7 | 4.714 | 4.386 | 1 | 10 |  | 3 | 1.333 | 4 | 7.250 | 0.003 |
| Who pays |  |  |  |  |  |  |  |  |  |  |  |
| Care recipient (p) | 7 | 0.286 | 0.488 | 0 | 1 |  | 3 | 0.000 | 4 | 0.500 | 0.286 |
| Neither (p) | 7 | 0.714 | 0.488 | 0 | 1 |  | 3 | 1.000 | 4 | 0.500 |
| Cost per single use (£) | 2 | 120 | 28 | 100 | 140 |  | 0 | 0 | 2 | 120 | - |
| **Advice** |  |  |  |  |  |  |  |  |  |  |  |
| Ever used (p) | 334 | 0.470 | 0.500 | 0 | 1 |  | 158 | 0.386 | 176 | 0.545 | 0.004 |
| Used in last 4 weeks (p) | 156 | 0.327 | 0.471 | 0 | 1 |  | 61 | 0.295 | 95 | 0.347 | 0.600 |
| Used in last 4 weeks (n) | 50 | 2.120 | 4.148 | 0 | 30 |  | 16 | 3.313 | 34 | 1.559 | 0.335 |
| Who pays |  |  |  |  |  |  |  |  |  |  |  |
| Neither (p) | 47 | 1.000 | 0.000 | 1 | 1 |  | 14 | 1.000 | 33 | 1.000 | - |
| Cost per single use (£) | 0 | 0 | 0 | 0 | 0 |  | 0 | 0 | 0 | 0 | - |
| **Support group** |  |  |  |  |  |  |  |  |  |  |  |
| Ever used (p) | 334 | 0.413 | 0.493 | 0 | 1 |  | 158 | 0.361 | 176 | 0.460 | 0.075 |
| Used in last 4 weeks (p) | 138 | 0.420 | 0.495 | 0 | 1 |  | 57 | 0.316 | 81 | 0.494 | 0.054 |
| Used in last 4 weeks (n) | 57 | 1.860 | 1.663 | 1 | 10 |  | 17 | 2.176 | 40 | 1.725 | 0.433 |
| Who pays |  |  |  |  |  |  |  |  |  |  |  |
| Carer (p) | 56 | 0.107 | 0.312 | 0 | 1 |  | 17 | 0.118 | 39 | 0.103 | 1.000 |
| Neither (p) | 56 | 0.893 | 0.312 | 0 | 1 |  | 17 | 0.882 | 39 | 0.897 |
| Cost per single use (£) | 5 | 6 | 2 | 3 | 8 |  | 2 | 7 | 3 | 6 | 0.914 |
| Obs=number of observations; SD=standard deviation; Δ=p-value of the t-test (bootstrapped with 1,000 replications) comparing the mean between AN and non-AN carers; p=proportion of carers; n=number of resources. | | | | | | | | | | | |

Table 59: Descriptive statistics of out-of-pocket costs for social care services for the person with dementia

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Variable** | **All carers** | | | | |  | **AN** | | **Non-AN** | | **Δ** |
| Obs | Mean | SD | Min | Max |  | Obs | Mean | Obs | Mean |
| **Day care centre** |  |  |  |  |  |  |  |  |  |  |  |
| Used in last 4 weeks (p) | 335 | 0.269 | 0.444 | 0 | 1 |  | 158 | 0.285 | 177 | 0.254 | 0.076 |
| Used in last 4 weeks (n) | 86 | 6.958 | 5.447 | 1 | 28 |  | 43 | 8.050 | 43 | 5.867 | 0.051 |
| Who pays |  |  |  |  |  |  |  |  |  |  |  |
| Carer (p) | 87 | 0.218 | 0.416 | 0 | 1 |  | 44 | 0.159 | 43 | 0.279 | 0.587 |
| Care recipient (p) | 87 | 0.149 | 0.359 | 0 | 1 |  | 44 | 0.159 | 43 | 0.140 |
| Both (p) | 87 | 0.253 | 0.437 | 0 | 1 |  | 44 | 0.295 | 43 | 0.209 |
| Neither (p) | 87 | 0.379 | 0.488 | 0 | 1 |  | 44 | 0.386 | 43 | 0.372 |
| Cost per single use (£) | 65 | 40 | 27 | 5 | 130 |  | 35 | 34 | 30 | 47 | 0.029 |
| **Other day care service** |  |  |  |  |  |  |  |  |  |  |  |
| Used in last 4 weeks (p) | 335 | 0.099 | 0.298 | 0 | 1 |  | 158 | 0.057 | 177 | 0.136 | 0.016 |
| Used in last 4 weeks (n) | 27 | 3.148 | 1.703 | 1 | 8 |  | 7 | 2.571 | 20 | 3.350 | 0.254 |
| Who pays |  |  |  |  |  |  |  |  |  |  |  |
| Carer (p) | 30 | 0.233 | 0.430 | 0 | 1 |  | 8 | 0.375 | 22 | 0.182 | 0.565 |
| Care recipient (p) | 30 | 0.300 | 0.466 | 0 | 1 |  | 8 | 0.375 | 22 | 0.273 |
| Both (p) | 30 | 0.100 | 0.305 | 0 | 1 |  | 8 | 0.000 | 22 | 0.136 |
| Neither (p) | 30 | 0.367 | 0.490 | 0 | 1 |  | 8 | 0.250 | 22 | 0.409 |
| Cost per single use (£) | 19 | 15 | 15 | 3 | 55 |  | 6 | 13 | 13 | 16 | 0.585 |
| **Home care** |  |  |  |  |  |  |  |  |  |  |  |
| Used in last 4 weeks (p) | 335 | 0.266 | 0.442 | 0 | 1 |  | 158 | 0.228 | 177 | 0.299 | 0.144 |
| Used in last 4 weeks (n) | 84 | 33.49 | 27.42 | 1 | 112 |  | 33 | 33.30 | 51 | 33.62 | 0.961 |
| Who pays |  |  |  |  |  |  |  |  |  |  |  |
| Carer (p) | 85 | 0.212 | 0.411 | 0 | 1 |  | 33 | 0.212 | 52 | 0.212 | 0.869 |
| Care recipient (p) | 85 | 0.447 | 0.500 | 0 | 1 |  | 33 | 0.424 | 52 | 0.462 |
| Both (p) | 85 | 0.082 | 0.277 | 0 | 1 |  | 33 | 0.061 | 52 | 0.096 |
| Neither (p) | 85 | 0.259 | 0.441 | 0 | 1 |  | 33 | 0.303 | 52 | 0.231 |
| Cost per single use (£) | 55 | 29 | 36 | 1 | 213 |  | 20 | 13 | 35 | 38 | 0.002 |
| **Meals** |  |  |  |  |  |  |  |  |  |  |  |
| Used in last 4 weeks (p) | 335 | 0.081 | 0.273 | 0 | 1 |  | 158 | 0.095 | 177 | 0.068 | 0.120 |
| Used in last 4 weeks (n) | 24 | 11.36 | 9.517 | 1 | 28 |  | 14 | 12.76 | 10 | 9.41 | 0.376 |
| Who pays |  |  |  |  |  |  |  |  |  |  |  |
| Carer (p) | 26 | 0.192 | 0.402 | 0 | 1 |  | 15 | 0.333 | 11 | 0.000 | 0.131 |
| Care recipient (p) | 26 | 0.385 | 0.496 | 0 | 1 |  | 15 | 0.267 | 11 | 0.545 |
| Both (p) | 26 | 0.346 | 0.485 | 0 | 1 |  | 15 | 0.333 | 11 | 0.364 |
| Neither (p) | 26 | 0.077 | 0.272 | 0 | 1 |  | 15 | 0.067 | 11 | 0.091 |
| Cost per single use (£) | 23 | 10 | 9 | 3 | 40 |  | 14 | 11 | 9 | 8 | 0.320 |
| **Social services** |  |  |  |  |  |  |  |  |  |  |  |
| Used in last 4 weeks (p) | 335 | 0.137 | 0.345 | 0 | 1 |  | 158 | 0.120 | 177 | 0.153 | 0.698 |
| Used in last 4 weeks (n) | 44 | 1.659 | 1.328 | 1 | 9 |  | 18 | 1.556 | 26 | 1.731 | 0.610 |
| Who pays |  |  |  |  |  |  |  |  |  |  |  |
| Care recipient (p) | 39 | 0.051 | 0.223 | 0 | 1 |  | 17 | 0.000 | 22 | 0.091 | 0.495 |
| Neither (p) | 39 | 0.949 | 0.223 | 0 | 1 |  | 17 | 1.000 | 22 | 0.909 |
| Cost per single use(£) | 2 | 30 | 14 | 20 | 40 |  | 0 | 0 | 2 | 30 | - |
| **Memory café** |  |  |  |  |  |  |  |  |  |  |  |
| Used in last 4 weeks (p) | 335 | 0.194 | 0.396 | 0 | 1 |  | 158 | 0.108 | 177 | 0.271 | 0.000 |
| Used in last 4 weeks (n) | 63 | 2.254 | 1.344 | 1 | 6 |  | 15 | 2.467 | 48 | 2.188 | 0.509 |
| Who pays |  |  |  |  |  |  |  |  |  |  |  |
| Carer (p) | 63 | 0.143 | 0.353 | 0 | 1 |  | 17 | 0.118 | 46 | 0.152 | 0.708 |
| Care recipient (p) | 63 | 0.064 | 0.246 | 0 | 1 |  | 17 | 0.000 | 46 | 0.087 |
| Both (p) | 63 | 0.254 | 0.439 | 0 | 1 |  | 17 | 0.235 | 46 | 0.261 |
| Neither (p) | 63 | 0.540 | 0.502 | 0 | 1 |  | 17 | 0.647 | 46 | 0.500 |
| Cost per single use (£) | 24 | 7 | 8 | 2 | 40 |  | 1 | 6 | 23 | 7 | 0.712 |
| Obs=number of observations; SD=standard deviation; Δ=p-value of the t-test (bootstrapped with 1,000 replications) comparing the mean between AN and non-AN carers. | | | | | | | | | | | |

Table 60: Descriptive statistics of informal care time and cost

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Variable** | **All carers** | | | | |  | **AN** | | **Non-AN** | | **Δ** |
| Obs | Mean | SD | Min | Max |  | Obs | Mean | Obs | Mean |
| **Informal care tasks** | | | | | | | | | | | |
| Personal care | 137 | 2.547 | 2.584 | 1 | 24 |  | 60 | 2.533 | 77 | 2.558 | 0.951 |
| Physical help | 66 | 3.152 | 4.203 | 1 | 24 |  | 27 | 2.481 | 39 | 3.615 | 0.209 |
| Help with care services | 62 | 1.984 | 1.895 | 1 | 11 |  | 12 | 1.583 | 50 | 2.080 | 0.166 |
| Help with paperwork | 68 | 2.147 | 2.377 | 1 | 15 |  | 12 | 1.667 | 56 | 2.250 | 0.176 |
| Other practical help | 243 | 3.650 | 3.030 | 1 | 24 |  | 105 | 3.686 | 138 | 3.623 | 0.874 |
| Keeping company | 183 | 7.120 | 6.115 | 1 | 24 |  | 80 | 8.188 | 103 | 6.291 | 0.035 |
| Taking out | 85 | 3.694 | 2.980 | 1 | 14 |  | 22 | 3.545 | 63 | 3.746 | 0.773 |
| Giving medicines | 67 | 2.448 | 4.190 | 1 | 24 |  | 16 | 2.688 | 51 | 2.373 | 0.788 |
| Keeping an eye | 216 | 11.25 | 7.861 | 1 | 24 |  | 97 | 12.63 | 119 | 10.12 | 0.017 |
| Any other help | 13 | 6.846 | 7.163 | 1 | 24 |  | 5 | 7.600 | 8 | 6.375 | 0.790 |
| **Informal care costs (£): opportunity cost method** | | | | | | | | | | | |
| Personal care | 137 | 40 | 41 | 16 | 377 |  | 60 | 40 | 77 | 40 | 0.951 |
| Physical help | 66 | 50 | 66 | 16 | 377 |  | 27 | 39 | 39 | 57 | 0.209 |
| Help with care services | 62 | 31 | 30 | 16 | 173 |  | 12 | 25 | 50 | 33 | 0.166 |
| Help with paperwork | 68 | 34 | 37 | 16 | 236 |  | 12 | 26 | 56 | 35 | 0.176 |
| Other practical help | 243 | 57 | 48 | 16 | 377 |  | 105 | 58 | 138 | 57 | 0.874 |
| Keeping company | 183 | 112 | 96 | 16 | 377 |  | 80 | 129 | 103 | 99 | 0.035 |
| Taking out | 85 | 58 | 47 | 16 | 220 |  | 22 | 56 | 63 | 59 | 0.773 |
| Giving medicines | 67 | 38 | 66 | 16 | 377 |  | 16 | 42 | 51 | 37 | 0.788 |
| Keeping an eye | 216 | 177 | 124 | 16 | 377 |  | 97 | 199 | 119 | 159 | 0.017 |
| Any other help | 13 | 108 | 113 | 16 | 377 |  | 5 | 120 | 8 | 100 | 0.790 |
| Total costs | 323 | 293 | 267 | 16 | 1902 |  | 149 | 283 | 174 | 301 | 0.547 |
| **Informal care costs (£): proxy good method** | | | | | | | | | | | |
| Personal care | 137 | 63 | 64 | 25 | 590 |  | 60 | 62 | 77 | 63 | 0.951 |
| Physical help | 66 | 78 | 103 | 25 | 590 |  | 27 | 61 | 39 | 89 | 0.209 |
| Help with care services | 62 | 103 | 99 | 52 | 572 |  | 12 | 82 | 50 | 108 | 0.166 |
| Help with paperwork | 68 | 54 | 59 | 25 | 375 |  | 12 | 42 | 56 | 56 | 0.176 |
| Other practical help | 243 | 77 | 64 | 21 | 504 |  | 105 | 77 | 138 | 76 | 0.874 |
| Keeping company | 183 | 175 | 150 | 25 | 590 |  | 80 | 201 | 103 | 155 | 0.035 |
| Taking out | 85 | 91 | 73 | 25 | 344 |  | 22 | 87 | 63 | 92 | 0.773 |
| Giving medicines | 67 | 60 | 103 | 25 | 590 |  | 16 | 66 | 51 | 58 | 0.788 |
| Keeping an eye | 216 | 277 | 193 | 25 | 590 |  | 97 | 311 | 119 | 249 | 0.017 |
| Any other help | 13 | 168 | 176 | 25 | 590 |  | 5 | 187 | 8 | 157 | 0.790 |
| Total costs | 323 | 459 | 427 | 25 | 3181 |  | 149 | 437 | 174 | 477 | 0.393 |
| Obs=number of observations; SD=standard deviation; Δ=p-value of the t-test (bootstrapped with 1,000 replications) comparing the mean between AN and non-AN carers. | | | | | | | | | | | | |

Table 61: Descriptive statistics of the use of the AN service

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Variable** | **Obs** | **Mean** | **SD** | **Min** | **Max** |
| **Use of AN** | | | | | |
| Yes | 158 | 0.886 | 0.319 | 0 | 1 |
| No | 158 | 0.101 | 0.303 | 0 | 1 |
| Don't know | 158 | 0.013 | 0.112 | 0 | 1 |
| **First use** | | | | | |
| < 1 month ago | 158 | 0.076 | 0.266 | 0 | 1 |
| 1 to 2 months ago | 158 | 0.076 | 0.266 | 0 | 1 |
| 3 to 6 months ago | 158 | 0.165 | 0.372 | 0 | 1 |
| 7 to 12 months ago | 158 | 0.139 | 0.347 | 0 | 1 |
| 1 to 2 years ago | 158 | 0.177 | 0.383 | 0 | 1 |
| 2 to 5 years ago | 158 | 0.139 | 0.347 | 0 | 1 |
| > 5 years ago | 158 | 0.051 | 0.220 | 0 | 1 |
| Don't know | 158 | 0.025 | 0.158 | 0 | 1 |
| Did not answer | 158 | 0.152 | 0.360 | 0 | 1 |
| **Last use** | | | | | |
| Up to 6 months | 158 | 0.772 | 0.421 | 0 | 1 |
| 7 to 12 months ago | 158 | 0.032 | 0.176 | 0 | 1 |
| 1 to 2 years ago | 158 | 0.032 | 0.176 | 0 | 1 |
| Don't know | 158 | 0.025 | 0.158 | 0 | 1 |
| Did not answer | 158 | 0.139 | 0.347 | 0 | 1 |
| **Kind of contact** | | | | | |
| Face-to-face visit | 158 | 0.835 | 0.372 | 0 | 1 |
| Telephone contact | 158 | 0.481 | 0.501 | 0 | 1 |
| E-mail contact | 158 | 0.089 | 0.285 | 0 | 1 |
| Support group meeting | 158 | 0.177 | 0.383 | 0 | 1 |
| Other contact | 158 | 0.038 | 0.192 | 0 | 1 |
| **Use of AN last 4 weeks** | | | | | |
| Yes | 158 | 0.563 | 0.498 | 0 | 1 |
| No | 158 | 0.310 | 0.464 | 0 | 1 |
| Did not answer | 158 | 0.127 | 0.334 | 0 | 1 |
| **Contacts last 4 weeks** | | | | | |
| Face-to-face visit | 135 | 0.704 | 0.754 | 0 | 3 |
| Telephone contact | 135 | 0.333 | 0.743 | 0 | 4 |
| E-mail contact | 135 | 0.200 | 0.871 | 0 | 6 |
| Support group meeting | 135 | 0.156 | 0.531 | 0 | 4 |
| Other contact | 135 | 0.015 | 0.121 | 0 | 1 |
| **Cost of AN last 4 weeks (£)** | 86 | 136 | 78 | 11 | 440 |
| Obs=number of observations |  |  |  |  |  |

Table 62: Cost of the AN service

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Type of cost** | **Project 1** | **Project 2** | **Project 3** | **Project 4** | **Project 5** | **Project 6** | **General template** | **Average** |
| Recruitment, year 1 | 4,103 | NR | 3,000 | 3000 | NR | NR | 4,265 | 3,592 |
| Employment |  |  |  |  |  |  |  |  |
| Year 1 | 39,582 | 33,630 | 45346 | 45346 | 41,678 | 38,281 | 41,145 | 40,715 |
| Year 2 | 41,459 |  |  |  | 37,873 |  | 41,557 | 40,296 |
| Training | 3% of salary |  |  |  |  |  |  |  |
| Year 1 | 1,026 | 1,200 |  |  | 1,800 |  | 1,077 | 1,276 |
| Year 2 | 1,056 |  |  |  | 135 |  | 1,077 | 756 |
| Travel |  |  |  |  |  |  |  |  |
| Year 1 | 4,500 | 1,814 | 3,421 | 3421 | 1,149 | 8,969 | 4,500 | 3,968 |
| Year 2 | 4,500 |  |  |  | 4,227 |  | 4,500 | 4,409 |
| Subscription and insurance/year | 70 | 100 | 704 | 704 |  |  | 100 | 395 |
| Equipment |  |  |  |  |  |  |  |  |
| Year 1 | 1,618 | 8,411 | 850 | 850 | 4,101 | 1,000 | 1,618 | 2,635 |
| Year 2 | 550 |  |  |  | 322 |  | 450 | 441 |
| Indirect costs  (HR, Finance)/year | 987 | NR | NR | NR |  |  | =project 1 | 987 |
| Overheads/year |  | 3000 | 3000 | 3,000 | 2,000 | NR | NR | 2,750 |
| **DUK costs** |  |  |  |  |  |  |  |  |
| Database license/year | 600 | 600 | 600 | 600 | 600 | 875 | 600 |  |
| Academy support/year | 3,500 | 3,000 | 3,000 | 3,000 | 3,000 | 1,750 | 2,000 |  |
| DUK Pioneer time | NR | 4,000 | 2,000 | 2,000 | 3,000 | 600 | 4,900 |  |
| DUK overheads | NR | NR | NR | NR | 4,000 | NR | 5,964 |  |
| Management recharge cost | 9,156 |  |  |  |  |  | 9,473 |  |

Table 63: Descriptive statistics of the covariates

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Covariate** | | **All carers** | | | |  | **AN** | **Non-AN** |
| Mean | SD | Min | Max |  | Mean | Mean |
| Carer's characteristics | Male (ref) | 0.309 | 0.463 | 0 | 1 |  | 0.341 | 0.280 |
| Female | 0.691 | 0.463 | 0 | 1 |  | 0.659 | 0.720 |
| 16 to 54 years (ref) | 0.177 | 0.383 | 0 | 1 |  | 0.121 | 0.227 |
| 55 to 64 years | 0.252 | 0.435 | 0 | 1 |  | 0.220 | 0.280 |
| 65 to 69 years | 0.110 | 0.313 | 0 | 1 |  | 0.129 | 0.093 |
| 70 to 74 years | 0.149 | 0.357 | 0 | 1 |  | 0.167 | 0.133 |
| 75 years or older | 0.312 | 0.464 | 0 | 1 |  | 0.364 | 0.267 |
| Below university (ref) | 0.720 | 0.450 | 0 | 1 |  | 0.773 | 0.673 |
| Bachelor's | 0.195 | 0.397 | 0 | 1 |  | 0.197 | 0.193 |
| Master's and above | 0.085 | 0.280 | 0 | 1 |  | 0.030 | 0.133 |
| Full/part-time job | 0.209 | 0.407 | 0 | 1 |  | 0.159 | 0.253 |
| Look after full time | 0.248 | 0.433 | 0 | 1 |  | 0.295 | 0.207 |
| Retired | 0.582 | 0.494 | 0 | 1 |  | 0.614 | 0.553 |
| No difficulties (ref) | 0.234 | 0.424 | 0 | 1 |  | 0.197 | 0.267 |
| Some difficulties | 0.326 | 0.470 | 0 | 1 |  | 0.311 | 0.340 |
| Severe difficulties | 0.316 | 0.466 | 0 | 1 |  | 0.379 | 0.260 |
| Don't know/prefer not to say | 0.124 | 0.330 | 0 | 1 |  | 0.114 | 0.133 |
| EQ-5D score | 0.774 | 0.182 | 0 | 1 |  | 0.752 | 0.793 |
| Caring role | Main carer (ref) | 0.926 | 0.263 | 0 | 1 |  | 0.977 | 0.880 |
| Joint or not main carer | 0.075 | 0.263 | 0 | 1 |  | 0.023 | 0.120 |
| Spouse/partner (ref) | 0.674 | 0.470 | 0 | 1 |  | 0.742 | 0.613 |
| Parent/parent-in-law | 0.287 | 0.453 | 0 | 1 |  | 0.227 | 0.340 |
| Other relationship | 0.039 | 0.194 | 0 | 1 |  | 0.030 | 0.047 |
| Personal care | 0.702 | 0.458 | 0 | 1 |  | 0.750 | 0.660 |
| Physical care | 0.482 | 0.501 | 0 | 1 |  | 0.538 | 0.433 |
| Total hours | 12 | 7 | 0 | 24 |  | 13 | 11 |
| Under 1 year (ref) | 0.064 | 0.245 | 0 | 1 |  | 0.046 | 0.080 |
| 1 to 3 years | 0.323 | 0.468 | 0 | 1 |  | 0.364 | 0.287 |
| 3 to 5 years | 0.277 | 0.448 | 0 | 1 |  | 0.235 | 0.313 |
| 5 to 10 years | 0.234 | 0.424 | 0 | 1 |  | 0.250 | 0.220 |
| 10 years or more | 0.103 | 0.304 | 0 | 1 |  | 0.106 | 0.100 |
| Replacement for a break (ref) | 0.411 | 0.493 | 0 | 1 |  | 0.326 | 0.487 |
| No replacement for a break | 0.589 | 0.493 | 0 | 1 |  | 0.674 | 0.513 |
| Admiral nursing | 0.468 | 0.500 | 0 | 1 |  | 1.000 | 0.000 |
| Care recipient's characteristics | 45 to 64 years (ref) | 0.099 | 0.300 | 0 | 1 |  | 0.076 | 0.120 |
| 65 to 74 years | 0.202 | 0.402 | 0 | 1 |  | 0.212 | 0.193 |
| 75 years or older | 0.699 | 0.460 | 0 | 1 |  | 0.712 | 0.687 |
| Under 1 year (ref) | 0.046 | 0.210 | 0 | 1 |  | 0.061 | 0.033 |
| 1 to 5 years | 0.589 | 0.493 | 0 | 1 |  | 0.598 | 0.580 |
| 6 to 10 years | 0.280 | 0.450 | 0 | 1 |  | 0.265 | 0.293 |
| 11 years or more | 0.085 | 0.280 | 0 | 1 |  | 0.076 | 0.093 |
| Formal diagnosis (ref) | 0.965 | 0.185 | 0 | 1 |  | 0.970 | 0.960 |
| No diagnosis/don't know | 0.036 | 0.185 | 0 | 1 |  | 0.030 | 0.040 |
| Alzheimer's | 0.606 | 0.489 | 0 | 1 |  | 0.515 | 0.687 |
| Vascular dementia | 0.333 | 0.472 | 0 | 1 |  | 0.439 | 0.240 |
| Other dementia | 0.270 | 0.444 | 0 | 1 |  | 0.258 | 0.280 |
| Mild (ref) | 0.103 | 0.304 | 0 | 1 |  | 0.068 | 0.133 |
| Moderate | 0.631 | 0.483 | 0 | 1 |  | 0.644 | 0.620 |
| Severe | 0.266 | 0.443 | 0 | 1 |  | 0.288 | 0.247 |
| Descriptive statistics are based on the ASCOT's score sample (All carers=282; AN=132: non-AN=150). | | | | | | | | |
| SD=standard deviation; ref=reference category. | | | | | | | | |

Table 64: Outcomes: Regression results

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Variable** | | **ASCOT score** | **Self-efficacy on symptoms management** | **Self-efficacy on service use** | **Overall life satisfaction** | **Happiness yesterday** |
|  | Admiral nursing | 0.382 | 1.243 | 1.990\* | 0.087 | 0.433 |
| (0.397) | (1.317) | (1.060) | (0.266) | (0.279) |
| Carer's characteristics | Female | -0.539 | -2.384 | -3.842\*\*\* | -0.166 | 0.001 |
| 55 to 64 years old | -0.134 | -2.399 | -1.712 | -0.387 | -0.618 |
| 65 to 69 years old | 0.127 | -2.214 | 0.596 | -0.181 | -0.300 |
| 70 to 74 years old | 0.202 | -1.761 | 1.448 | -0.015 | 0.227 |
| 75 years old or older | 0.833 | -3.149 | -5.370\* | 0.629 | 0.545 |
| Bachelor's degree | -0.483 | -2.408\* | -2.403\* | -0.456 | -0.467 |
| Master's degree and above | -0.871 | -3.096 | -1.205 | -0.083 | 0.157 |
| Full/part-time job | 1.212\* | 2.045 | 1.227 | 0.069 | -0.042 |
| Look after full time | 0.273 | 0.264 | 0.743 | 0.050 | 0.055 |
| Retired | 1.159\*\* | 2.216 | 2.152 | 0.289 | 0.499 |
| Some financial difficulties | -1.531\*\*\* | -1.384 | -3.928\*\*\* | -0.830\*\* | -1.075\*\*\* |
| Severe financial difficulties | -2.281\*\*\* | -2.936 | -3.926\*\*\* | -1.308\*\*\* | -1.382\*\*\* |
| Don't know/prefer not to say | -2.636\*\*\* | -1.904 | -4.371\*\* | -0.740 | -1.136\*\* |
| EQ-5D score | 7.131\*\*\* | 13.295\*\*\* | 8.581\*\*\* | 4.129\*\*\* | 4.160\*\*\* |
| Caring role | Joint or not main carer | 0.543 | 2.790 | 3.307 | 0.823\* | 0.535 |
| Parent/parent-in-law | 0.889 | 0.375 | -2.327 | 0.336 | 0.407 |
| Other relationship | 0.063 | -4.703 | -5.352\* | -0.200 | -0.206 |
| Personal care | -0.495 | -1.076 | -0.896 | -0.214 | -0.031 |
| Physical care | -0.578 | 2.578\* | 0.964 | 0.108 | 0.003 |
| Total hours | -0.084\*\*\* | 0.213\*\* | 0.042 | -0.023 | -0.029 |
| Duration 1 to 3 years | -0.142 | 2.512 | 6.458\*\*\* | 0.274 | 0.765 |
| Duration 3 to 5 years | -0.195 | 1.496 | 4.667\*\* | 0.331 | 0.895 |
| Duration 5 to 10 years | -0.108 | 2.149 | 5.895\*\* | -0.141 | 0.453 |
| Duration 10 years or more | -0.658 | 0.493 | 4.568 | -0.021 | 0.360 |
| No replacement for a break | -1.192\*\*\* | -3.433\*\* | -2.829\*\*\* | -0.746\*\*\* | -0.772\*\*\* |
| Care recipient's characteristics | 65 to 74 years old | 0.782 | 0.187 | 1.552 | 0.529 | 0.640 |
| 75 years old or older | 0.665 | 2.396 | 4.932\*\* | 0.290 | 0.367 |
| symptoms for 1 to 5 years | 0.107 | 1.565 | 0.402 | 0.961 | -0.185 |
| symptoms for 6 to 10 years | -0.247 | 2.725 | 0.117 | 1.260 | 0.429 |
| symptoms for 11 years or more | 0.993 | 6.705 | 1.174 | 1.567\* | 0.985 |
| No diagnosis/don't know | -1.424 | -6.734\*\*\* | -4.891\* | -0.208 | -0.329 |
| Vascular dementia | -0.722 | -1.211 | -1.682 | -0.096 | 0.159 |
| Other dementia | -0.561 | -0.827 | -4.162\*\*\* | -0.062 | 0.218 |
| Moderate severity | -0.585 | -2.828 | -3.692\*\* | -0.827\* | -1.012\* |
| Severe severity | -1.722\*\* | -5.450\*\* | -4.208\*\* | -1.574\*\*\* | -1.795\*\*\* |
|  | Constant | 7.928\*\*\* | 17.986\*\*\* | 18.970\*\*\* | 2.271 | 2.782\* |
| Observations | | 282 | 274 | 268 | 287 | 285 |
| R-squared | | 0.459 | 0.260 | 0.350 | 0.340 | 0.335 |
| Most of the coefficients on dummies are interpreted in relation to the reference category. The reference categories for carer characteristics are respectively: Male, Age 16 to 54 years, Below university education, No financial difficulties. The reference categories for the characteristics of the caring role are: Main carer status, Person with dementia is spouse/partner, Duration of caring under 1 year. Finally, the reference categories for the care recipient characteristics are: Age 45 to 64, Duration of symptoms under 1 year, Severity of dementia is Mild. Table 61 shows the reference categories. | | | | | | |
| Robust standard errors in parentheses; \*\*\* p<0.01, \*\* p<0.05, \* p<0.1. | | | | | | |

Table 65: Costs: Regression results

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Variable** | | **Overall costs** | **Carer's total healthcare costs** | **Care recipient's total healthcare costs** | **Care recipient's total social care costs** |
|  | Admiral nursing | 26.575 | -170.163 | -96.722 | 58.072 |
| (202.900) | (145.300) | (132.800) | (146.100) |
| Carer's characteristics | Female | -39.048 | 249.835 | 20.416 | 11.324 |
| 55 to 64 years old | -467.576 | 128.496 | -141.026 | -335.640 |
| 65 to 69 years old | -334.156 | 291.419 | -73.958 | -339.032 |
| 70 to 74 years old | -123.763 | 195.256 | 300.093 | -556.264\* |
| 75 years old or older | -251.914 | 477.933 | -23.456 | -270.283 |
| Bachelor's degree | 366.745 | -132.246\* | -121.511 | 347.939\*\* |
| Master's degree and above | 356.185 | -24.123 | -148.834 | 288.675 |
| Full/part-time job | 106.192 | -161.379 | 200.487 | -159.649 |
| Look after full time | -207.212 | -130.192 | -64.121 | -68.701 |
| Retired | 273.644 | 62.005 | 23.403 | 324.513\* |
| Some financial difficulties | 70.590 | -5.400 | 36.713 | -38.273 |
| Severe financial difficulties | 32.179 | 148.637 | -86.977 | 222.563 |
| Don't know/prefer not to say | 714.671 | 339.305 | 457.131 | 104.296 |
| EQ-5D score | 287.667 | -480.094 | -39.793 | 272.184 |
| Caring role | Joint or not main carer | 52.862 | -175.647 | 83.663 | 12.641 |
| Parent/parent-in-law | 12.912 | 133.233 | -100.213 | 101.146 |
| Other relationship | 195.767 | 131.535 | -79.843 | 115.261 |
| Personal care | 191.701 | 77.500 | -79.857 | 129.525 |
| Physical care | 193.175 | 33.166 | 206.183 | 17.289 |
| Total hours | 3.924 | -10.643 | 10.046 | -13.727 |
| Duration 1 to 3 years | 398.569 | 110.028 | 160.741 | 141.011 |
| Duration 3 to 5 years | 440.687 | -148.956 | 257.482 | 138.329 |
| Duration 5 to 10 years | 208.638 | -146.994 | -145.185 | 397.548 |
| Duration 10 years or more | 213.159 | -403.659\* | -441.864 | 699.565\* |
| No replacement for a break | -6.526 | -246.425\* | -124.837 | 40.765 |
| Care recipient's characteristics | 65 to 74 years old | -179.399 | -89.527 | -149.343 | 101.373 |
| 75 years old or older | -9.698 | -58.444 | 123.903 | -75.069 |
| symptoms for 1 to 5 years | -333.064 | 300.841\* | -1.208 | -65.940 |
| symptoms for 6 to 10 years | -280.120 | 224.415 | 46.416 | -117.714 |
| symptoms for 11 years or more | 29.423 | 317.816 | 562.790 | -404.817 |
| No diagnosis/don't know | 173.043 | -193.276 | 89.217 | -227.561 |
| Vascular dementia | 2.554 | -20.470 | 274.529\*\* | -199.234 |
| Other dementia | 26.060 | 133.562 | 239.774 | -76.373 |
| Moderate severity | -182.493 | 71.698 | -189.708 | 29.877 |
| Severe severity | 480.491 | 480.773 | -2.824 | 561.472\*\* |
|  | Constant | 407.519 | 113.887 | 112.560 | 179.663 |
| Observations | | 227 | 269 | 259 | 266 |
| R-squared | | 0.173 | 0.174 | 0.170 | 0.164 |
| Most of the coefficients on dummies are interpreted in relation to the reference category. Table 61 shows the reference categories. | | | | | |
| Robust standard errors in parentheses; \*\*\* p<0.01, \*\* p<0.05, \* p<0.1. | | | | | |

Table 66: ASCOT score: choice of PSM technique

|  |  |  |  |
| --- | --- | --- | --- |
| **Technique** | **Sample** | **Mean bias** | **Median bias** |
| Kernel | Unmatched | 14.4 | 11.4 |
| Matched | 3.4 | 3.1 |
| Nearest neighbour | Unmatched | 14.4 | 11.4 |
| Matched | 8.4 | 7.6 |
| Calliper (0.2) | Unmatched | 14.4 | 11.4 |
| Matched | 8.4 | 7.6 |

Table 67: Outcomes: propensity score matching results

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Variable** | | **ASCOT score** | **Self-efficacy on symptoms management** | **Self-efficacy on service use** | **Overall life satisfaction** | **Happiness yesterday** |
|  | Admiral nursing | 0.648 | 1.618 | 2.634 | 0.171 | 0.575 |
| (0.562) | (1.505) | (1.328)\*\* | (0.333) | (0.346)\* |
| Coefficient on covariates from logit regression where the admiral nursing dummy is the dependent variable | | | | | | |
|
| Carer's characteristics | Female | 0.816 | 0.972 | 0.901 | 0.897 | 0.914 |
| 55 to 64 years old | 1.905 | 1.698 | 1.590 | 1.933 | 1.674 |
| 65 to 69 years old | 3.129 | 3.204 | 2.943 | 3.588\* | 3.075 |
| 70 to 74 years old | 2.036 | 1.943 | 2.195 | 2.356 | 1.861 |
| 75 years old or older | 1.935 | 2.206 | 2.048 | 2.587 | 1.948 |
| Bachelor's degree | 1.015 | 1.124 | 1.003 | 1.055 | 1.027 |
| Master's degree and above | 0.222\*\* | 0.165\*\* | 0.153\*\*\* | 0.233\*\* | 0.233\*\* |
| Full/part-time job | 1.115 | 0.946 | 0.895 | 1.245 | 1.083 |
| Look after full time | 1.241 | 1.261 | 1.043 | 1.285 | 1.289 |
| Retired | 0.832 | 0.763 | 0.729 | 0.837 | 0.793 |
| Some financial difficulties | 1.088 | 1.153 | 1.152 | 1.062 | 1.044 |
| Severe financial difficulties | 1.697 | 1.852 | 1.822 | 1.604 | 1.645 |
| Don't know/prefer not to say | 1.258 | 1.225 | 1.243 | 1.202 | 1.145 |
| EQ-5D score | 0.483 | 0.429 | 0.586 | 0.483 | 0.475 |
| Caring role | Joint or not main carer | 0.398 | 0.283\* | 0.267\* | 0.289\* | 0.328 |
| Parent/parent-in-law | 0.829 | 0.784 | 0.776 | 0.873 | 0.726 |
| Other relationship | 1.154 | 1.201 | 1.197 | 1.368 | 1.122 |
| Personal care | 1.300 | 1.587 | 1.437 | 1.347 | 1.284 |
| Physical care | 1.117 | 0.979 | 1.061 | 1.074 | 1.135 |
| Total hours | 1.009 | 1.000 | 1.000 | 1.007 | 1.006 |
| Duration 1 to 3 years | 3.834\* | 3.673 | 3.845\* | 3.814\* | 3.965\* |
| Duration 3 to 5 years | 2.327 | 2.378 | 2.592 | 2.502 | 2.677 |
| Duration 5 to 10 years | 3.860 | 3.725 | 3.954 | 4.692\* | 4.598\* |
| Duration 10 years or more | 3.871 | 3.814 | 4.408 | 4.509 | 4.366 |
| No replacement for a break | 1.512 | 1.634 | 1.505 | 1.613 | 1.560 |
| Care recipient's characteristics | 65 to 74 years old | 0.986 | 1.028 | 0.980 | 0.944 | 0.999 |
| 75 years old or older | 1.132 | 1.024 | 1.096 | 0.978 | 1.152 |
| symptoms for 1 to 5 years | 0.135\*\* | 0.141\*\* | 0.140\*\* | 0.122\*\* | 0.136\*\* |
| symptoms for 6 to 10 years | 0.084\*\* | 0.082\*\* | 0.085\*\* | 0.068\*\*\* | 0.078\*\* |
| symptoms for 11 years or more | 0.067\*\* | 0.075\*\* | 0.090\*\* | 0.057\*\* | 0.065\*\* |
| No diagnosis/don't know | 0.668 | 0.545 | 0.484 | 0.539 | 0.540 |
| Vascular dementia | 2.456\*\*\* | 2.479\*\*\* | 2.359\*\* | 2.329\*\*\* | 2.263\*\* |
| Other dementia | 1.055 | 0.988 | 1.090 | 1.045 | 1.035 |
| Moderate severity | 2.367 | 2.367 | 2.278 | 2.346 | 2.291 |
| Severe severity | 2.444 | 2.380 | 2.091 | 2.347 | 2.241 |
|  | Constant | 0.440 | 0.475 | 0.466 | 0.417 | 0.479 |
| Observations | | 282 | 274 | 268 | 287 | 285 |
| Most of the coefficients on dummies are interpreted in relation to the reference category. Table 61 shows the reference categories. Odds ratios are showed for the logit regression. | | | | | | |

Table 68: Costs: propensity score matching results

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Variable** | | **Overall costs** | **Carer's total healthcare costs** | **Care recipient's total healthcare costs** | **Care recipient's total social care costs** |
|  | Admiral nursing | -113.215 | -207.220 | -186.252 | 10.682 |
| (215.731) | (145.259) | (142.972) | (144.031) |
| Coefficient on covariates from logit regression where the admiral nursing dummy is the dependent variable | | | | | |
|
| Carer's characteristics | Female | 0.799 | 0.881 | 0.976 | 0.801 |
| 55 to 64 years old | 1.287 | 1.825 | 1.831 | 1.490 |
| 65 to 69 years old | 2.562 | 2.750 | 3.088 | 3.270 |
| 70 to 74 years old | 1.811 | 2.238 | 2.115 | 1.786 |
| 75 years old or older | 1.055 | 1.655 | 1.815 | 1.632 |
| Bachelor's degree | 1.386 | 0.965 | 1.179 | 1.045 |
| Master's degree and above | 0.155\*\* | 0.268\*\* | 0.261\*\* | 0.164\*\* |
| Full/part-time job | 0.882 | 1.068 | 0.864 | 0.939 |
| Look after full time | 1.172 | 1.094 | 1.121 | 1.231 |
| Retired | 0.641 | 0.858 | 0.619 | 0.713 |
| Some financial difficulties | 1.536 | 1.000 | 1.097 | 1.346 |
| Severe financial difficulties | 2.705\*\* | 1.430 | 1.723 | 2.215\* |
| Don't know/prefer not to say | 1.667 | 1.064 | 1.370 | 1.232 |
| EQ-5D score | 0.775 | 0.329 | 0.680 | 0.400 |
| Caring role | Joint or not main carer | 0.441 | 0.268\* | 0.284\* | 0.367 |
| Parent/parent-in-law | 0.527 | 0.777 | 0.593 | 0.710 |
| Other relationship | 0.432 | 1.027 | 0.596 | 1.125 |
| Personal care | 1.493 | 1.188 | 1.389 | 1.347 |
| Physical care | 1.412 | 1.383 | 1.263 | 0.987 |
| Total hours | 1.015 | 1.004 | 1.007 | 1.016 |
| Duration 1 to 3 years | 3.830 | 4.196\* | 4.467\* | 3.810 |
| Duration 3 to 5 years | 2.364 | 2.585 | 2.712 | 2.950 |
| Duration 5 to 10 years | 3.737 | 4.696\* | 5.076\* | 4.249 |
| Duration 10 years or more | 2.286 | 3.665 | 3.707 | 4.370 |
| No replacement for a break | 1.653 | 1.583 | 1.487 | 1.519 |
| Care recipient's characteristics | 65 to 74 years old | 1.123 | 0.999 | 0.854 | 1.156 |
| 75 years old or older | 1.966 | 1.033 | 1.301 | 1.398 |
| symptoms for 1 to 5 years | 0.238 | 0.125\*\* | 0.151\* | 0.153\*\* |
| symptoms for 6 to 10 years | 0.198 | 0.089\*\* | 0.098\*\* | 0.084\*\* |
| symptoms for 11 years or more | 0.217 | 0.070\*\* | 0.085\*\* | 0.071\*\* |
| No diagnosis/don't know | 0.359 | 0.398 | 0.325 | 0.606 |
| Vascular dementia | 2.334\*\* | 1.922\*\* | 2.065\*\* | 2.270\*\* |
| Other dementia | 0.817 | 0.932 | 0.903 | 0.872 |
| Moderate severity | 1.660 | 2.293 | 2.221 | 2.009 |
| Severe severity | 1.233 | 2.213 | 1.892 | 2.256 |
|  | Constant | 0.170 | 0.875 | 0.388 | 0.478 |
| Observations | | 227 | 269 | 259 | 266 |
| Most of the coefficients on dummies are interpreted in relation to the reference category. Table 61 shows the reference categories. Odds ratios are showed for the logit regression. | | | | | |

Table 69: Descriptive statistics of instruments

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Variable** | **All carers** | | | | |  | **AN** | | **Non-AN** | | **Δ** |
| Obs | Mean | SD | Min | Max |  | Obs | Mean | Obs | Mean |
| Travel time (hours) | 327 | 0.222 | 0.151 | 0 | 1 |  | 155 | 0.151 | 172 | 0.286 | 0.000 |
| Type of local authority | | | | | | | | | | | |
| County | 327 | 0.287 | 0.453 | 0 | 1 |  | 155 | 0.484 | 172 | 0.110 | 0.000 |
| London | 0.131 | 0.338 | 0 | 1 |  | 0.116 | 0.145 |
| Metropolitan | 0.217 | 0.413 | 0 | 1 |  | 0.194 | 0.238 |
| Unitary | 0.364 | 0.482 | 0 | 1 |  | 0.206 | 0.506 |
| SD=standard deviation; Δ=p-value of the Fisher's exact test comparing distributions between AN and non-AN carers. | | | | | | | | | | | |

Table 70: Outcomes: IV results

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Variable** | | **ASCOT score** | **Self-efficacy on symptoms management** | **Self-efficacy on service use** | **Overall life satisfaction** | **Happiness yesterday** |
|  | Admiral nursing | 1.462\* | 2.871 | 3.276 | 0.249 | 0.989 |
| (0.854) | (3.130) | (2.633) | (0.658) | (0.636) |
| Carer's characteristics | Female | -0.494 | -2.532\* | -3.951\*\*\* | -0.173 | -0.019 |
| 55 to 64 years | -0.266 | -2.572 | -1.835 | -0.407 | -0.670 |
| 65 to 69 years | -0.122 | -2.542 | 0.345 | -0.217 | -0.413 |
| 70 to 74 years | 0.060 | -1.903 | 1.291 | -0.037 | 0.175 |
| 75 years or older | 0.704 | -3.031 | -5.289\*\* | 0.623 | 0.539 |
| Bachelor's | -0.490 | -2.513\* | -2.458\*\* | -0.461 | -0.480 |
| Master's and above | -0.606 | -2.924 | -1.027 | -0.061 | 0.246 |
| Full/part-time job | 1.191\* | 1.989 | 1.213 | 0.059 | -0.060 |
| Look after full time | 0.213 | 0.015 | 0.619 | 0.033 | -0.001 |
| Retired | 1.189\*\* | 2.299 | 2.233 | 0.293 | 0.518 |
| Some difficulties | -1.543\*\*\* | -1.395 | -3.937\*\*\* | -0.829\*\* | -1.072\*\*\* |
| Severe difficulties | -2.407\*\*\* | -2.917\* | -3.933\*\*\* | -1.311\*\*\* | -1.404\*\*\* |
| Don't know/prefer not to say | -2.684\*\*\* | -1.986 | -4.443\*\* | -0.746\* | -1.153\*\* |
| EQ-5D score | 7.298\*\*\* | 13.911\*\*\* | 8.962\*\*\* | 4.176\*\*\* | 4.306\*\*\* |
| Caring role | Joint or not main carer | 0.654 | 3.149\* | 3.596\* | 0.855\* | 0.632 |
| Parent/parent-in-law | 0.932 | 0.669 | -2.088 | 0.354 | 0.483 |
| Other relationship | 0.042 | -4.439 | -5.139\* | -0.189 | -0.156 |
| Personal care | -0.552 | -1.060 | -0.868 | -0.213 | -0.029 |
| Physical care | -0.593 | 2.230\* | 0.707 | 0.084 | -0.071 |
| Total hours | -0.087\*\*\* | 0.226\*\*\* | 0.052 | -0.022 | -0.027 |
| 1 to 3 years | -0.389 | 2.215 | 6.206\*\*\* | 0.241 | 0.642 |
| 3 to 5 years | -0.327 | 1.635 | 4.723\*\* | 0.331 | 0.870 |
| 5 to 10 years | -0.350 | 1.876 | 5.646\*\* | -0.176 | 0.328 |
| 10 years or more | -0.901 | 0.339 | 4.382 | -0.048 | 0.261 |
| No replacement for a break | -1.279\*\*\* | -3.537\*\*\* | -2.895\*\*\* | -0.758\*\*\* | -0.809\*\*\* |
| Care recipient's characteristics | 65 to 74 years | 0.774 | 0.062 | 1.469 | 0.523 | 0.619 |
| 75 years or older | 0.613 | 2.399 | 4.906\*\* | 0.290 | 0.346 |
| 1 to 5 years | 0.497 | 2.048 | 0.800 | 1.016 | -0.002 |
| 6 to 10 years | 0.249 | 3.239 | 0.562 | 1.325 | 0.647 |
| 11 years or more | 1.547 | 7.128 | 1.520 | 1.631\* | 1.209 |
| No diagnosis/don't know | -1.336 | -6.644\*\*\* | -4.785\*\* | -0.196 | -0.280 |
| Vascular dementia | -0.919\*\* | -1.533 | -1.936\* | -0.125 | 0.064 |
| Other dementia | -0.578 | -0.536 | -3.979\*\*\* | -0.045 | 0.264 |
| Moderate | -0.782 | -3.192 | -3.986\*\* | -0.860\* | -1.120\*\* |
| Severe | -1.932\*\* | -5.480\*\* | -4.241\*\* | -1.587\*\*\* | -1.846\*\*\* |
|  | Constant | 7.594\*\*\* | 16.919\*\*\* | 18.190\*\*\* | 2.186 | 2.503\* |
| Observations | | 281 | 273 | 267 | 286 | 284 |
| R-squared | | 0.442 | 0.254 | 0.343 | 0.337 | 0.320 |
| First-stage estimated coefficient of the instrument and F statistic | | | | | | |
|
|  | Travel time | -1.314\*\*\* | -1.242\*\*\* | -1.303\*\*\* | -1.267\*\*\* | -1.284\*\*\* |
| (0.140) | (0.142) | (0.153) | (0.141) | (0.143) |
| Cragg-Donald F statistic | | 48.153 | 41.741 | 41.138 | 45.057 | 45.341 |
| Most of the coefficients on dummies are interpreted in relation to the reference category. Table 61 shows the reference categories. | | | | | | |
| Robust standard errors in parentheses; \*\*\* p<0.01, \*\* p<0.05, \* p<0.1. | | | | | | |

Table 71: Costs: IV results

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Variable** | | **Overall costs** | **Carer's total healthcare costs** | **Care recipient's total healthcare costs** | **Care recipient's total social care costs** |
|  | Admiral nursing | -84.789 | -26.945 | 183.325 | -485.907 |
| (424.300) | (220.400) | (235.300) | (325.800) |
| Carer's characteristics | Female | -43.503 | 247.528 | 15.399 | -10.760 |
| 55 to 64 years | -460.986 | 111.659 | -172.661 | -290.753 |
| 65 to 69 years | -311.635 | 264.837 | -136.340 | -206.945 |
| 70 to 74 years | -111.880 | 174.031 | 263.621 | -497.466\* |
| 75 years or older | -250.737 | 478.223\* | -43.945 | -226.171 |
| Bachelor's | 374.071\* | -132.752\* | -133.293 | 354.348\*\* |
| Master's and above | 325.279 | -4.059 | -97.005 | 132.848 |
| Full/part-time job | 101.672 | -164.674 | 208.777 | -167.638 |
| Look after full time | -203.433 | -138.609 | -77.242 | -40.900 |
| Retired | 262.168 | 64.582 | 47.587 | 287.262 |
| Some difficulties | 79.236 | -2.703 | 33.939 | -9.724 |
| Severe difficulties | 54.450 | 146.511 | -112.209 | 312.202\* |
| Don't know/prefer not to say | 726.467\* | 337.062 | 439.764 | 130.765 |
| EQ-5D score | 282.471 | -432.785 | -6.379 | 171.143 |
| Caring role | Joint or not main carer | 39.986 | -144.610 | 133.295 | -56.076 |
| Parent/parent-in-law | -2.780 | 147.888 | -63.445 | 54.819 |
| Other relationship | 172.630 | 143.890 | -38.175 | 93.189 |
| Personal care | 199.606 | 80.022 | -94.520 | 156.414 |
| Physical care | 201.990 | 8.679 | 183.537 | 22.129 |
| Total hours | 4.180 | -10.290 | 9.859 | -12.197 |
| 1 to 3 years | 424.923 | 78.139 | 92.416 | 270.099 |
| 3 to 5 years | 456.227 | -154.424 | 229.955 | 235.502 |
| 5 to 10 years | 234.233 | -178.270 | -216.822 | 535.651 |
| 10 years or more | 228.892 | -423.710\* | -492.216 | 838.114\*\* |
| No replacement for a break | 4.059 | -257.263\* | -144.867 | 82.728 |
| Care recipient's characteristics | 65 to 74 years | -174.957 | -94.208 | -143.724 | 123.119 |
| 75 years or older | 7.603 | -59.864 | 106.349 | -25.234 |
| 1 to 5 years | -360.584 | 348.865\*\* | 86.623 | -248.950 |
| 6 to 10 years | -311.801 | 275.298 | 155.216 | -363.265 |
| 11 years or more | -2.090 | 374.579 | 677.913 | -673.275 |
| No diagnosis/don't know | 151.458 | -170.216 | 147.718 | -279.431 |
| Vascular dementia | 20.869 | -38.935 | 234.759\*\* | -112.184 |
| Other dementia | 21.787 | 146.556 | 255.082 | -91.738 |
| Moderate | -170.357 | 43.524 | -238.101 | 111.622 |
| Severe | 486.253 | 465.856 | -32.586 | 654.281\*\* |
|  | Constant | 422.567 | 26.884 | 14.125 | 362.846 |
| Observations | | 227 | 268 | 258 | 266 |
| R-squared | | 0.171 | 0.170 | 0.150 | 0.105 |
| First-stage estimated coefficient of the instrument and F statistic | | | | | |
|
|  | Travel time | -1.376\*\*\* | -1.354\*\*\* | -1.444\*\*\* | -1.277\*\*\* |
| (0.141) | (0.141) | (0.136) | (0.142) |
| Cragg-Donald F statistic | | 47.155 | 49.597 | 56.661 | 43.216 |
| Most of the coefficients on dummies are interpreted in relation to the reference category. Table 61 shows the reference categories. | | | | | |
| Robust standard errors in parentheses; \*\*\* p<0.01, \*\* p<0.05, \* p<0.1. | | | | | |

Table 72: Outcomes: IV with additional instruments

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Variable** | | **ASCOT score** | **Self-efficacy on symptoms management** | **Self-efficacy on service use** | **Overall life satisfaction** | **Happiness yesterday** |
|  | Admiral nursing | 0.910 | 2.514 | 3.149\* | 0.005 | 0.609 |
| (0.642) | (2.367) | (1.811) | (0.468) | (0.458) |
| Observations | | 281 | 273 | 267 | 286 | 284 |
| R-squared | | 0.454 | 0.256 | 0.344 | 0.338 | 0.331 |
| First-stage estimated coefficient of the instrument and F statistic | | | | | | |
|
|  | Travel time | -1.119\*\*\* | -1.088\*\*\* | -1.145\*\*\* | -1.127\*\*\* | -1.123\*\*\* |
|  | County LA | 0.418\*\*\* | 0.395\*\*\* | 0.428\*\*\* | 0.386\*\*\* | 0.399\*\*\* |
|  | London LA | 0.052 | -0.003 | -0.015 | -0.004 | 0.015 |
|  | Metropolitan LA | 0.090 | 0.086 | 0.080 | 0.068 | 0.071 |
| Cragg-Donald F statistic | | 25.267 | 0.630 | 24.255 | 22.990 | 23.712 |
| Sargan-Hansen test (p-value) | | 0.187 | 0.889 | 0.112 | 0.783 | 0.441 |
| Covariates are not reported. | | | | | | |
| Robust standard errors in parentheses; \*\*\* p<0.01, \*\* p<0.05, \* p<0.1. | | | | | | |

Table 73: Recruitment of professionals to Work Package 4 and areas of responsibility of those interviewed

|  |  |  |  |
| --- | --- | --- | --- |
| **Case study site** | **Professionals invited to take part** | **Professionals agreed to be interviewed** | **Areas of responsibility of professionals interviewed** |
| Site 1 | 14 | 7 | Commissioning (health), commissioning (social care), Admiral Nursing, palliative care, dementia charity (x2), ‘other’ community organisation. |
| Site 2 | 16 | 5 | Commissioning (joint health and social care), Admiral Nursing, occupational therapy, carers’ charity, dementia charity. |
| Site 3 | 10 | 4 | Commissioning (health), commissioning (social care), memory services (x2). |
| Site 4 | 18 | 4 | Commissioning (social care), memory services, carers' charity, dementia charity. |
| **Overall** | **58** | **20** | **Commissioning (health and social care), dementia charities, carers’ charities, Admiral Nursing, palliative care, occupational therapy, memory services and one ‘other’ community organisation.** |

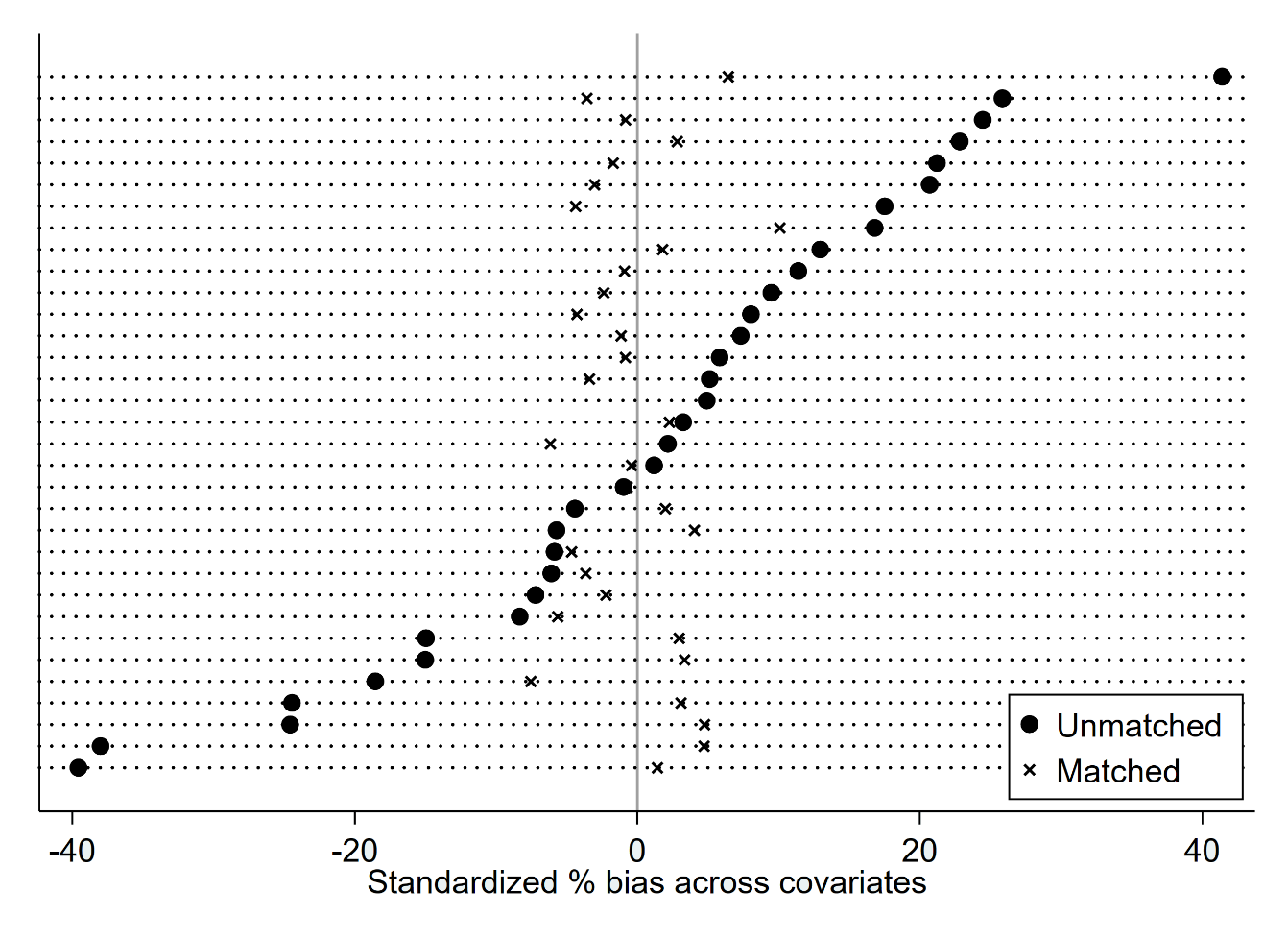


Figure 6: ASCOT score: bias reduction for each covariate after matching

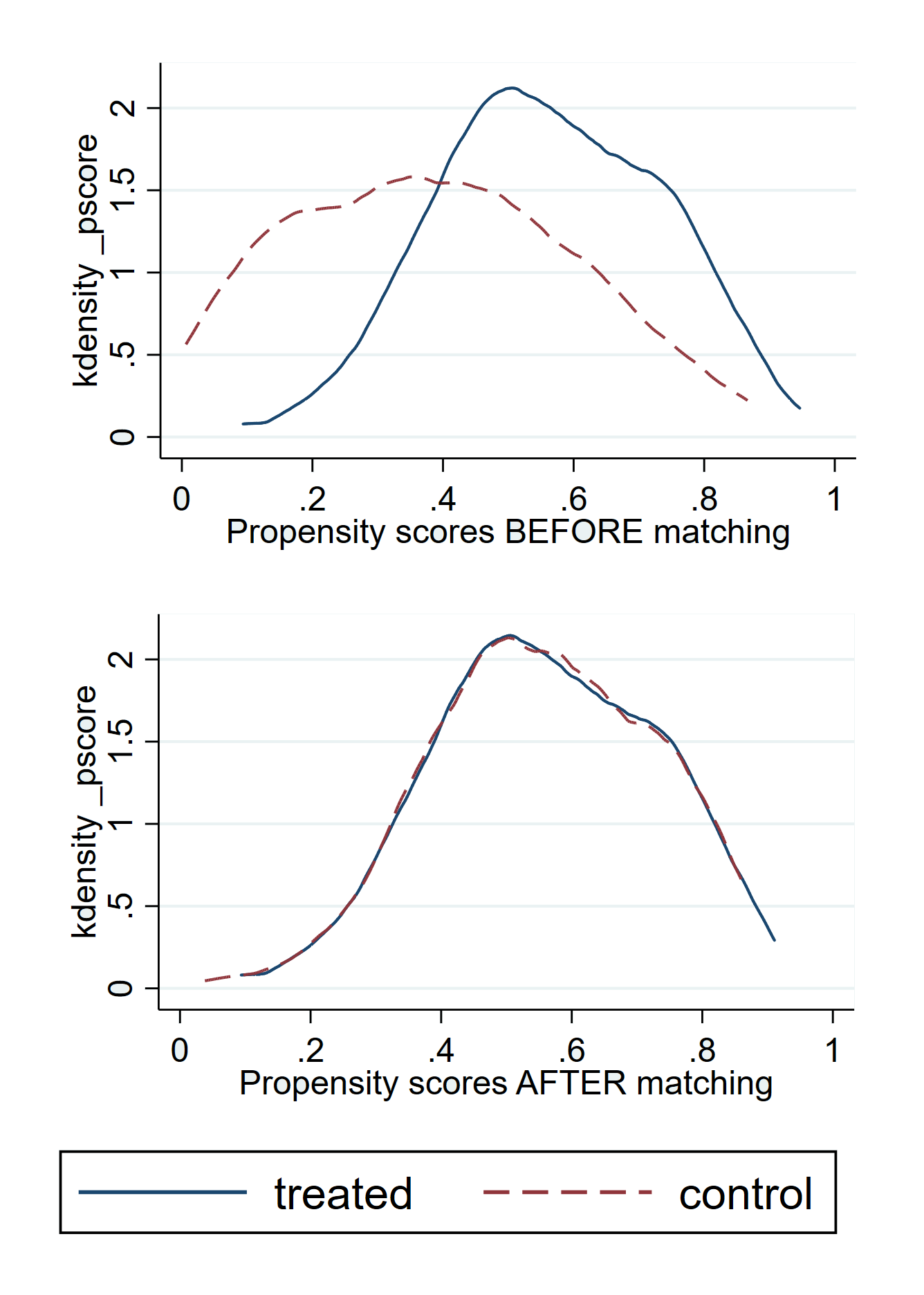


Figure 7: ASCOT score: propensity score distributions before and after matching

Appendix 2 Support for carers of people with   
dementia survey



**Support for Carers of People with Dementia**

This questionnaire is about **YOU** and your role caring for someone with dementia.   
It is anonymous and the answers you give will be kept secure and confidential.   
They will only be used in this study to understand the support available for people who care for someone with dementia as described in the information sheet enclosed.

We are focusing on people who support someone with dementia who is still living at home. So that we do not waste your time, the first questions below are about your **CURRENT** caring situation. Please tick the answer that is closest to your situation at the moment:

1. I care for a person with dementia who lives at home with me. ❑
2. I care for a person with dementia who lives at home with others   
   *(for example, with a spouse, other relative, etc.)* ❑
3. I care for a person with dementia who lives at home alone. ❑
4. I care for a person with dementia who lives in sheltered or   
   supported accommodation. ❑
5. I care for a person with dementia who lives in a care home or   
   nursing home. ❑
6. I am not caring for a person with dementia at the moment. ❑

**If you have ticked Question 5 or 6, you do not need to answer any more questions.** Thank you for your time. Please return the questionnaire in the pre-paid envelope enclosed. You do not need a stamp.

**If you have ticked Questions 1, 2, 3, or 4, please turn over and continue the survey.**

*Please turn over…*

If you have any questions or would like help completing the questionnaire, please email [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk) or [fiona.aspinal@york.ac.uk](mailto:fiona.aspinal@york.ac.uk) or telephone   
01904 321950 and ask to speak to Kate Gridley or Fiona Aspinal.

**We hope you enjoy completing the survey and thank you for helping us to build a picture of what support is available to people who care for someone with dementia.** Please remember that participation is optional.

Once you have completed the questionnaire, please return it in the pre-paid envelope enclosed. You do not need a stamp.

**Thank you**

This part of the questionnaire is about you and the person you care for. It helps us to understand people’s answers if we know a bit about them, and it also tells us if there are any groups of people who have not had their voices heard.

You do not have to answer the questions about your personal details if you would prefer not to – you can just tick ‘prefer not to say’ and move on to the next question.

1. **ABOUT THE PERSON YOU CARE FOR**
   1. **Who is it that you look after or help?**

🔾 Spouse/partner

🔾 Parent

🔾 Parent-in-law

🔾 Grandparent

🔾 Other relative

🔾 Friend or neighbour

🔾 Other *(please provide details)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

🔾 Prefer not to say

* 1. **What is his/her sex?**

🔾 Male

🔾 Female

🔾 Prefer not to say

* 1. **Which of the following age bands does s/he fit into?**

🔾 Under 45 years of age

🔾 45-54

🔾 55-64

🔾 65-74

🔾 75-84

🔾 85-94

🔾 95 and over

🔾 Prefer not to say

* 1. **Which of these groups does the person you care for belong to?***Choose one option that best describes his or her ethnic group or background.*

🔾 White

🔾 Mixed/Multiple ethnic groups

🔾 Asian/Asian British

🔾 Black/African/Caribbean/Black British

🔾 Other ethnic group

🔾 Prefer not to say

* 1. **How long have you been aware of his or her dementia symptoms?**

🔾 Under 1 year

🔾 1-5 years

🔾 6-10 years

🔾 11 years or more

* 1. **Has the person you care for been formally diagnosed with dementia, for example after tests or a brain scan?**

🔾 Yes

🔾 No

🔾 Don’t know

* 1. **What type of dementia does the person you care for have?***Please tick ALL that apply.*

🔾 Alzheimer’s Disease

🔾 Vascular dementia

🔾 Dementia with Lewy Bodies

🔾 Fronto-temporal dementia

🔾 Other type *(please provide details)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

🔾 Don’t know

* 1. **How severe would YOU say his/her dementia is?**

🔾 Mild

🔾 Moderate

🔾 Severe

1. **THE NEXT FEW QUESTIONS ARE ABOUT YOU**
   1. **What is your sex?**

🔾 Male

🔾 Female

🔾 Prefer not to say

* 1. **Which of the following age bands do you fit into?**

🔾 Under 16 years of age

🔾 16-24

🔾 25-34

🔾 35-44

🔾 45-54

🔾 55-64

🔾 65-69

🔾 70-74

🔾 75 or over

🔾 Prefer not to say

* 1. **Which of these groups do you consider you belong to?**

🔾 White

🔾 Mixed/Multiple ethnic groups

🔾 Asian/Asian British

🔾 Black/African/Caribbean/Black British

🔾 Other ethnic group

🔾 Prefer not to say

* 1. **What level of qualification do you have?** *Please tick the highest that applies.*

🔾 Secondary school and equivalent qualifications *(for example, School Certificate, O-Level, CSE, GCSE, NVQ Levels 1 to 3, OND/ONC, Traditional or Modern Apprenticeship, City and Guilds, RSA)*

🔾 Over 16 qualifications *(for example, AS-Level, A-Level, Scottish 6th Year Certificate, Higher School Certificate, Access qualification)*

🔾 College level qualifications *(for example, NVQ Levels 4 & 5, Foundation degree, RSA higher, HMC/HND, BTEC higher, nursing qualification below degree level, other higher education below degree level)*

🔾 Bachelor’s level qualifications *(for example, University/CNAA Bachelor degree, teaching qualification)*

🔾 Master’s level qualification and above *(for example, Higher degree, Doctorate)*

🔾 None of these

🔾 Prefer not to say

* 1. **Which of these statements describe your work situation?***Please tick ALL that apply to you currently.*

🔾 I am in full-time paid work

🔾 I am in part-time paid work

🔾 I look after the home full-time

🔾 I am fully retired from paid work

🔾 I have a long-term illness or disability that prevents me from having paid work

🔾 I am currently unemployed

🔾 I am in full-time education

🔾 I am in part-time education

🔾 Other *(please provide details)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

🔾 Prefer not to say

1. **ABOUT CARING FOR THE PERSON WITH DEMENTIA**
   1. **How long have you been caring for the person that you support?***(that is, doing things for him/her over and above what you would normally do)*

🔾 Less than 6 months

🔾 Between 6 months and 1 year

🔾 Between 1 and 3 years

🔾 Between 3 and 5 years

🔾 Between 5 and 10 years

🔾 Between 10 and 15 years

🔾 15 years or more

* 1. **Apart from any people paid to provide care, such as nurses or care workers, is there anyone else who regularly also looks after the person you care for – for example, another member of your household, another member of your family, a relative or a friend?**

🔾 Yes **Go to next Question 3.3 (below).**

🔾 No **Go to Question 3.4** **(below).**

🔾 Don’t know **Go to Question 3.4** **(below).**

* 1. **Do any of these people (including anyone in your household) spend more time than you do looking after the person you care for?**

🔾 Yes

🔾 No

🔾 Other person spends equal time

🔾 Don’t know

* 1. **If you needed a break for a couple of days, is there someone you could rely on to look after the person you care for?**

🔾 Yes **Go to next Question 3.5 (on page 8).**

🔾 No  **Go to Question 3.6 (on page 8).**

* 1. **Who are you able to rely on if you want a break for a couple of days?**

🔾 Relative, friend or neighbour

🔾 Service arranged with the NHS, local authority or charity/voluntary organisation

🔾 Paid helper

🔾 Other *(please provide details)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**TYPE OF SUPPORT PROVIDED**

* 1. **What kind of things do you usually do for the person you care for?**   
     *Please tick ALL that apply.*

🔾 Helping with personal care, such as dressing, bathing, washing, shaving, cutting nails, feeding, and using the toilet

🔾 Physical help, such as walking, getting up and down stairs, and getting into and out of bed

🔾 Helping with dealing with care services and benefits, such as making appointments and telephone calls, and filling in forms

🔾 Helping with other paperwork or financial matters, such as writing letters, sending cards, filling in forms, dealing with bills and banking

🔾 Other practical help, such as preparing the meals, doing his/her shopping, laundry, housework, gardening, decorating, household repairs, and taking to a doctor’s or hospital appointment

🔾 Keeping him/her company, such as visiting, sitting with, reading to, talking to, and playing cards or games

🔾 Taking him/her out, such as taking out for a walk or drive, and taking to see friends or relatives

🔾 Giving medicines, such as making sure he/she takes tablets, giving injections and changing dressings

🔾 Keeping an eye on him/her to see if he/she is alright

🔾 Any other help not included above? *(please provide details below)*:

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**If you have ticked TWO OR MORE answers above, please go to the   
next Question 3.7.**

**If you have ticked ONE answer above, please go to Question 3.8 (on page 10).**

* 1. **Thinking only about the last 24 hours, how much time did you spend doing the things you ticked above?** Don’t worry if this was not a usual sort of day for you; we are interested in what you actually did yesterday.

If you spent less than an hour on any type of help record this as 1 hour.

**If you do more than three things on the list, please just provide details for the THREE that you spent most time doing.**

🔾 Hours spent yesterday helping with personal care, such as dressing, bathing, washing, shaving, cutting nails, feeding, and using the toilet hours

🔾 Hours spent yesterday giving physical help, such as walking, getting up and down the stairs, and getting into and out of bed hours

🔾 Hours spent yesterday helping with dealing with care services and benefits,   
such as making appointments and telephone calls, and   
filling in forms hours

🔾 Hours spent yesterday helping with other paperwork or financial matters,   
such as writing letters, sending cards, filling in forms, dealing with   
bills and banking hours

🔾 Hours spent yesterday giving other practical help, such as preparing meals, doing his/her shopping, laundry, housework, gardening, decorating, household repairs, and taking to a doctor’s or hospital appointment hours

🔾 Hours spent yesterday keeping him/her company, such as visiting, sitting with, reading to, talking to, and playing cards or games hours

🔾 Hours spent yesterday taking him/her out, such as taking out for a walk or drive, and taking to see friends or relatives hours

🔾 Hours spent yesterday giving medicines, such as making sure he/she takes tablets, giving injections and changing dressings hours

🔾 Hours spent yesterday keeping an eye on him/her to see if   
he/she is alright hours

🔾 Hours spent yesterday on any other help not included above? hours

* 1. **Thinking about the last 24 hours, how much time in TOTAL did you spend caring?** Don’t worry if this was not a usual sort of day for you; we are interested in what you actually did yesterday.

**Total number of hours spent caring yesterday hours**

**THE IMPACT OF CARING**

We are interested in the impact that getting or not getting support has on carers' quality of life and health. The next section has questions that are used regularly in research to measure these sorts of effects.

1. **THE NEXT SEVEN QUESTIONS ASK YOU ABOUT YOUR QUALITY OF LIFE AS A CARER**
   1. **Which of the following statements best describes how you spend your time?** When you are thinking about how you spend your time, please include anything you value or enjoy, including leisure activities, formal employment, voluntary or unpaid work, and caring for others. *Please tick ONE only.*

🔾 I'm able to spend my time as I want, doing things I value or enjoy

🔾 I'm able to do enough of the things I value or enjoy with my time

🔾 I do some of the things I value or enjoy with my time, but not enough

🔾 I don't do anything I value or enjoy with my time

* 1. **Which of the following statements best describes how much control you have over your daily life?** *Please tick ONE only.*

🔾 I have as much control over my daily life as I want

🔾 I have adequate control over my daily life

🔾 I have some control over my daily life, but not enough

🔾 I have no control over my daily life

* 1. **Thinking about how well you look after yourself - such as, getting enough sleep or eating well - which statement best describes your present situation?***Please tick ONE only.*

🔾 I look after myself as well as I want

🔾 I look after myself well enough

🔾 Sometimes I can't look after myself well enough

🔾 I feel I am neglecting myself

* 1. **Which of the following statements best describes how safe you feel?** By ‘feeling safe’ we mean feeling safe from fear of abuse, being attacked or other physical harm, such as accidents, which are a result of your caring role.   
     *Please tick ONE only.*

🔾 I feel as safe as I want

🔾 Generally I feel adequately safe, but not as safe as I would like

🔾 I feel less than adequately safe

🔾 I don't feel at all safe

* 1. **Thinking about how much contact you have with people you like, which of the following statements best describes your social situation?** *Please tick ONE only.*

🔾 I have as much social contact as I want with people I like

🔾 I have adequate social contact with people

🔾 I have some social contact with people, but not enough

🔾 I have little social contact with people and feel socially isolated

* 1. **Thinking about the space and time you have to be yourself in your daily life, which of the following statements best describes your present situation?** *Please tick ONE only.*

🔾 I have all the space and time I need to be myself

🔾 I have adequate space and time to be myself

🔾 I have some of the space and time I need to be myself, but not enough

🔾 I don't have any space or time to be myself

* 1. **Thinking about feeling supported and encouraged in your caring role, which of the following statements best describes your present situation?** This question is asking about feeling supported and encouraged, rather than how you are supported and encouraged by particular people or organisations.   
     *Please tick ONE only.*

🔾 I feel I have the encouragement and support I want

🔾 I feel I have adequate encouragement and support

🔾 I feel I have some encouragement and support, but not enough

🔾 I feel I have no encouragement and support

1. **THE FOLLOWING SIX QUESTIONS ARE ABOUT YOUR HEALTH TODAY**

**For the following six questions, please tick the ONE that best describes your health TODAY.**

**5.1. MOBILITY**

🔾 I have no problems in walking about

🔾 I have slight problems in walking about

🔾 I have moderate problems in walking about

🔾 I have severe problems in walking about

🔾 I am unable to walk about

**5.2. SELF-CARE**

🔾 I have no problems washing or dressing myself

🔾 I have slight problems washing or dressing myself

🔾 I have moderate problems washing or dressing myself

🔾 I have severe problems washing or dressing myself

🔾 I am unable to wash or dress myself

**5.3. USUAL ACTIVITIES** *(for example, work, study, housework, family or   
 leisure activities)*

🔾 I have no problems doing my usual activities

🔾 I have slight problems doing my usual activities

🔾 I have moderate problems doing my usual activities

🔾 I have severe problems doing my usual activities

🔾 I am unable to do my usual activities

**5.4. PAIN/DISCOMFORT**

🔾 I have no pain or discomfort

🔾 I have slight pain or discomfort

🔾 I have moderate pain or discomfort

🔾 I have severe pain or discomfort

🔾 I have extreme pain or discomfort

**5.5. ANXIETY/DEPRESSION**

🔾 I am not anxious or depressed

🔾 I am slightly anxious or depressed

🔾 I am moderately anxious or depressed

🔾 I am severely anxious or depressed

🔾 I am extremely anxious or depressed

**6. THE FOLLOWING TWO QUESTIONS ASK YOU TO SUMMARISE HOW YOU FEEL AT THE MOMENT**

* 1. **Overall, how satisfied are you with your life nowadays?** *Please tick ONE only.*
* **0** means not at all satisfied
* **10** means completely satisfied

**Not at all satisfied Completely satisfied**

**1**

**10**

**9**

**8**

**7**

**6**

**5**

**4**

**3**

**2**

**0**

* 🔾 🔾 🔾 🔾 🔾 🔾 🔾 🔾 🔾 🔾
  1. **Overall, how happy did you feel yesterday?** *Please tick ONE only.*
* **0** means not at all happy
* **10** means completely happy

**Not at all happy Completely happy**

**10**

**9**

**8**

**7**

**6**

**5**

**4**

**3**

**2**

**1**

**0**

* 🔾 🔾 🔾 🔾 🔾 🔾 🔾 🔾 🔾 🔾

**7. THE NEXT QUESTION ASKS YOU TO THINK ABOUT HOW YOU FEEL YOU ARE MANAGING WITH YOUR CARING RESPONSIBILITIES AT THE MOMENT**

On a scale of 1 to 10, where **1 means not at all certain** and **10 means very certain**, how certain are you right now that you can:

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Not at all certain 1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **Very certain 10** |
| **7.1.** Handle any problems your relative has, like memory loss, wandering or behavioural problems? |  |  |  |  |  |  |  |  |  |  |
| **7.2.** Handle any problems that might come up in the future with your relative's care? |  |  |  |  |  |  |  |  |  |  |
| **7.3.** Deal with the frustrations of caring for your relative? |  |  |  |  |  |  |  |  |  |  |
| **7.4.** Do something to keep your relative as independent as possible? |  |  |  |  |  |  |  |  |  |  |
|  | **Not at all certain 1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **Very certain 10** |
| **7.5.** Get answers to all your questions about your relative's problems? |  |  |  |  |  |  |  |  |  |  |
| **7.6.** Care for your relative without help from organisations or agencies that provide services? |  |  |  |  |  |  |  |  |  |  |
| **7.7.** Find organisations or agencies in the community that provide services to help you care for your relative? |  |  |  |  |  |  |  |  |  |  |
| **7.8.** Get answers to all of your questions about these services? |  |  |  |  |  |  |  |  |  |  |
| **7.9.** Arrange for these services yourself? |  |  |  |  |  |  |  |  |  |  |
| **7.10.** Find ways to pay for these services? |  |  |  |  |  |  |  |  |  |  |

**8. SERVICES FOR CARERS**

**The next questions ask about any contact you may have with services that are meant to support you in your role as a carer for a person with dementia.**

**8.1.** **Admiral Nurses provide specialist support to carers of people with dementia** *(the information sheet enclosed describes the Admiral Nurse service).*

**Have you ever used an Admiral Nurse service?**

🔾 Yes **Go to next Question 8.2 (below).**

🔾 No **Go to Question 8.8 (on page 20).**

🔾 Don’t know **Go to Question 8.8 (on page 20).**

**8.2. How long ago did you first use the Admiral Nursing service?**

🔾 Less than a month ago

🔾 Between 1 and 2 months ago

🔾 Between 3 and 6 months ago

🔾 Between 7 and 12 months ago

🔾 Between 1 and 2 years ago

🔾 Between 2 and 5 years ago

🔾 More than 5 years ago

🔾 Don't know

**8.3. When were you last in contact with the Admiral Nursing service?**

🔾 Up to 6 months ago

🔾 Between 7 and 12 months ago

🔾 Between 1 and 2 years ago

🔾 Between 2 and 5 years ago

🔾 More than 5 years ago

🔾 Don't know

**8.4. What kind of contacts have you had with the Admiral Nurse service?**   
*Please tick ALL that apply.*

🔾 Face-to-face visits

🔾 Telephone contact

🔾 Email contact

🔾 Support group meetings

🔾 Other *(please provide details)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**8.5. Have you used the Admiral Nursing service in the last four weeks?**

🔾 Yes **Go to next Question 8.6 (below).**

🔾 No **Go to Question 8.8 (on page 20).**

**8.6.** **Thinking about the last four weeks only, how many times have you been in contact with the Admiral Nurse service?** We are interested here **in each type of contact you have had.** *Please write in the number below.*

|  |  |
| --- | --- |
|  | Number of times I have had this sort of contact in the last four weeks |
| Face-to-face visits |  |
| Telephone contact |  |
| Email contact |  |
| Support group meetings |  |
| Other *(please provide details below)*: |  |
|  |  |
|  |  |
|  |  |

**8.7. What type of support do you feel you get or got from the Admiral   
 Nurse service?** *Please tick ALL that apply.*

🔾 Emotional and social support (including discussion with you about YOUR problems and concerns)

🔾 Information, advice and knowledge

🔾 Practical help (including referral to, and liaison with, other services)

🔾 Educating and supporting other professionals that you are in   
 contact with

🔾 Assessing your needs

🔾 Recommendations about medication for the person you care for

🔾 Clinical examination of the person you care for

🔾 Going to support groups and training for carers that the Admiral Nurse service organises

🔾 Other *(please provide details)*:

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**8.8.** **There are other sorts of services that are set-up specially to   
 support carers. This next few questions are about some of  
 these. We will be asking about other types of services later  
 on. Please tick below to show the services for carers you have  
 used OR have never used.** *Please choose one answer for each type of service.*

|  |  |  |
| --- | --- | --- |
|  | **I have used this sort of service** | **I have never used this sort of service** |
| Short breaks/respite when the person you care for is looked after away from home |  |  |
| Someone to sit with the person you care for or take them out during the day while you do other things |  |  |
| A night-time sitting service at home to help you get a full night's sleep |  |  |
| A carers' advice service |  |  |
| A support group for carers |  |  |

**If you have used NONE of these services, please go to Question 9.1.   
(on page 25).**

**If you have used ANY of these services, please go to the next   
Question 8.9.**

**8.9. What type of support do you feel you get or got from the service? Please tick ALL the types of support you feel you get or got.**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Type of support you get from this service** | | | | | | | | |
|  | Not applicable –  I have never used this service | Emotional and social support (including discussing  YOUR problems and concerns) | Information, advice and knowledge | Practical help (including referral to, and liaison with, other services) | Time for yourself or to do other things | Assessment of your needs | Some other type of support | No support |
| Short breaks/respite when the person you care for is looked after away from home |  |  |  |  |  |  |  |  |
| Someone to sit with the person you care for or take them out during the day while you do other things |  |  |  |  |  |  |  |  |
| A night-time sitting service at home to help you get a full night’s sleep |  |  |  |  |  |  |  |  |
| A carers’ advice service |  |  |  |  |  |  |  |  |
| A support group for carers |  |  |  |  |  |  |  |  |

**8.10. The next few questions are about your use of carers’ services  
 in the last four weeks only, and whether you paid anything   
 for them.**

**How many times have you used these services in the last   
four weeks?**

|  |  |  |
| --- | --- | --- |
|  | **Not at all** | **Number of times** |
| Short breaks/respite when the person you care for is looked after away from home | 🔾 |  |
| Someone to sit with the person you care for or take them out during the day while you do other things | 🔾 |  |
| A night-time sitting service at home to help you get a full night's sleep | 🔾 |  |
| A carers' advice service | 🔾 |  |
| A support group for carers | 🔾 |  |

**If you have used ANY of these services in the last four weeks, please go to Question 8.11 (on page 23).**

**If you have used NONE of these services in the last four weeks, please go to Question 9.1 (on page 25).**

**8.11. Do you or the person you care for pay anything for this service?**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **I pay for this service** | **The person I care for pays for this service** | **We both pay something towards this service** | **Neither of us pays anything for this service** | **Not applicable – service not used in past four weeks** |
| Short breaks/respite when the person you care for is looked after away from home | 🔾 | 🔾 | 🔾 | 🔾 | 🔾 |
| Someone to sit with the person you care for or take them out during the day while you do other things | 🔾 | 🔾 | 🔾 | 🔾 | 🔾 |
| A night-time sitting service at home to help you get a full night's sleep | 🔾 | 🔾 | 🔾 | 🔾 | 🔾 |
| A carers' advice service | 🔾 | 🔾 | 🔾 | 🔾 | 🔾 |
| A support group for carers | 🔾 | 🔾 | 🔾 | 🔾 | 🔾 |

**If you or the person you care for DO PAY for any service listed above, please go to the next Question 8.12 (on page 24).**

**If you or the person you care for DO NOT PAY for any service listed above, please go to Question 9.1. (on page 25).**

**8.12. This question asks how much you or the person you care for   
 pays for the service each time you use it.**

|  |  |  |
| --- | --- | --- |
|  | **Not applicable – service not used/not paid for in last four weeks** | **How much (to the nearest £) do you pay for this service each time you use it?** |
| Short breaks/respite when the person you care for is looked after away from home | 🔾 |  |
| Someone to sit with the person you care for or take them out during the day while you do other things | 🔾 |  |
| A night-time sitting service at home to help you get a full night's sleep | 🔾 |  |
| A carers' advice service | 🔾 |  |
| A support group for carers | 🔾 |  |

**9. HEALTH SERVICES THAT YOU USE**

**Now we are moving on to ask about health services that you may use. First we ask about health services that YOU have used for yourself in the last four weeks.**

**9.1 In the last four weeks how many times have you used ANY of the following hospital services for yourself?** *If you have not used the service please tick NONE.*

|  |  |  |
| --- | --- | --- |
|  | **Number of times I have used this service  in the last four weeks** | |
| **None** | **Number of times** |
| Outpatient appointment | 🔾 |  |
| Planned hospital admission without staying overnight | 🔾 |  |
| Planned hospital admission with an overnight stay | 🔾 |  |
| Unplanned or emergency hospital admission | 🔾 |  |
| Any other hospital appointment | 🔾 |  |

**9.2. In the last four weeks, how many times have you used ANY of these other health services?** *If you have not used the service please tick NONE.*

|  |  |  |
| --- | --- | --- |
|  | **Number of times I have used this service  in the last four weeks** | |
| **None** | **Number of times** |
| A GP, either at the health centre or at home | 🔾 |  |
| A practice or district nurse | 🔾 |  |
| A nurse specialist (other than an Admiral Nurse) | 🔾 |  |
| A therapist (including occupation therapist, physiotherapist, speech therapist) | 🔾 |  |

**10. HEALTH SERVICES THAT THE PERSON YOU CARE FOR USES**

**Now we would like to ask you about any health services the person you care for has used in the last four weeks.**

**10.1. In the last four weeks, how many times has the person you care for used ANY of the following hospital services? If the person you care for has NOT USED the service, please tick NONE.**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Number of times the person you care for used this service in the last four weeks** | | |
| **None** | **Number of times** | **Don’t know** |
| Outpatient appointment | 🔾 |  | 🔾 |
| Planned hospital admission without staying overnight | 🔾 |  | 🔾 |
| Planned hospital admission with an overnight stay | 🔾 |  | 🔾 |
| Unplanned or emergency hospital admission | 🔾 |  | 🔾 |
| Any other hospital appointment | 🔾 |  | 🔾 |

**10.2. In the last four weeks, how many times has the person you care for used ANY of these other health care services? If the person you care for has NOT USED the service, please tick NONE.**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Number of times the person you care for used this service in the last four weeks** | | |
| **None** | **Number of times** | **Don’t know** |
| A GP, either at the health centre or at home | 🔾 |  | 🔾 |
| A practice or district nurse | 🔾 |  | 🔾 |
| A nurse specialist (other than an Admiral Nurse) | 🔾 |  | 🔾 |
| A therapist (including occupational therapist, physiotherapist, speech therapist) | 🔾 |  | 🔾 |

**The next questions are about any other services that the person you care for may have used in the last four weeks. If the person you care for has NOT USED the service, please tick NONE.**

**10.3. In the last four weeks, how many times has the person you care for used ANY of the services below?**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Number of times the person you care for used this service in the last four weeks** | | |
| **None** | **Number of times** | **Don’t know** |
| Day care centre | 🔾 |  | 🔾 |
| Other type of day care service | 🔾 |  | 🔾 |
| Home care | 🔾 |  | 🔾 |
| Meals (for example, via meals on wheels, luncheon club, etc.) | 🔾 |  | 🔾 |
| Appointment with someone from social services | 🔾 |  | 🔾 |
| Memory café | 🔾 |  | 🔾 |

**If the person you care for has used ANY of these services in the last four weeks, please go to the next Question 10.4 (on page 28).**

**If the person you care for has used NONE of these services in the last four weeks, please go to Question 10.6 (on page 29).**

**10.4. Do you or the person you care for pay anything for this service?**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **I pay for the service** | **The person I care for pays for the service** | **We both pay something towards the service** | **Neither of us pays anything for the service** | **Not applicable – service not used in past four weeks** |
| Day care centre | 🔾 | 🔾 | 🔾 | 🔾 | 🔾 |
| Home care | 🔾 | 🔾 | 🔾 | 🔾 | 🔾 |
| Meals (for example, via meals on wheels, luncheon club, etc.) | 🔾 | 🔾 | 🔾 | 🔾 | 🔾 |
| Appointment with someone from social services | 🔾 | 🔾 | 🔾 | 🔾 | 🔾 |
| Memory café | 🔾 | 🔾 | 🔾 | 🔾 | 🔾 |
| Other type of day care service | 🔾 | 🔾 | 🔾 | 🔾 | 🔾 |

**If you or the person you care for pay for ANY service listed above please go to the next Question 10.5.**

**If you or the person you care for DO NOT PAY for any services listed above, please go to Question 10.6. (on page 29).**

**10.5. This question asks how much you or the person you care for pays for the service each time you or he/she uses it.**

|  |  |  |
| --- | --- | --- |
|  | **Not applicable – service not used/paid for in past four weeks** | **How much (to the nearest £) is paid for this service each time it is used?** |
| Day care centre | 🔾 |  |
| Home care | 🔾 |  |
| Meals (for example, via meals on wheels, luncheon club, etc.) | 🔾 |  |
| Appointment with someone from  social services | 🔾 |  |
| Memory café | 🔾 |  |
| Other type of day care service | 🔾 |  |

**10.6. Are there any other health or care services that you or the person you care for have used in the last four weeks?**

🔾 Yes

🔾 No

**10.7. Please write in below the other services you have used in the last four weeks.**

**1. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**2. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**3. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**11. HOUSEHOLD INCOME**

**We are interested in whether carers' finances influence what services they use and how much they may pay for them. So the next few questions are about your household finances and how you feel you are getting on financially.**

**This information, like all the personal details you have supplied, is CONFIDENTIAL and will not be shared with anyone outside the research team. But if you do not want to answer these questions just tick 'Rather not say'.**

**11.1. We would like you to think about ALL the money that comes into your household - including wages, pensions, savings, benefits from all household members and before any deductions, such as tax or national insurance.**

**We just need a rough estimate - please don't worry if you are not sure of the exact amount.**

**You can give your answer as a weekly, or a monthly or an annual estimate by following the instructions here:**

🔾 Income each week **Go to next Question 11.2 (below).**

🔾 Income each month **Go to Question 11.3 (on page 31).**

🔾 Income each year **Go to Question 11.4 (on page 32).**

🔾 Rather not say **Go to Question 11.5 (on page 33).**

**INCOME EACH WEEK**

**11.2. Thinking about ALL the money that comes into your household - including wages, pensions, savings, benefits from all household members and before any deductions, such as tax or national insurance - which amount is closest to your TOTAL household income per week?** *Please tick ONE only.*

🔾 up to £290 a week

🔾 £291 - £385

🔾 £386 - £480

🔾 £481 - £580

🔾 £581 - £675

🔾 £676 - £770

🔾 £771 or more a week

**Please go to Question 11.5 (on page 33).**

**INCOME EACH MONTH**

**11.3. Thinking about ALL the money that comes into your household -   
 including wages, pensions, savings, benefits from all household  
 members and before any deductions, such as tax or national   
 insurance - which amount is closest to your TOTAL household  
 income per month?** *Please tick ONE only.*

🔾 up to £1250 a month

🔾 £1251-£1670

🔾 £1671-£2085

🔾 £2086-£2500

🔾 £2501-£2920

🔾 £2921-£3335

🔾 £3336 or more a month

**Please go to Question 11.5 (on page 33).**

**INCOME EACH YEAR**

**11.4. Thinking about ALL the money that comes into your household -   
 including wages, pensions, savings, benefits from all household   
 members and before any deductions, such as tax or national  
 insurance - which amount is closest to your TOTAL household  
 income per year?** *Please tick ONE only.*

🔾 up to £15,000 a year

🔾 £15,000 to £19,999

🔾 £20,000 to £24,999

🔾 £25,000 to £29,999

🔾 £30,000 to £34,999

🔾 £35,000 to £39,999

🔾 £40,000 or more a year

**11.5. Which of the statements below best sums up how your household is getting on financially nowadays?**

🔾 I/We manage very well

🔾 I/We manage quite well

🔾 I/We get by OK

🔾 I/We have some financial difficulties

🔾 I/We have severe financial difficulties

🔾 Don’t know

🔾 Rather not say

**12. FINAL SECTION**

**12.1. We need to be sure that we have covered the right areas in our survey and we can do this if we know what the first half of your postcode is.**

**Please write in the first half of your postcode in the box below –***for example, if your postcode is YO10 5DD, you would only need to write YO10.*

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  |  |

**ANY FURTHER COMMENTS**

**12.2. If you would like to provide more information or comment on any aspect of this questionnaire, please write your comments in the box below:**

**We would like to acknowledge the time you have taken in helping us with this research, with a small gift of £10. We are also keen to share the results of our research with people who have taken part. These will be available in the late summer next year 2017. If you would like us to send the gift and/or the summary of our findings please tick below and provide your email address or postal address. We will not use your address for any other purposes and will remove it from our records once we have sent you the gift and/or the summary.**

🔾 I would like to be sent a £10 gift **Go to next Question 12.3 (below).**

🔾 I would like to be sent a summary of the findings in summer 2017   
**Go to next Question 12.3 (below).**

🔾 I do not want a gift or a summary.

**12.3. Please write your email address or postal address in capital letters below.**

🔾 Email address \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

🔾 Postal address \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**If completing this survey has raised any issues that you would like to talk over with someone, we have given details of sources of support on the enclosed information sheet.**

**Thank you for completing this survey. The information will be very useful in helping us to understand what support is available to people who support someone with dementia. You cannot be identified from the information you have provided. The questionnaire will be treated confidentially and kept secure. If you have any questions, please email** [**kate.gridley@york.ac.uk**](file:///\\storage.its.york.ac.uk\spsw\spru\Admiral%20Nursing\FINAL%20REPORT\kate.gridley@york.ac.uk%20) **or** [**fiona.aspinal@york.ac.uk**](file:///\\storage.its.york.ac.uk\spsw\spru\Admiral%20Nursing\FINAL%20REPORT\fiona.aspinal@york.ac.uk%20) **or telephone 01904 321950 and ask to speak to Kate or Fiona.**

**Please check you are happy with your answers, then return the questionnaire in the pre-paid envelope enclosed. You do not need a stamp.**

**Thank you for completing this questionnaire**

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EQ-5D: Copyright © EuroQol Research Foundation. EQ-5D™ is a trade mark of the EuroQol Research Foundation. Self-efficacy for Managing Dementia scale: Copyright © 2002 Fortinsky *et al*. Survey of carers in households 2009/10: Copyright © 2010, The Health and Social Care Information Centre. All Rights Reserved (Question: 'What kinds of things do you usually do for him/her over and above what you would normally do for someone?').

Appendix 3 Analysis from Chapter 5

Exploration of outcome measures by characteristics on which AN and non-AN carers differed

Carer age and EQ5D

Following guidance on the presentation of EQ-5D results in survey research93, for this part of our analysis we dichotomised the EQ-5D levels into ‘no problems’ and ‘problems’ and presented the results as frequencies (*Table 40*).

There were strong linear and significant relationships between carer age and the reporting of problems in three dimensions – mobility, usual activity and pain/discomfort. While older people were also more likely to report problems in relation to self-care, this difference did not reach statistical significance. The relationship with age and anxiety/depression appeared to be more complex, with those aged 55-64 more likely and the oldest (75 and over) less likely than would be expected to report problems in this area; again, however, the difference did not reach statistical significance.

In sum, then it is clear that age is related to problems in most EQ-5D dimensions. Whether the restrictions in usual activities is related to mobility issues or to the restrictions that caring for a person with dementia can create is not immediately clear.

Carer age and ASCOT Carer

We took the same approach to exploring the relationship between carer age and ASCOT Carer score, converting the data into ‘needs’ and ‘no needs’ and reporting frequencies in each of the seven domains (see *Table 41*). We also explored the total ASCOT Carer score, as recommended by its developers46.

Unlike the EQ-5D, there was only one domain in ASCOT Carer with a strong linear relationship to age – control over daily life, where younger carers (under 55) were much less likely to report feeling that they had only some or no control over their daily life. There was also a significant, but weaker, relationship between age and feeling supported or encouraged, but this was not easy to interpret as it was the 55-64 year olds who were most likely to report needs in this area. As we say above, this was also the age group most likely to report problems in the anxiety/depression domain of the EQ-5D.

ASCOT Carer scores can be simply summed to give a total score that ranges from 0 (lowest social care related quality of life) to 21 (highest). First, we explored the distribution of this total score across the group as a whole, using the Kolmogorov-Smirnov test. This showed that the distribution of the ASCOT carer total score was not normal (K-S statistic = 0.092, df=317, p=<.001). Given this, we used non-parametric tests to explore total score by age of carer. This showed that there was no difference in the total score by carer age (Kruskal Wallis χ2 = 3.45, df=3. P=0.328). For presentation here we also divided the scores roughly into quartiles. The frequencies of ASCOT Carer total scores by age of carer are in *Table 42*.

Carer age and carer self-efficacy

Our chosen outcome measure in this area was the Caregiver Self-Efficacy for Managing Dementia (SEMD) scale47. This was the only one of our measures that had been developed specifically with and for carers of people with dementia. The measure has ten domains, nine of which load onto two factors – carers’ self-efficacy in relation to dementia symptom management (SXEFF) and in relation to community support service use (SERVEFF). We analysed results for all ten domains and the summary scores on the two main factors.

None of the distributions for the individual domains, nor those for the two summary scores was normally distributed, tested by the Kolmogorov-Smirnov test. As with ASCOT Carer, then, we used non-parametric tests to explore the relationship between SEMD scores and carers’ age. Two of the individual domains were significantly related to age of the carer (tested using the Kruskal Wallis test) – how certain carers felt about being able to get answers about the problems experienced by the person with dementia (K-W χ2 = 8.22, df = 3, p = 0.042, n = 314) and their certainty about getting answers to their questions about support services (K-W χ2 = 12.67, df = 3, p = 0.005, n = 308). Both these questions contribute to the SERVEFF measure, so it was not surprising to find that this also varied by age (K-W χ2 = 9.36, df = 3, p = 0.025, n = 302). However, the direction of the relationship was not linear – those aged 65 to 74 were the most confident (mean rank = 174.74), followed by those aged 75 and over (150.60), then those aged under 55 (149.17) and finally those aged 55 to 64 (141.84).

The symptom management summary score did not vary with age.

There were more missing cases for this measure than for the others we used. This perhaps reflects the length of the scale. However, we are also aware that in the paper version of the questionnaire some respondents turned over two pages at once – thus, for this measure, missing out questions five to ten. It is not possible to calculate the summary scores without answers to these questions; as a result there were 37 missing cases for SXEFF and 44 for SERVEFF.

Relationship to person with dementia and EQ5D-5L

None of the EQ5D-5L domains showed any difference in reporting of problems versus no problems when examined alongside the type of relationship between the carer and the person with dementia.

Relationship to person with dementia and ASCOT carer

Three ASCOT Carer domains showed a statistically significant relationship with relationship of the carer to the person with dementia (*Table 43*). In all three – how carers spent their time, how much control they felt they had over their daily lives, and whether they had space and time to be themselves – spouses/partners were more likely than expected to report needs than were the other two groups.

These findings may reflect whether or not the carer and person with dementia were living in the same household, which we explore below.

The total ASCOT Carer score also varied with relationship to the person with dementia, with those caring for spouses/partners more likely (51 per cent) and those caring for parents/parents-in-law less likely (36 per cent) to score below nine (the lower the score the more problems reported), when the score was analysed in quartiles. However, this difference did not reach statistical significance (χ2 = 10.02, df = 6, p=0.124).

Relationship to person with dementia and SEMD

Two of the individual dimensions of the SEMD were significantly related to relationship – how certain the carer felt about being able to handle any problems the person with dementia might have and being able to deal with any frustrations of caring. In both cases, however, the mean rank scores suggested that it was those caring for ‘other’ relatives/friends/neighbours who were least likely to feel confident about handling these issues. There were only 12 such people in the sample, so this result needs to be treated carefully.

There were no differences in the SXEFF or SERVEFF summary scores.

Carer educational level and outcome measures

Only two domains of the EQ5D showed any relationship with the carers’ educational level; those who had no qualifications were significantly more likely to report mobility problems (chi=squared = 16.89, df=6, p = 0.01), while those who preferred not to say what qualifications they had were more likely to report problems with self- care.

None of the ASCOT carer domains or the total ASCOT score showed any relationship with carer qualifications.

There was only one significant relationship between individual SEMD questions and carers’ qualification level; those with no qualifications or qualifications at secondary level only were more likely to feel confident about caring without help than were those with higher level qualifications (Kruskal Wallis test, χ2 = 16.49, df = 5, p = 0.006, n=308). Indeed, the relationship here was completely linear (mean ranks: no qualifications 177.86, secondary level 171.04, 16+ qualifications 161.30, college level qualifications 146.68, Bachelor’s level 137.79, Master’s level and above 108.76).

There were no differences in SXEFF or SERVEFF summary scores.

Carer economic activity and outcome measures

Two EQ5D domains displayed a relationship with carers’ economic activity. Those in full-time work were less likely to report problems in relation both to mobility (χ2 = 8.03, df=1, p = 0.005) and usual activity (χ2 = 7.17, df = 1, p = 0.007), while those who were retired were more likely to report problems with mobility (χ2 = = 10.19, df = 1, p = 0.001). Both of these sets of relationships seem highly likely to be related to age.

There was only one significant relationship between any ASCOT carer domain and carers’ economic activity; those who were in full time work were less likely to report having problems with control over their daily life (χ2 = 4.81, df = 1, p = 0.028).

There was no relationship between any of the individual SEMD questions or the SXEFF and SERVEFF summary scores and whether or not carers were in full-time work. By contrast, being retired was associated with being more confident about finding support services (Wilcoxon test, Z = -2.548, p = 0.011) and getting answers about such services (Z = -2.937, p = 0.005). As a consequence, those who were retired also had higher overall SERVEFF summary scores (Wilcoxon test, Z = -2.749, p = 0.006).

Carer status and outcome measures

We saw earlier that AN carers were much more likely to be the sole or main carer (spending the most time caring) than were those in non-AN areas.

The only difference in EQ5D domains related to sole/main carer status was usual activity, where sole/main carers were much more likely to report problems doing their usual activities (χ2 = 8.69, df = 2, p = 0.013). This is an interesting finding, suggesting that despite the wording of the EQ5D, which focuses on health, carers may have been interpreting the question in terms of restrictions on their lives that arose from being a carer.

*Table 44* shows that four domains of ASCOT Carer were highly sensitive to carer status. Sole/main carers were much more likely than would be expected to report needs in relation to how they spent their time, control over their daily life, social contact, and the space and time to be themselves. By contrast, there were no obvious differences in relation looking after themselves, feeling safe, and feeling supported and encouraged.

Although the total ASCOT carer scores, when analysed by quartiles, did not show an overall significant difference by carer status, the adjusted standardised residuals showed that those who were sole/main carers were much lesslikely (22 per cent) to have a total score of 13 or more (a score that indicates a higher quality of life) than were joint main carers (33 per cent) and people who were not main carers at all (53 per cent).

Only one individual question in the SEMD showed any relationship with carer status; those who were not main carers were more likely to feel confident with getting answers about support services (Kruskal Wallis χ2 = 6.06, df = 2, p = 0.048). Overall, this sub-group also scored the highest on the SERVEFF summary (Kruskal Wallis χ2 = 6.27, df = 2, p = 0.044).

Although there was a very strong relationship between age and main carer status (35 per cent of main carers were aged 75 and over, compared to none of the joint main carers and ten per cent of those who were not main carers, χ2 = 61.76, df = 6, p<.001) the analysis in this section, and the contrast with the section that explored carers’ age, suggests that the two variables may be operating differently in relation to our outcome measures.

There were very strong relationships between ASCOT carer scores and whether or not carers were providing the most intense type of care, as defined by our typology (see above). Those providing both personal and physical care were more likely to report problems in how they spent their time (χ2 = 4.89, df=1, p = 0.027), how much control they had over their daily lives (χ2 = 20.37, df = 1, p < 0.001), their ability to look after themselves (χ2 = 8.78, df = 1, p = 0.003), whether or not they felt safe (χ2 = 4.19, df = 1, p = 0.041), and the space to be themselves (χ2 = = 8.28, df = 1, p = 0.004). There were no differences in relation to social contact or feeling supported or encouraged. As would be expected given these differences on individual dimensions, carers providing both personal and physical care were much more likely to have total ASCOT Carers scores in the lowest quartile than were other carers (χ2 = 11.86, df = 3, p = 0.008).

None of the EQ5D dimensions showed any differences between those providing both personal and physical care and other carers. This was also the case with the SEMD individual questions and the SEXEFF and SERVEFF summary scores.

Finally, in this section, we explore whether total hours of care in the previous 24 hours was related to any of our outcome measures.

In terms of the EQ5D, carers who reported caring for 18 or more hours the previous day were more likely than others to report mobility problems (χ2 = 8.56, df = 3, p = 0.039), and restricted activity (χ2 = 11.36, df = 3, p = 0.010). No other dimensions showed any significant relationship with hours of care.

By contrast, with the exception of feeling safe, ASCOT Carer scores were highly sensitive to hours of care (*Table 45*).

As would be expected, total ASCOT Carer score, recoded into quartiles, also showed that those caring for 18 or more hours in the previous day were most likely to have scores indicating the poorest quality of life (χ2 = 33.16, df = 9, p < 0.001). In all, 39 per cent of those caring for this number of hours were in the lowest quartile, compared with 32 per cent of those caring for 12-17 hours, 22 per cent of those caring for 6-11 hours, and 11 per cent of those caring for five or fewer hours.

Some questions in the SEMD varied with hours of care – confidence about keeping the person with dementia independent (K-W χ2 =8.43, df = 3, p=0.038), getting answers about about dementia (K-W χ2 = 11.49, df = 3, p = 0.009), finding services (K-W χ2 = 9.17, df = 3, p = 0.027), getting answers about services (K-W χ2 = 8.13, df = 3, p = 0.043), and arranging services (K-W χ2 = 12.65, df = 3, p = 0.005). Both the SXEFF (K-W χ2 = 9.55, df = 3, p = 0.023) and the SERVEFF (K-W χ2 = 13.61, df = 3, p = 0.003) also varied with hours of care.

As with age of the carer, examining the mean ranks showed that the relationships between hours of care and carer-self efficacy were not linear. Those least confident about managing dementia were those caring for between 6 and 11 hours, while those who were most confident were caring for eighteen or more hours. In relation to confidence about services, those least confident were caring for 6 to 11 hours and those most confident caring for up to five hours. The relationships with SXEFF and SERVEFF were also non-linear.

Overall, this could suggest that the SEMD is sensitive to contact with services – younger and less heavily involved carers may be less likely to be in contact with services and therefore less confident about their ability to care and to find and engage with services. This will be explored later.

Type of dementia and the outcome measures

We saw earlier that the two groups (AN and non-AN area) differed in the reported type of dementia of the person the carer supported, with AN carers being less likely that non-AN area carers to be supporting someone with Alzheimer’s disease and more likely to be supporting someone with vascular dementia.

Analysis of the five EQ5D-5L dimensions by type of dementia showed no significant differences in reporting of problems in any dimension.

By contrast, there were significant differences in five of the ASCOT carer dimensions. People supporting someone with Alzheimer’s disease were less likely than expected to report problems in relation to how they spent their time, control over their daily lives, being able to look after themselves, social contact and feeling supported and encouraged (*Table 46*). In three domains – how the carers spent their time, being able to look after themselves, and feeling supported and encouraged, the main contrast was between those caring for people with Alzheimer’s disease and those caring for people with ‘other’ types of dementia.

As would be expected given the individual domain scores, total ASCOT carer score also varied for those caring for someone with Alzheimer’s disease, who were least likely to have scores between 0 and 7 and most likely to have scores of 13 or more, when analysed in quartiles (χ2 = 16.32, df = 6 , p = 0.012). Again, the contrast here was with those caring for people with ‘other’ types of dementia, who were most likely to have scores between 0 and 7, and least likely to have scores of 13 or more (χ2 = 16.32, df=6, p = 0.012)

There were also differences in the SEMD between those caring for someone with Alzheimer’s disease and other carers. In two SEMD areas, carers of people with Alzheimer’s disease were on average more confident than other carers; these were getting answers about support services (Kruskal Wallis test, χ2 = 7.84, df = 2, p = 0.020), and arranging for such services (Kruskal Wallis test, χ2 = 13.59, df = 2, p = 0.01). In relation to paying for services those caring for people with ‘other’ types of dementia were less likely to feel confident than those caring for someone with Alzheimer’s Disease or vascular dementia (Kruskal Wallis test, χ2 = 8.65, df = 2, p = 0.013).

As would be expected, given the differences on the individual elements of the SEMD, carers of people with Alzheimer’s disease had higher (better) overall SERVEFF scores, followed by those caring for people with vascular dementia and then, with the lowest level of overall confidence, those caring for people with ‘other’ types of dementia (Kruskal Wallis test, χ2 = =6.98, df = 2, p = 0.03). There was no difference in the SXEFF scores.

There were no significant differences in reported severity of dementia symptoms by type of dementia. Indeed, those caring for people with Alzheimer’s disease were slightly more likely than others to report that the dementia was ‘severe’ (29 per cent Alzheimer’s Disease (AD), 24 per cent vascular, 23 per cent ‘other), while those caring for people with ‘other’ types of dementia were slightly more likely to report that the dementia was ‘mild’ (nine per cent AD, three per cent vascular, 17 per cent ‘other’). Perceived severity of the condition is not, therefore, a likely explanation for these differences in ASCOT Carer and SEMD scores.

Appendix 4 Analysis from Chapter 6

Summary of analytical methods in econometric terms

Regression analysis

Regression analysis estimates the average treatment effect on the treated (ATET)94 (p.897-904) as follows:



where *yi* is the outcome or cost of the carer *i*=1,…,N, *di* is a dummy variable indicating whether the carer receives AN services, *Xi* is a vector of covariates that control for differences across carers (for example, age, relationship with care recipient), and *εi* is the error term capturing all unobserved factors that influence *yi*.

Our key coefficient of interest was *β*, which estimates the ATET. It captures whether AN carers have on average different levels of outcomes or costs than non-AN carers. For example, *β*>0 indicates that AN carers had greater levels of outcomes or costs compared to non-AN carers.

The regression model in the equation is estimated by the Ordinary Least Square (OLS) estimator. A crucial assumption for the unbiasedness of the OLS is exogeneity, that is, no correlation between independent variables and error term. In this context, unbiasedness relies on a weaker condition, called the ignorability assumption, which implies that the intervention assignment is independent of (that is, ‘ignores’) the outcome of the untreated individuals, conditional on *Xi*. This implies that *Xi* should include all potential factors correlated with both *yi* and *di*. Since carers are not randomly assigned to the AN service but are generally admitted after a triage process that assesses their needs, those with high needs are more likely to access AN and also to have low quality of life. Instead, carers that are not referred to AN are more likely to have low needs and higher quality of life. If *Xi* does not allow for such a difference in the carers’ needs, the regression will underestimate the true ATET on outcomes.

The OLS estimator is the Best Linear Unbiased Estimator (BLUE) under the standard Gauss-Markov assumptions95 (p.52): (i) there exists a liner relationship between dependent and independent variables, which implies that the model in (2) is linear in its parameters while non-linearity may occur in the variables (for example, a squared or log-transformed covariate); (ii) observations in the sample are randomly drawn; (iii) there is no perfect collinearity between independent variables; (iv) the independent variables are exogenous, that is, there is no correlation between the independent variables and the error term; and (v) the variance of *εi* is homoscedastic, that is, it is constant conditional on the independent variables. If assumption (v) is violated, then OLS is no longer BLUE but it is still an attractive estimator because unbiased and consistent.

We relax the homoscedasticity assumption and estimate standard errors that are robust to heteroscedasticity96 because the variance of the error term may vary systematically across observations. For example, suppose that there is a positive relationship between using AN services and outcomes (that is, suppose *β>*0). The variability of such a relationship may increase with the carer’s age because older carers may have greater needs and their outcome may therefore be more uncertain. If we do not account for this, standard errors and, in turn, inference will be invalid.

Propensity score matching

The PSM is implemented in three steps. First, we regress the treatment variable *di* on the covariates *Xi* using a logit. Under the assumption that this model is well specified, the propensity scores, *p*(*Xi*), are computed as the predicted values of the dependent variable (*d̂i*) which capture the carers’ conditional probability of receiving AN given the observed characteristics *Xi*. Second, we match carers in the treatment and control group with similar propensity scores through the kernel matching. The kernel matching compares each treated individual with a counterfactual constructed as the kernel weighted average of multiple individuals in the control group. The counterfactual will depend on the distance between propensity scores of the treated and untreated individual within a specific bandwidth. We set the bandwidth to 0.06 to optimise the trade-off between variance and bias of the matching estimator.97 Finally, we estimate the ATET by comparing the average outcome or cost of the treated and untreated carer in the matched sample.

As well as regression analysis, PSM requires the ignorability assumption for the estimation of the ATET but now conditional on *p*(*Xi*) instead of *Xi*. In addition, we assume weak overlap (or common support) which implies that the sample includes treated and untreated individuals with the same propensity score. We test this assumption through visual inspection of the propensity score’s distribution between AN and non-AN carers.

Unlike regression analysis, PSM is non-parametric and it therefore avoids the linearity assumption by dropping all observations with no common support. Instead, regression analysis preserves portions of sample with no overlap between treated and untreated individuals by replacing the missing observations through extrapolation. Jones and Rice (p.899) suggest that good estimates of the ATET in regression analysis depend on the balancing of the means of the covariates between the treatment and control group.94 If common support is small and linearity does not hold true, extrapolation may perform poorly and, in turn, the means of the covariates may not be balanced.

Overall, as Horvitz and Thompson 98 show (p.61), PSM and linear regression are similar. Angrist and Hahn 99, however, argue that PSM may produce more precise estimates of the ATET (that is, estimates with smaller standard errors) in finite samples compared to regression analysis. Such an instance may occur in the presence of omitted covariates that do not predict the intervention but have a statistically small impact on the outcome. More precisely, omitting some covariates that help to predict the outcome (although only to a lesser extent) but not the treatment from a regression will decrease precision but their inclusion will reduce statistical power with small samples. Omitting the same covariates from the PSM, however, will not affect precision. This may well be our case because of the limited sample size and availability of covariates. For example, having polite neighbours might reduce stress and marginally improve the outcome of the carer, but polite neighbours are unlikely to influence directly the use of AN. Since we do not observe the politeness of neighbours, PSM might be preferable over regression analysis.

Validity of propensity score matching

We assessed the validity of the PSM analysis in a number of ways. First, we tested the balancing property to check the balance of the covariates within a specific number of blocks of the propensity score distribution. This is always satisfied with 5 blocks, with the exception of the self-efficacy measure on symptoms management for which the balancing property is satisfied under less desirable conditions, that is, 11 blocks. Then, we check whether the standardised difference for each covariate between AN and non-AN carers is reduced because of the matching. For ASCOT, for example, Figure 6 shows that the standardised difference is reduced below ten for most of the covariates (a similar result is observed for all other outcome and cost measures). Moreover, we test the presence of common support through visual inspection of the propensity score distribution in the two groups of carers before and after the matching. Again for ASCOT, for example, Figure 7 shows that there is a good overlap between propensity score distributions before the matching, and that such an overlap becomes almost perfect after the matching (a similar result is observed for all other outcome and cost measures). Finally, we choose the kernel PSM technique because it minimises the average standardised difference of the covariates. *Table 66* shows that kernel PSM has the smaller average standardised difference of the covariates compared to the nearest neighbour and the calliper technique.

IV analysis

We implement an IV approach using the distance between the carer and the AN provider as an instrument (*zi*). The IV approach relaxes the ignorability assumption and assumes that the instrument is relevant, that is, correlated to the treatment variable, and exogenous, that is, not correlated to the outcome and to unobserved factors having an effect on the outcome. The distance between carer and AN provider is likely to be relevant because carers living far apart from the AN provider may not be eligible because the service is delimited to a specific geographical area. Moreover, carers living at long travel distances from the AN provider may have lower chances to be informed about AN compared to carers living in proximity of AN teams. Carers living in rural areas, for example, may have fewer peers and lower chances to be informed about AN compared to carers living in urban areas where AN teams are usually based. This implies that carers living nearby AN providers are more likely to be eligible or to access the service. We test relevance through the Cragg-Donald F-statistic. As a rule of thumb, instruments are relevant if the F-statistic is greater than 10.100 *zi* is also likely to be exogenous because the distance is predetermined with respect to the location of the AN provider: carers are likely to live either close or far from the AN provider regardless of their levels of needs or care-related quality of life.

We use the types of local authority as an additional set of instruments in the regression of the outcomes. Following Forder *et al*.55 we argue that the types of local authority determine different cultures and, in turn, different propensity to invest in support services for carers. Some local authorities will therefore be more willing to fund AN services than others but the culture will not have a direct effect on outcomes. We use these additional instruments to implement the Sargan-Hansen over-identification test of exogeneity.

We estimate the IV regression using the two-stage least square (2SLS) estimator and, similarly to regression analysis, we compute robust standard errors. The 2SLS estimates the local average treatment effect (LATE) rather than the ATET. LATE measures the treatment effect on the ‘compliers’, that is, the individuals that are induced to participate in the treatment because of the change in *zi*. Intuitively, in our study, compliers are carers who live closer to the AN provider. In practice, the use of a continuous instrument, such as travel time makes the interpretation of LATE more complex because the resulting estimate is a weighted average across groups of compliers. The identification of the LATE also requires the monotonicity assumption, which implies that the closer carers are to the AN services the higher the probability to use AN101, p. 885.

Sensitivity analysis

Methods

We ran seven types of sensitivity check to test the robustness of our results.

First, we implemented regression and PSM analysis by focusing on carers who looked after a spouse/partner because we believed, based on Chapter 5, that these carers were more likely to share similar needs.

Secondly, we carried out regression analysis for all outcome and cost measures, after accounting for whether the carer completed an electronic or paper questionnaire (see *Chapter 5* for further details).

Thirdly, we tested any effect of AN on the EQ-5D-5L score and on the EQ-5D-3L.73

Fourthly, we checked the effect of AN on all outcome and cost measures by regression and PSM analysis after classifying carers as AN or non-AN according to their responses in the survey rather than the way they received the questionnaire (via an AN service or via other organisations in areas without AN services). Although all AN carers were on the caseload of an AN service, some indicated that they had not received AN services; conversely, some non-AN carers had indicated that they had received an AN service (see Chapter 5). These answers may reflect confusion about the AN service or may reflect the services that these carers actually received. If this is the case, there may be some non-AN carers in the AN carer group and vice-versa, which would dilute our measures of association. For this reason, we tested whether the results changed if we classified carers according to their answers rather than their route of recruitment to the survey.

Fifthly, we carried out regression and PSM analysis on a sub-sample in which all carers completed questions for all the variables in the analysis (complete case analysis).

Sixthly, we estimated the effect of AN on health care and AN costs (excluding social care costs) through regressions and PSM.

Finally, in regression analysis, we undertook sub-group analysis: exploring the impact of gender, severity of dementia, and relationship with the care recipient on the outcome in the two groups through interacting the AN dummy with the female dummy, the severity of dementia dummies, and the relationship with the care recipient dummies, respectively.

Results

All tables including the results of the sensitivity analysis are available in ‘Report Supplementary Material 1’ (see [https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/1415407/#/](https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/1415407/%23/)). The regression (*Table S1 and S2*) and PSM results (*Table S3 and S4*), after focusing on a more homogenous group of carers who look after their spouse/partner, also suggested no effect of AN on outcomes, except for self-efficacy on service use (at ten per cent significance level in regression analysis and at five per cent level in PSM), and costs.

Regression results after controlling for whether the carer completed an electronic or paper questionnaire are in line with key results presented so far, showing no or weak statistical significance for the outcome and cost measures (*Table S5 and S6*). As expected, AN has no effect on HRQoL as measured by EQ-5D-5L and EQ-5D-3L, since the estimated coefficient on the AN dummy in both regression and PSM analysis, although negative, is small and non-significant (*Table S7*). The results are also similar to the main analysis when we re-analyse all outcome and cost measures by regression and PSM analysis after classifying carers as AN or non-AN according to their responses in the survey, rather than the way they received the questionnaire (*Table S8-S11*), and when running the complete case analysis (*Table S12-S15*). The effect of AN on healthcare and AN costs (excluding social care costs) estimated through regression and PSM is also statistically insignificant (*Table S16*).

Finally, the analysis of interactions between the AN dummy and some variables suggested that AN has a significantly positive effect on females compared to males, and that self-efficacy on service use significantly increases more for carers looking after someone with any relationship other than a spouse/partner or parent/parent-in-law (although this group includes only 14 carers) (*Table S17*). The results are similar to the base-case in the regression analysis on costs (*Table S18*).

Appendix 5 Work Packages 5 and 6: ensuring the study findings inform future research and practice

Work Package 5

Work Package 5 was designed to ensure that the learning from this research informed practice and supports future service evaluation. We proposed to work with Dementia UK to inform their data collection processes using the data collection framework established in WP2 as a starting point. The aim was to improve systems to collect data required for future evaluative research while also meeting their administrative needs. 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.

WP5 began with a meeting between the University of York research team and the Dementia UK research team, as well the Dementia UK Director of Clinical Services, IT development leads and Professional and Practice Development lead. It was agreed to concentrate on encouraging and supporting a local Admiral Nursing team to use the three standardized measures of carer outcome selected for the national survey (ASCOT Carer, EQ5D and the Caregiver Self-Efficacy for Managing Dementia Scale) in their routine work.

An AN service was invited and agreed to take part. The researchers provided training to staff from this service, along with other interested Admiral Nurses, at a practice development day in June 2017. The training covered:

* Findings of the development work leading to the selection of the three outcome measures (WP2);
* What these measures can be used for;
* How to use the measures (including how to attribute scores and measure change over time).

Participants tried using the three measures during the session through role play and fed back to colleagues and the research team about their experiences. ASCOT Carer and the Self-Efficacy Scale were felt to be very relevant to the work of the Admiral Nurses. It was noted that all three measures were straightforward to use, especially as self-complete questionnaires. In interview form the questions could, however, sound cumbersome, and it was noted that being asked to verbally respond to the nurse who delivered their care might encourage carers to respond in ways they perceive to be desirable.

Participants considered the possibility of posting out the ASCOT Carer to carers before their first appointment. As it is a short and user-friendly tool it was generally felt that this could be successful. The selected service settled on this as their approach to pilot for WP5.

The Self-Efficacy Scale was felt to be particularly suited to measuring the outcomes of the training the Admiral Nurses provide. Again, the selected service agreed to pilot the use of this tool, encouraging carers to complete it before they began training, at the end of the training and at a follow-up point.

The research team kept in contact with the service over the following months. However, the service manager reported experiencing staffing shortages over this time and towards the end of the pilot period reported that there had not yet been any opportunity to build the new measures into their working practices. She was hopeful that over time they would be able to use the measures, but this would not be within the lifetime of the current NIHR HS&DR project.

Towards the end of the project, a representative from our research team joined a Dementia UK meeting to discuss and agree the outcome measures to be integrated into a new national Admiral Nursing data collection system. In light of the findings from this research, and other feedback from key stakeholders, the tools chosen to measure outcomes for carers were ASCOT Carer and the Caregiver Self-Efficacy for Managing Dementia Scale.

Work Package 6

The final stage of our project, WP6, centred on a stakeholder workshop. Here we presented findings of all elements of the research and worked with stakeholders to:

**a)** Identify key messages arising from the research

**b)** Discuss the collection of data at a local level to inform both service development and evaluation.

We invited a range of stakeholders to the workshop, including people with dementia and carers, decision-makers from health and social care commissioning and provider organisations (including the third sector), and local and national policy-makers.

Key messages arising from the research:

The workshop was attended by 36 stakeholders, including carers, practitioners, commissioners and six members of the research team. Participants discussed the research findings and fed back key messages and implications. These have been grouped below under three headings: 1) Overall messages from the research; 2) Messages relating to Admiral Nursing in particular; and 3) Messages relating to the future evaluation of services for carers of people with dementia.

1. **Overall messages from the research:**

* Participants noted the inconsistency of carer support across the country.
* Continuity of support for carers of people with dementia is very important – people do not stop having dementia, so carers’ needs are ongoing.
* Participants were struck by the financial pressures carers are under (as evidenced by the survey findings). Statutory services do not always understand the financial impact of caring.
* Sleep deprivation seems to have a huge impact of carers’ lives. Night sitting services are therefore very important, but also very costly.

1. **Messages relating to Admiral Nursing in particular:**

* The specialist knowledge that ANs have (their unique insight into dementia and the service landscape, as well as their clinical background) is key.
* AN support and education is an important way to create, maintain and improve carer confidence (for example, positive steps programme). It is likely to enable the carers to carry on caring at home for longer.
* ANs also work across service and professional boundaries to ensure access to other services.
* ANs are a valuable resource, but they cannot be the answer for everything. In particular, they are only involved in the more complex cases, while carers want the practitioners they deal with to have the type of expertise that ANs have.
* There are not enough ANs to help all carers and not all carers have complex needs. However, preventing carers’ needs from escalating is also important. ANs need to work collaboratively with other support workers to have the greatest reach, facilitating continuity and access to specialist knowledge more widely.

1. **Messages relating to the future evaluation of services for carers of people with dementia:**

* This research seems to have looked at two different populations (one of carers with particularly complex needs (recruited through Admiral Nursing), and a ‘comparison’ group of carers with lower needs (recruited through voluntary sector organisations and carers’ groups). What population of carers would be comparable to the carers who receive Admiral Nursing services?
* Part of the problem of identifying carers for research is that there is nowhere that carers are routinely and formally identified. People do not always self-identify as carers and so it can be difficult to know how many carers of people with dementia there are.
* As well as hidden carers, there are carers whose full caring roles are hidden (such as those caring for more than one person) and carers with co-morbidities.
* It is important to collect evidence of things that are harder to quantify, such as the impact of ANs and other support services for carers.

Collecting data at a local level to inform both service development and evaluation:

In the second group work session of the day, participants were asked about the information services currently collect from dementia carers and what other information might be useful for service evaluation. Key points have been grouped under three headings: 1) Problems/challenges with evaluating carers’ services; 2) Missed opportunities/things that could be done better; and 3) Ways forward.

1. **Problems/challenges with evaluating carers’ services:**

* Carers get asked the same questions repeatedly. This is probably because services and assessments are fragmented.
* Voluntary sector organisations might not have the infrastructure to collect all the information that commissioners are asking for.
* There is variability in the quality of commissioning of services for carers of people with dementia.
* There are many things that could be measured and a multiplicity of commissioners and funders who may want different data about different outcomes. This can be a burden on services and on carers.
* When assessing services and aiming to improve them, it is important to consider context. We are currently in a service and policy context of austerity (cost-savings) and this will influences what information can/should be collected.
* What do you do with the data when you have it?

1. **Missed opportunities/things that could be done better:**

* Different measures are used by different services (so the evidence is not comparable).
* Some services use outcome measures at initial assessment (baseline) but these are not followed-up later on.
* Not all carers are getting Carers’ Assessments and if they are, these are not often reviewed. The carers who do get a Carer’s Assessment are asked important questions, but often nothing is done with the information collected. Carers’ Assessments and reviews need to be turned into action.
* Outcomes measures are used in other services – why not dementia/carers’ services? Some collect a lot of statistics about service user characteristics but nothing about outcomes. We need a change is culture.

1. **Ways forward:**

* It would help to have a steer from commissioners about what outcomes they want to see.
* In some localities, qualitative key performance indicators (KPIs) were used to shape the outcomes commissioners want.
* Case studies can be used to demonstrate impact in business cases.
* It’s important to have a baseline for measurement. Carer’s Assessments could be used to create a real foundation for carer-related baseline information.
* Goal-setting with individuals and monitoring progress could be another solution. This can be embedded into everyday practice with the carer but it is important that workers are committed to the measure.
* Sensitivity and good communication skills are needed to enable staff to ask baseline questions early in the service provision relationship.
* It is easier to do before and after assessments when it comes to evaluating training. (Perhaps this is why there is more evidence on the impact of carer training than on other forms of intervention?)
* In other areas of health and social care, the expectation is often that a person will get better, this is not the case for people with dementia and so services (and carers) need to manage their deterioration. This requires access to information through learning, education and support. Good questions to assess whether a service is supporting a carer well are:
  + How confident do carers feel in making decisions about the person they care for?
  + How much confidence do carers have in the professionals they come into contact with?

These key points will be circulated to workshop participants for final comments and then used alongside the project findings to inform a four-page project summary, which will be distributed widely as one of our project outputs.

Flyer from Workshop

* Be the first to hear the findings of this ground   
  breaking research project
* Have your say
* Contribute to guidance for services supporting   
  carers of people with dementia

You are invited to participate in a workshop discussing   
the findings of the first large scale independent study   
of the Admiral Nursing service.

**The research:**

The research was conducted by the Social Policy Research Unit (part of the University of York) and involved:

* Qualitative research with over 50 carers and professionals
* A national survey of 340 carers of people with dementia

**To book your place or for more information contact** [**kate.gridley@york.ac.uk**](mailto:kate.gridley@york.ac.uk)

**Evaluation of Support for Carers of   
People with Dementia**

**Stakeholder Workshop: 26th September 2017**

**What’s special about this research?** This is the first large scale, independent study of the Admiral Nursing service.

**Who did the research?** This study was a collaboration between the Social Policy Research Unit, part of the University of York, and Dementia UK.

**Who funded the research?** This was independent research funded by the National Institute for Health Research, the research funding arm of the NHS.

**Workshop details:**

Date: **Tuesday 26th September 2017**

Time: **10 am – 3pm**

Venue: **Wedgewood Room, Principal Hotel York, Station Road, York, YO24 1AA**

**Admission is free. Two-course lunch provided.**



