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Specialist nursing case management support for carers of people with dementia: A qualitative study comparing experiences of carers with and without Admiral Nursing

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Abstract

Carers of people with dementia can experience reduced health and well-being, but little is known about how best to support them. There is some evidence to suggest that case management may improve outcomes for carers but less evidence about the features of case management services that can effectively support carers of people with dementia. Admiral Nursing operates a case management approach staffed by specialist nurses and is the only service of its kind in the United Kingdom dedicated to helping people with dementia *and* their carers. This paper reports qualitative findings from a mixed methods study of Admiral Nursing. For the qualitative strand of the project, data were collected in focus groups and in-depth interviews with carers of people with dementia ($n = 35$) and analysed thematically using the framework approach. The aim of this analysis was to understand differences between the experiences of the carers in our sample with and without Admiral Nursing, applying Freeman's model of continuity of care (Freeman et al., *Continuity of care*, 2000). Participants who had received Admiral Nursing were recruited from two geographical locations and carers without experience of this service were recruited from two different areas. We found that carers in our sample felt 'supported' in circumstances where they received an ongoing service from an Admiral Nurse or other professional with expertise in dementia who was able to develop a meaningful relationship with them over time. We conclude that ongoing support, expertise in dementia and a meaningful relationship are key features of relationship continuity common in carers' reports of feeling supported. Specialist nurses are well placed to provide this continuity.

KEYWORDS

continuity of care, dementia, dementia care, family carers, practitioner-service user relationships, specialist nursing

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1 | INTRODUCTION

In the United Kingdom, an estimated 885,000 people currently live with dementia (Wittenberg et al., 2019), supported by at least 700,000 unpaid carers (Alzheimer's Research UK, 2015). On average, carers report poorer well-being than non-carers (Van den Berg et al., 2014) and as caring commitments increase, so health-related quality of life decreases (Thomas et al., 2015). Carers of people with dementia have been shown to have significantly poorer health-related quality of life, greater comorbid risk, higher work absenteeism and greater healthcare resource use than non-carers (Goren et al., 2016). There is also evidence to suggest that they experience greater strain and mental and physical health problems than carers of people with other conditions (Dassel & Carr, 2016; Hirst, 2005; Pinquart & Sörensen, 2003; Schoenmakers et al., 2010).

While much is known about the challenges facing carers of people with dementia, less is known about how to support them effectively. A meta-review of the international evidence on interventions to support carers found some promising evidence (with specific reference to carers of people with dementia) for cognitive reframing, psychosocial interventions, educational interventions, meditation-based interventions, telephone counselling and support groups (Thomas et al., 2017). These interventions seem somewhat disparate in content, but the authors note that they all bring carers together with 'people who know about dementia' in one way or another (p. 76).

Case management is one approach that has shown potential in supporting people with dementia and their families (Iliffe et al., 2019). The NICE dementia guideline (2018) identified moderate-quality evidence (from eight randomised controlled trials) that case management reduced carer burden, improved quality of life for the person with dementia and reduced rates of entry into residential care (although on other measures such as carer depressive symptoms and carer quality of life there appeared to be no difference against usual care). Larger gains were seen in studies where the case manager was a nurse providing face-to-face support in the person's home with frequent follow-up.

Case management is a specific approach that originated in the United States in the 1970s (Denning et al., 2017) and is now used internationally to support people with a range of long-term conditions, particularly those affecting mental health (Dieterich et al., 2017). It can be defined as 'a collaborative process of assessment, planning, facilitation, care coordination, evaluation and advocacy for options and services to meet an individual's and family's comprehensive health needs...' (Case Management Society of America, 2017). Research about dementia case management provided by nurses in the community is sparse, with most studies of dementia nursing tending to focus on nursing home or acute settings (e.g. Ellison et al., 2014; Griffiths et al., 2013; Williams et al., 2005). Even for general populations of people with long-term conditions, evidence on case management approaches is limited (Knapp et al., 2014). One UK study of nurse case managers of people with long-term conditions found that these nurses were valued for their clinical

What is known about this topic

- Carers of people with dementia face multiple challenges
- Case management is increasingly seen as a promising approach to support carers and people with dementia but little is known about the key features of an effective service.

What this paper adds

- Our findings suggest that relationship continuity is central to carers of people with dementia feeling supported.
- The relationship continuity that carers in our sample said contributed to feeling supported had three key elements:
 1. Ongoing support over time
 2. Expertise in dementia
 3. A meaningful relationship (between the practitioner and carer) leading to an understanding of the carer's unique situation

expertise, provision of continuity of care and the therapeutic effect of the psychosocial support they provided (Goodman et al., 2010). One study of intensive case management for people with dementia in the Netherlands indicated that this model may improve quality of life and be more cost-effective than a less intensive alternative (or usual care; MacNeil Vroomen et al., 2016). An American study comparing the outcomes of an existing dementia case management service with nurse case management for dementia found that carer outcomes (stress, well-being and endurance potential) for the nursing group were substantially more positive than for the comparison group (Specht et al., 2009).

In the United Kingdom, the only specialist nursing case management service specifically targeting carers of people with dementia is Admiral Nursing (Denning et al., 2017). Admiral Nurses are registered nurses who have specialised in the care of people with dementia and their carers. Each Admiral Nursing service is operated as a partnership between Dementia UK (a registered charity <https://www.dementiauk.org/>) and a host organisation (NHS, local authority or third sector). A systematic review of Admiral Nursing (Bunn et al., 2016) concluded that carers tend to express high levels of satisfaction with this type of service, but found little robust evidence for its cost-effectiveness. In order to begin addressing this gap, we undertook a study to understand the context within which Admiral Nursing (as a UK example of specialist nursing case management for carers of people with dementia) is delivered, along with its potential effects and the feasibility of full-scale evaluation. The full findings of this study are published elsewhere (Gridley et al., 2019). In this paper, we present findings from our qualitative analysis of the carers' accounts of experiences of support collected as part of this larger study.

TABLE 1 Participants' gender, caring status and relationship with the person with dementia across the two types of site (those with and without Admiral Nursing)

| | Gender of carer | Current or former carer | Relationship to person with dementia |
|--------------------------------------|------------------------|---------------------------|--------------------------------------|
| Admiral nursing (<i>n</i> = 18) | Female: 10 Male: 8 | Current: 16 Former: 2 | Spouse: 12 Adult child: 6 |
| Non-admiral nursing (<i>n</i> = 17) | Female: 9 Male: 8 | Current: 11 Former: 6 | Spouse: 10 Adult child: 7 |
| Total (<i>n</i> = 35) | Female: 19 Male: 16 | Current: 27 Former: 12 | Spouse: 22 Adult child: 13 |

We note in the full report that the carers in our qualitative sample appeared to consider 'feeling supported' as an outcome in itself, in keeping with previous research that identified 'feeling supported and encouraged' as a core element of quality of life (Rand et al., 2015). Moreover, the carers with Admiral Nurses were more likely to report feeling supported than those without an Admiral Nurse. We therefore set out, through further analysis, to understand the reasons behind this. A key theme in our analysis was continuity and so we drew on Freeman's model of continuity of care to help organise and make sense of our findings (Freeman et al., 2000). According to Freeman, continuity is multidimensional, consisting of continuity of information; cross-boundary and team continuity; flexible continuity; longitudinal continuity; and relational (later relationship) continuity (Freeman et al., 2007).

2 | METHODS

We aimed to recruit 30 carers, purposively sampled to represent a wide range of characteristics and circumstances, roughly half with an Admiral Nurse and half without experience of this service. Carers were invited to take part by Dementia UK in two geographical areas with Admiral Nursing (AN areas) and through alternative routes (including carers' centres, carer-led peer support groups and the tide—Together in Dementia Everyday—network) in two comparable areas that did not have an Admiral Nursing service (non-AN areas). Those who expressed an initial interest were contacted by a researcher (not affiliated to Dementia UK) who discussed the research in more detail, answered any questions and obtained written informed consent. Participants were asked which mode (focus group or interview) they would prefer and offered reimbursement for travel expenses and the costs of substitute care. The study received full ethical approval from the Health Research Authority London—Chelsea Research Ethics Committee (Integrated Research Application System identification number 195413).

We used similar in-depth, qualitative methods in both the interviews and the focus groups to explore with carers the outcomes they felt they had, or would like to have, experienced from support services, as well as the outcomes of not receiving support and what contributed to these outcomes. Topic guides were structured around established types of carer support, such as emotional and financial support (King's Fund Informal Care Programme, 1988).

Focus groups and interviews were audio-recorded (with participants' permission). All interviews and one of the focus groups were fully transcribed and data from five other focus groups were incorporated directly from the audio files (Halcomb & Davidson, 2006). The lead author led the data collection and analysis, with support from the principal investigator. We used the framework principles of data reduction through summarisation and synthesis to organise our case and theme-based analysis (Ritchie & Lewis, 2003). A central chart was then devised to map experiences of support against type of support with thematic categories, including 'continuity over time'; 'relationship with a professional' and 'expertise in dementia' developed inductively. Freeman's model was then mapped onto this chart to identify areas of convergence and divergence.

3 | FINDINGS

Thirty-five carers of people with dementia took part in total. While we recruited a slightly larger than anticipated total sample, we were unable to recruit participants from a diverse range of ethnic backgrounds. The female-to-male ratio was more reflective of the spread in the wider population, as was the spouse-to-adult child ratio, and these ratios were mostly consistent across the AN and non-AN sites (see Table 1).

Across the four sites, we carried out six small focus groups (each had two to five participants) in a range of venues including a church hall, a community centre, a university meeting room and a carer's house. A further 13 in-depth interviews were conducted (including one joint interview with a father and daughter of the same person)—all in participants' own homes.

Application of Freeman's model of continuity of care (Freeman et al., 2000) highlighted the importance of relationship continuity in particular as a factor contributing to carers feeling supported. Relationship continuity in this context required three key elements:

1. Ongoing support over time
2. Expertise in dementia
3. A meaningful relationship (between the practitioner and carer) leading to an understanding of the carer's unique situation

While these elements are interrelated, we address them in turn below in order to demonstrate their importance to the whole.

3.1 | Ongoing support over time

Participants valued the ongoing, accessible support provided by a named professional over time. The Admiral Nursing models operating in our research sites tended to require nurses to be allocated to families over the long term. Thus, while these nurses might have had periods of lesser or greater activity with a family, depending on the carer or the person with dementia's needs at particular times, they generally remained involved at some level as the dementia progressed. Participants explained that having regular contact (telephone and email, as well as face to face) with an Admiral Nurse over an extended period of time meant that, when new needs arose, they knew who to turn to for support. It was easy to contact their nurse if they had a question and they felt that they could rely on the answers they received because the nurses were experts in dementia and familiar with their circumstances.

This continuity in itself was unusual in the experience of many of the carers. Social services closed cases when discrete pieces of work were completed, reallocating service users to the next available social worker if and when a new need arose (or even the same need recurred). While GPs might once have provided some continuity, it is now less easy in England for people to see the same doctor each time they attend their practice (Freeman & Hughes, 2010). Even some of those who had regular memory service appointments complained that they saw different professionals each time they attended. In this context, a named practitioner allocated to a family was highly valued. This did not have to be an Admiral Nurse; some participants in areas without Admiral Nursing had other named professionals allocated to them (e.g. a psychiatric nurse or a social worker), but they explained that the key to feeling supported was that they had developed a relationship with a well-informed professional over time.

The significance of this relationship continuity went beyond simply avoiding the frustrations of having to start from scratch with services each time a new need arose. Dementia is a dynamic disease, and as symptoms progress and circumstances change, people with dementia and their carers are continually faced with new challenges. A professional who is involved from the beginning can help patients and carers to prepare for different stages, or if they are not yet ready to face a particular challenge, to support and encourage them until they are. As this interviewee explained:

I mean ... [husband] was visiting the clinic to see consultants ... but it was a different one every time... there was no continuity there. So as I was going through the different stages with [husband] [AN] was helping me, asking how I was coping with each one, and then he would advise me to try different things, and preparing me for the next stage...

(Interview with AN2C1).

This carer felt she would not have managed without the ongoing support of, and sensitive treatment from, her Admiral Nurse. As her husband's condition deteriorated, the nurse played a crucial role in

both sensitively raising the issue of end-of-life care and organising support that suited their specific situation:

...as he saw [husband] deteriorating he, we had long chats and he said, well I think perhaps we ought to look at palliative care because he knew how, you know, destructive the hospital visit had been; and he organised all of that, the meeting at the house with the GPs and nurses and, and the family...

(Interview with AN2C1).

Here, relationship continuity facilitated management continuity, whereby support is coordinated across boundaries to smooth the involvement of multiple services and practitioners (Haggerty et al., 2003).

The level of support described above contrasted with the reports of several of the carers of people with dementia we spoke to in areas without Admiral Nursing, who said they often did not know where to turn for help. They explained how draining this could be: '...it's another thing that you've got to do, it's stressful...' (NAN1FG1) and said how helpful it would have been if services had offered more proactive help. One carer expressed anxiety at not knowing what 'stage' of dementia his wife was in and said he felt that there was no one who would answer his questions about this. Another said she felt as though no one was 'bothered' that she could not cope and had felt suicidal at times (NAN2C7). A different interviewee expressed similar feelings, saying at times she had felt she was 'sinking' and could not believe that there was no one to help her:

... somebody somewhere's got to have something, I know ultimately, yeah, my mum's got dementia and I know it's terminal and, sadly, it'll get worse, I understand that, but surely there's got to be somebody there to support and help you...

(Interview with NAN2C6).

3.2 | Expertise in dementia

The expertise of the Admiral Nurses was a subject participants returned to repeatedly. All Admiral Nurses are dementia specialist nurses. Their clinical background meant that they could make recommendations about medication which, some carers said, had made a considerable difference to the well-being of the person with dementia. The nurses' expertise in dementia care also meant that recommendations relating to important decisions, such as care home choice, were taken very seriously:

... she is in and out of these places, she's seeing people, and she understands as a qualified mental health nurse what is going on. Whereas you and I, we'd walk in and see things cosmetically...

(AN Site 1, Focus Group 1).

Most notably, carers valued the nurses' understanding of dementia as it is experienced day to day: how symptoms can manifest, how they might develop and how they can be managed. Participants explained that when they encountered situations that they had not encountered before, they could ask the Admiral Nurses whether this was 'normal' and the nurses would explain, advise and reassure. When there was no treatment or definitive solution to the problem (as is often the case), they would offer ways to manage the situation. Participants felt that they could not get this kind of support and advice from other professionals because they did not have the same level of expertise in dementia:

A: ... like I said, it's important. The Admiral Nurse is at the forefront because of her professional knowledge and overall experience in this particular area

(Interview with AN1C6).

'... she actually can explain everything, if you want, and has more knowledge across, than any of them [referring to the memory clinic, mental health team and GP]

(AN Site 1, Focus Group 1).

The problem of when and how much information to give to carers and people with dementia at any one time is much debated (Livingston et al., 2010) as there can be a trade-off between under-informing and overloading. One solution is to accompany the person and their carer as the dementia progresses and sensitively deliver information along the way, when carers and people with dementia are ready to receive it:

F ...that's the main thing for me, she's, she really listens and makes suggestions ...she's quite a gentle person but she said quite early on, in a very gentle way, I don't know if you picked up on this, this is a terminal illness; and I think she's gauging how much we can sort of take it in...

(From joint interview in AN Site 2).

This information does not have to be provided by an Admiral Nurse. One participant in an area without Admiral Nursing said that he had similar support from a psychiatric social worker and the senior staff nurse above her. This (NHS) social worker visited him monthly for 3 or 4 years and he described her support as 'extremely good' (NAN1FG2). The key here was that information was being provided by a worker who was highly qualified (and supported by a clinical team), visited regularly and stayed involved for a long period of time. This participant's experience was, however, an exceptional case in our data. His experience contrasted with most other accounts from people without an Admiral Nurse who tended to obtain information piecemeal, often in writing or over the Internet:

We were given documented information which we took away with us, but other than that really, from

admission, we weren't given anything...and then there was no input from anybody apart from just 4–6 monthly appointments with the consultant...

(Non-AN Site 2, Focus Group 1).

I've got a couple of books at home that I found really helpful, but I found them too late

(Non-AN Site 1, Focus Group 1).

Some found online forums such as the Alzheimer's Society's 'Talking Point' a useful resource, both for information and for emotional support, but still these tended to be 'stumbled across' (NAN1FG1) rather than systematically referred to. One participant expressed his dismay at being told to 'Google it' when he asked a professional for some specific information about a service (NAN2FG1).

Some found that they knew considerably more about the condition—through their lived experience and their own research online and in books—than the professionals they came into contact with, which they found frustrating and unhelpful. This was particularly so in the case of rarer forms of dementia such as frontotemporal dementia (FTD). One focus group participant from an area without Admiral Nursing was surprised and delighted when he met an Admiral Nurse in another city who did know about FTD:

It was one of those epiphany moments of 'Oh my god, someone knows what FTD is!'

(Non-AN Site 2, Focus Group 1)

3.3 | A meaningful relationship leading to an understanding of the carer's unique situation

The Admiral Nurses themselves, by virtue of their expertise in dementia and close relationships with families, were felt by many to 'get it' in a way no one else did:

The Admiral Nurse was just there by my side all the way through ... There's no-one else in the world who gets it. Your Admiral Nurse gets it

(AN site 1, Focus Group 1).

Central to the Admiral Nurses' ability to understand the unique situations of individual families was the relationship continuity they could offer. Having a single professional allocated to a patient and carer over time, when their needs are great but also when they are less so, might not seem like the most efficient use of scarce resources. However, carers saw it as an effective (and very welcome) approach to crisis prevention through the early identification and management of issues which could otherwise have led to crisis. Carers said that their Admiral Nurses knew what it looked like when things were going well for them, and also what it looked like when they were not. Consequently, they could 'spot' things they needed help with

as their situations changed, and being an expert, they knew what action to take:

P1: Of course, [AN] knows our partners and she knows more about them than probably even our own GPs, our own consultants... I think that's critical in everything... [AN] is spending more time, she's getting closer, has a greater understanding, not just of our partners' needs, but our own needs, and the circumstances we're in...

P2: ...the outcome is, of course, knowing all that, she can then point you, advise you, to practical services that may be help[ful] specifically to you (AN Site 1, Focus Group 1).

Helplines exist both nationally and in many localities, which are intended to help families in, or on the verge of, crises. However, some carers felt that these were less helpful than more personalised services because they were staffed by workers who, however expert, did not know the person with dementia or the particular circumstances of the family:

...I thought ooh, I just don't know what to do, it's not working, it's not helping. So I rang the nurse helpline at the memory clinic and then she says "Oh I don't know your mum, I've never met you". And I thought it, it should be that you do know us, to be quite honest...

(Interview with NAN2C6).

However, a professional simply visiting regularly was not enough to provide the desired personalised service; they had to engage with the family and take an interest in their circumstances. In one of the focus groups in a non-AN area, for example, a carer explained that a community psychiatric nurse (CPN) came to the house at roughly 6-week intervals for a half-hour chat with his wife. The CPN would 'tick some boxes' on these occasions and then leave without speaking in any depth to the carer. There was rarely opportunity for the husband to say much to the CPN about how he was feeling or what he was struggling with and as such he did not feel particularly supported by the nurse. By way of contrast, a carer with an Admiral Nurse who visited regularly said that he saw these visits as a source of comfort and the Admiral Nurse 'like a friend'. He was aware that this nurse was continually assessing his mental health, and viewed this positively:

M: ... the questions she asks it's obvious she's, she's just weighing me up all the time...

Q: ... how do you feel about that?

M: I don't mind, she's like a friend really... (From joint interview in AN Site 2)

This was not the only carer who talked about their Admiral Nurse as a 'friend' or commented on the 'bond' they had. The difference, however, between the nurse asking about the carer's mental health

and a friend doing so is that, as an expert in dementia care, the nurse can pull in or directly provide appropriate support if and when unmet needs are identified:

It's having somebody who's knowledgeable in that field who can, oh right, OK, you're gonna need this, you're gonna need that, and how's about the other...

(Interview with AN1C1).

While not all of our participants with an Admiral Nurse said they had gone to their Admiral Nurse for emotional support, they did all say that they felt they could if they needed to. The overriding message was of the value of having someone who takes an interest and is there as the disease progresses, and that this person understands dementia and dementia care so that they can offer support and advice, and help the family access other services as and when needs arise. This ongoing relationship with a professional who had the time to get to know the family well, enquired proactively about their well-being and could offer informed support was what those without an Admiral Nurse said they missed, and what those who did have an Admiral Nurse (or equivalent, in the case of the participant with a psychiatric social worker) valued most:

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...

(AN Site 2, Focus Group 1).

4 | DISCUSSION

Admiral Nursing is a UK-based model of case management, but there is growing interest internationally in case management for dementia care (Reilly et al., 2015) and the factors that contribute to the success or otherwise of such models (Goeman et al., 2016). This paper presents the findings of analysis of qualitative data provided by carers of people with dementia for a study about specialist nursing case management, using Admiral Nursing as an example. We compared the experiences of carers who had an Admiral Nurse against those who did not, paying particular attention to the factors that contributed to carers expressing that they felt 'supported'. Participants with an Admiral Nurse consistently reported feeling well supported by these nurses, even if their experiences of other professionals and services were patchy. Carers without access to an Admiral Nurse or equivalent tended to describe their support in less positive terms with some describing sensations of 'sinking' or not knowing where to turn.

The Freeman model of continuity of care (Freeman et al., 2000) was helpful in making sense of our findings. Relationship continuity in particular appears to be centrally important to the experience of carers of people with dementia. 'Relational support' (including taking a

carer-centred approach, providing individually tailored support and being a 'friend') has been established as a key feature of the Admiral Nursing service (Bunn et al., 2016). Admiral Nurses work in ways that enable them to get to know carers and their circumstances well. The closeness of regular contact, extended visits and continuity over time enables them to give support and advice that is informed by an understanding of the unique and dynamic circumstances of the individual and their family. This is important since, as the needs of the person with dementia change, so the circumstances and needs of the carer change too.

In Newbronner et al.'s (2013) study of support over time for carers of people with dementia, carers stressed how much they wanted 'regular ongoing contact with, and support from, health services' and continued:

A number of carers in the survey said that not having one individual who knew what was going on and was a point of contact was the biggest gap in services/support that they had experienced. (2013, pp. 38–39)

Participants in our study were very clear, however, that this ongoing relationship, while necessary, was not sufficient for them to feel supported. Expertise and previous experience of dementia were also vitally important. This tallies with Izumi et al.'s (2018) study of nurse care coordinators which concluded that the most critical competency for care coordination was their integration of 'medical and system knowledge with the patient's context' (p. 55) which enabled them to bridge the gap between the patient and the healthcare system. Goeman et al. (2016) similarly found that key worker models which had a positive impact on carer burden and improved quality of life shared components including face-to-face contact, ongoing follow-up and the health/clinical background of workers. At the other extreme, carers interviewed by Laparidou et al. (2019) described the damaging effects of healthcare professionals' lack of understanding of how it was to live with dementia. This fits with the accounts of carers in our study who commented that generalist health and social care professionals and even some memory service staff did not understand the challenges they faced.

Quinn et al. (2008) documented the problems that carers can have trying to understand what is happening to their partners as their dementia progresses and concluded that limited understanding of dementia 'could add considerably to the difficulties faced by caregivers' (p. 776). In such circumstances, ongoing access to a professional with expertise in dementia seems vital. The specialist expertise and condition-specific experience of the Admiral Nurses were highly valued and at times expressly articulated as *the* thing that made the difference between a worker merely sympathising, and being able to give useful advice and support. This could explain why services designed to deliver emotional support and friendship via a non-specialist, for example, through a volunteer befriending scheme, have not proved effective for carers of people with dementia (Charlesworth et al., 2008). The Dutch 'Geriant' model of dementia care services now only employs professional nurses

as case managers as, through experience, the organisation 'found that sufficient knowledge on dementia and nursing skills were required to perform the broad range of tasks inherent to the position' (Glimmerveen & Nies, 2015, p. 8).

Recent NICE guidelines recommend that people with dementia be provided with 'a single named health or social care professional who is responsible for coordinating their care', but do not specify who this professional should be or their qualifications (National Institute for Health and Care Excellence [NICE], 2018, p. 33). Carers of people with dementia participating in our study clearly articulated the value they saw in having an experienced nurse with expertise in dementia coordinating their care and accompanying them as the dementia progressed.

4.1 | Limitations

While our approach to recruitment for this study was purposive in intent, it was pragmatic in execution. Participants in the Admiral Nursing group were initially invited to take part by Dementia UK, as they run the Admiral Nursing services and so have direct access to carers' contact details. While guidance was given on how to select participants, we cannot guarantee that there was no bias in the sampling towards positive experiences. This could go some way towards explaining the consistently positive messages from participants with Admiral Nurses about the outcomes of the services they received. However, the focus of the analysis presented here is factors which contribute to these positive outcomes. As such, while we may have missed some negative cases, we can be fairly confident in our conclusions about the role of the three elements of relationship continuity we identified in the achievement of positive outcomes.

The most notable gap in our data is the experiences of carers from black and minority ethnic groups. While data from our subsequent survey do show that Admiral Nurses support carers from a wide range of ethnic backgrounds (Gridley et al., 2019), these were not present in our qualitative sample. Similarly, we were unsuccessful in recruiting carers from black and minority ethnic groups in the non-Admiral Nursing sites. As a consequence, our findings cannot be said to be generalisable to all groups. It is likely that a more targeted approach to recruitment (e.g. through specialist organisations) is required to address this gap.

5 | CONCLUSION

In summary, the relationship continuity described above had three key elements, each of which appeared to be required for carers to feel supported:

1. Ongoing support over time
2. Expertise in dementia
3. A meaningful relationship (between the practitioner and the carer) leading to an understanding of the carer's unique situation

A continuous relationship without expertise (e.g. from an unqualified voluntary sector worker), while valued, was not considered to provide adequate support, particularly when the condition deteriorated and new challenges arose. Expertise in dementia (e.g. the expertise of a consultant at a memory service) was similarly considered insufficient if it came without continuity or knowledge of the family's unique position. Expertise combined with ongoing support and an understanding of the family situation enabled Admiral Nurses to inform and prepare carers for future stages of dementia and prevent crises. While we found examples of other professionals providing elements of this continuity, instances where all three elements were combined were rare (we only identified one of a psychiatric social workers supported by a clinician). As such we would conclude that specialist nurses working closely with families over time, as Admiral Nurses do, are in an optimal position to deliver relationship continuity, contributing to carers of people with dementia feeling supported.

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CONFLICT OF INTEREST

Ms Kate Gridley – no conflicts of interest; Dr Gillian Parker – no conflicts of interest.

DATA AVAILABILITY STATEMENT

Author elects to not share data (consent was given by research participants for their data to be used only for this specific study).

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