Title

Specialist dementia nursing models and impacts: A systematic review

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ABSTRACT

Purpose of review:

Dementia policy priorities recommend that people who are living with dementia and their family should have access to support and interventions delivered by dementia specialists, including specialist nurses. However, specialist dementia nursing models and role-related competencies are not clearly defined. We systematically review the current evidence regarding specialist dementia nursing models and their impacts.

Recent findings

Thirty-one studies from across three databases, and grey literature were included in the review. One framework defining specific specialist dementia nursing competencies was found. We did not find convincing evidence of the effectiveness of specialist nursing dementia services, relative to standard models of care from the current, limited evidence base, although families living with dementia valued it. No RCT has compared the impact of specialist nursing on client and carer outcomes relative to less specialist care, although one non-randomised study reported that specialist dementia nursing reduces emergency and inpatient service use compared with a usual care group.

Summary

Current models of specialist dementia nursing are numerous and heterogeneous. Further exploration of the specialist nursing skills and the impact of specialist nursing interventions is needed to usefully inform workforce development strategies and clinical practice.

Key Words: Systematic Review, Specialist Nursing, Dementia, Interventions, Skills.

INTRODUCTION

Dementia, a progressive, neurodegenerative condition, currently affects around 50 million people worldwide [1]. English policy priorities for people living with dementia and their families, consistent with other developed nations, include improving care co-ordination, partnership working, and specialist health input [2]. Nurses who have specialist knowledge and skills in dementia management make an important contribution to this, usually working with people living with dementia and their families who have more complex needs, in community, palliative care, liaison and inpatient settings.

Specialist nursing roles encompass the Clinical Nurse Specialist and Nurse Practitioner/Advanced Nurse Practitioner [3]. Previous authors have described how definitions of specialist or advanced practice nursing vary between nations, though with a shared expectation that specialist nurses should have advanced expertise [4] that includes a master’s level education in their specialist area [5].

We systematically reviewed the evidence for specialist dementia nursing to answer the following research questions:

1. How is specialist nursing in dementia defined in terms of key skills and required competencies?
2. What is its impact on families and people living with dementia?

METHOD

We registered the review on PROSPERO.

Search strategy

We searched (to 1/11/2021): MEDLINE, CINAHL, PsycINFO, Grey literature (EThOS) and the National Institute for Health and Care Excellence (NICE) evidence search for Health & Social Care (https://www.evidence.nhs.uk/). We searched references of identified articles, including systematic reviews, and conducted forward searches for additional relevant studies. Terms related to specialist nursing ("admiral nurs*" or "nurse-led" or "clinical nurse specialist*" or "specialist nurs*" or "nurse practitioner" or "nurse specialist") were combined, using the Boolean operator "AND" with terms for dementia (dementia or alzheimer* or "vascular dementia" or "Lewy body dementia" or "Lewy body disease" or "rare dementia").

We limited the search to adult participants (aged 18+) and English language papers.

Study selection

We included primary qualitative and quantitative research studies that described specialist nursing or nurse-led services focussed on providing care to people living with dementia and/or their family carer, where care is mainly delivered by qualified nurses with a professional specialism in dementia. We excluded study protocols and studies where the nurse was only involved in screening for dementia rather than care delivery.

PB screened titles and abstracts; full text papers that met the inclusion criteria were included and reviewed for eligibility by AB or CC. Where inconsistencies were found, these were discussed and resolved by consensus.

Data extraction and quality assessment

Extracted data were entered into a spreadsheet; 10% of data was checked by CC for accuracy. See PRISMA flow diagram (Figure 1), and Tables 1-2c for details of data extracted. We sought to prioritise evidence from higher quality papers, and used the Mixed Methods Appraisal Tool, (MMAT) to assess study quality [6], Findings were then discussed and shared to check for consistency.

Analysis

We narratively synthesised findings, using guidance for studies with “considerable heterogeneity in terms of methods, participants, interventions and other unknown sources” [7].

RESULTS

Study characteristics

Most studies took place in the UK (n=18); of these, fourteen evaluated Admiral Nursing services (Table 1); two evaluated Advanced Nurse Practitioner-led interventions in a community memory clinic and day hospital setting respectively [8, 9] and two explored specialist nurse-led dementia inpatient services [10,11]. Of the eight USA studies included, five reported findings from a University of California, Los Angeles (UCLA) based dementia care specialist nurse and physician team [12,13,14,15,16] while three described Nurse Practitioner-led, community-based interventions [17,18,19]. Two studies, in Canada [20] and Switzerland [21] described work in long term care facilities by specialist dementia nurses. Two community-based studies (South Korea and the Netherlands), evaluated nurse-led education for family carers of people with dementia [22,23]. An Australian study evaluated work of a community-based Clinical Nurse Consultant [24].

Summary of reviewed studies

Tables 1 and 2 summarise study findings. Three studies contributed to our response to research question 1 (below) and we discuss these first. The remaining studies responded to question two and are discussed subsequently.

Research question 1: How is specialist nursing in dementia defined in terms of key skills and required competencies?

Two qualitative studies [25,26] specifically addressed Admiral Nurses skills and competencies. In the first [25], Admiral Nurses, Admiral Nursing team managers, family carers, and people with dementia worked together to shape the design, development, and testing of a new Admiral Nurse competency framework. The second study refined this original framework to define six core competencies: person-centred care, therapeutic skills, triadic relationships, sharing knowledge, best practice, and critical reflective practice [26]. Three levels of specialism for each competency are also defined which comprise the benchmarks for Admiral Nursing specialist practice [26].

Skills required to care at the end-of-life in dementia, were explored in a needs analysis of end-of-life masterclasses [27]. The Admiral Nurses who attended the masterclasses identified specific factors that would increase their confidence in Advanced Care Planning (ACP) in dementia at the end of life. Supervised practice of ACP was found to be the most significant intervention for the nurses to enhance their ability to undertake end-of-life care conversations.

Research question 2: What are the impacts of specialist nursing models on families and people living with dementia?

Studies in community/domiciliary settings (10 papers, 8 studies)

Studies comparing outcomes of specialist dementia services with usual care.

Four quantitative studies focussed on community settings. None of the four studies, including one Randomised Controlled Trial (RCT), reported statistically significant differences in outcomes between clients receiving specialist nursing and control groups after follow-up periods ranging between 12-weeks to 12-months. The RCT investigated the delivery of on-line, nurse-led support for managing behaviour changes to family carers of people living with dementia [28]. Family carers reported high levels of satisfaction with the online nurse-led interventions, but no statistically significant differences were found on primary outcomes between intervention and control groups after the 12-week study period. The other three studies were non-randomised designs: two involved UK Admiral Nursing services [29,30**], while the third evaluated USA primary care specialist nursing [18]. In the first Admiral Nursing study [29], carers receiving the Admiral Nursing intervention experienced significantly less anxiety and insomnia than the control group.

The second Admiral Nursing study was the only study to compare costs between specialist and standard nursing. It reported no significant differences between services received from specialist dementia nurses and non-specialist professionals, despite reported preconceptions from commissioners that specialist services would be expensive [30**].

The final community-based study compared the clinical outcomes of dyads receiving Nurse Practitioner-led interventions of in-home support, advice, and education sessions alongside Primary Care Physician (PCP) interventions of ‘usual care’ [18]. Patient neuropsychiatric symptoms and quality of life changes, caregiver depression, burden, and self-efficacy changes were not-

significantly different between intervention and control groups at 12-month follow-up. Overall satisfaction with the Nurse Practitioner intervention from patients, caregivers, and Primary Care Practitioners was high; satisfaction with usual care was not measured [18].

Single group studies exploring experiences of specialist dementia nursing (4 studies)

Three single group qualitative and one quantitative study explored the experiences of people receiving specialist dementia nursing. Two UK studies considered the impact on dyadic (carer and cared-for) and triadic (dyad and a dementia specialist nurse) relationships within Admiral Nursing family interventions [33,34]. The effects of caring on carer-identity, personhood, and confidence was examined in a further UK study which found that family carers who received support from Admiral Nurses felt less isolated and were enabled to successfully access necessary external support [34].

In Australia, a study of people with a six-month history of cognitive and functional decline, receiving pre- diagnosis support and interventions from a clinical nurse consultant with specialist skills in dementia found that families were helped to better manage changes caused by the dementia and to voice their needs and concerns. Professionals found the clinical nurse consultant helped to streamline health processes whilst sharing their expertise and knowledge [24]

A quantitative, single-group study of family carers of people with dementia found that the Admiral Nurse's knowledge, skills, rapport, and support for dyad needs were helpful to carers [35]. Supporting activities/stimulation, medication advice and care

coordination were found to be less helpful. More than 5 contacts with the nurse, and female gender predicted greater satisfaction. [35]

Studies in Clinic, Medical Centre, or Day Hospital settings (10 studies)

Findings from the UCLA ADC program

Five USA studies recruited participants from the UCLA Alzheimer's and Dementia Care (ADC) program, involving a co-management model (Nurse Dementia Care Manager and Primary Care Physician) [12-16*]. Nurse Dementia Care Managers were described as having geriatric and dementia expertise, recommended medication via the Primary Care physician, independently prescribed appropriate medications for dementia and/or depression, and can refer to relevant clinical specialists [12].

In the first of the studies that explored quality of care, the interventions delivered were found to be consistent with high quality dementia care in assessment, screening, and counselling, with some variability in patient adherence to treatment quality indicators. This was attributed to issues such as physician input to change medication, participant's lack of confidence in the study process, and system issues with documenting care and treatments [12]. A second study examined goal setting for care-dyads which found that 74% of the dyads achieved or exceeded their personal goals after six months; Dementia Care Managers reported better understanding of the care-dyad perspective [13]. A further study of predictors of clinical benefit in recipients of Dementia Care

Manager interventions, found at 1-year follow up that the person with dementia had worsened cognitive and functional status, however their behavioural and psychological symptoms and caregiver outcomes improved [14*]. An additional study explored reasons why 151/554 of care recipients did not derive clinical benefit from the intervention program. Despite a lack of reported statistical improvement, 85% of carers who were interviewed found the programme beneficial with improvements in mood and behaviour for the person with dementia, and reduced carer stress and depressive symptoms [16*].

The final study in this setting compared service utilisation between patients enrolled on the intervention program and those who were not enrolled [15**]. Nurse practitioner-primary care (co-managed) patients had fewer visits to emergency departments, shorter hospital length of stay, were less likely to be admitted to a long-term care facility, but more likely to receive hospice services in the last 6-months of life. The study found that health and institutional-related costs were positively influenced by the co-managed care interventions in comparison to controls [15**].

Findings from other clinic or day hospital-based studies (5 studies)

Five additional studies evaluated the impact of a specialist nurse clinic. One of these was an RCT, comparing a nurse-led clinic offering education and information on medication (Donepezil) for Alzheimer's disease with standard information provision to family carers of people newly diagnosed with Alzheimer's disease [22*]. Nurses with 'expert' knowledge of Alzheimer's disease offered up

to five psychoeducation sessions with family carers. After one year, neither donepezil discontinuation nor adherence rates significantly differed between groups [22*]

An 18-month action research study sought to refine and develop an Advanced Nurse Practitioner in dementia role within a UK community day hospital. People with dementia, family carers, and professionals were interviewed. The study found that the Advanced Nurse Practitioner was able to support the GP by providing initial assessments, and ongoing clinical intervention more quickly via a direct referral system. The researchers acknowledged that the Advanced Nurse Practitioner would require additional initial and ongoing training to effectively fulfil their role [9].

A survey of people with dementia and their carers following intervention by the Advanced Nurse Practitioner within a UK memory clinic setting found high levels of satisfaction with the Advanced Nurse Practitioner in ‘direct clinical practice’, and ‘quality of care’ [8].

A UK mixed methods UK study evaluated clinics offering appointments delivered by three Admiral Nurses over 4-days within work-based settings. 57 family carers received a one-off consultation during this period, with 87% of the family carers who attended reporting they would use the service again [36].

Finally, a qualitative study in the USA reported on a satisfaction questionnaire for 66 dyads who received a nurse-led dementia behaviour management clinic intervention. Care dyads found the nurse-led intervention helpful, but the study interventions were not well specified [17].

DISCUSSION

How is specialist nursing in dementia defined in terms of skills and training?

We found only three studies that explicitly evaluated the competencies and training needs of specialist nurses, all were related to UK Admiral Nursing, which adopts the Admiral Nurse Competency Framework [25*,26*,27*].

Of the seventeen studies that were unrelated to Admiral Nursing, seven focused on skills acquisition or the nurse's expertise/formal training, although studies have suggested that additional skills or training can be achieved informally by for example, Dementia Care Managers who were found to gain an improved knowledge of dementia 'on the job' as an alternative to more formal acquisition of expertise and skills [13].

Across many studies, there was a focus on the ability to enable person-centred relationships or to deliver relationship centred care as central to specialist nurse definition and practice [33,30,32]. A final common theme was a focus on case management [29,35,31,18]. In studies describing case management approaches, two suggested that the involvement with a specialist nurse

enhanced the experiences of people with dementia and their caregiver [9,18] or enhanced the process of assessment and care delivery [8,12-16,]. Other studies discussed the importance of the relationship between the specialist nurse and the family or specific approaches or interventions that improve the health or quality of life of people with dementia in care homes and end-of-life care [20,21,39].

What is the impact of specialist nursing?

There is a paucity of evidence in this area. Of the three RCTs we identified, one did not complete analyses due to poor recruitment [10], and two reported no difference between specialist nursing psychoeducation on donepezil discontinuation rates [22*] and with lower intensity support for family carers with behavioural challenges [28*].

Among four non-randomised controlled community studies, one, evaluating a USA Nurse Dementia Care Manager outpatient service reported fewer emergency room visits and hospital admissions in the intervention group [15**]. One study found that carers using a UK Admiral Nursing service reported no statistically significant cost differences compared to a control group [30**]. A non-randomised inpatient study found that specialist nurses trained to deliver a behavioural intervention increased use of analgesia (acetaminophen) and reduced patient length of stay [19**].

Despite being the subject of numerous small qualitative and service evaluation studies and being widely available across the UK, Admiral Nursing has only been evaluated in two quantitative studies with comparison groups. In one, now 20 years old, there were

no differences between groups after 8 months, however a notable subscale finding was improvement in sleep and anxiety for those in the Admiral Nurse service group [29]. One large study found no differences in costs between services received from specialist dementia nurses and non-specialist professionals, despite reported preconceptions from commissioners that specialist services would be expensive [30**]. Thus, while numerous studies have reported high satisfaction levels, definitive evidence for Admiral Nursing models is lacking, though a cost-benefit analysis would suggest that services are no more expensive than standard care [30**].

Strengths and limitations

This review has enabled the gathering of evidence of a broad range of specialist dementia nursing approaches, models, and interventions; however, the results lack generalisability as to the study type, settings, context, interventions, and the study periods that were described. All the studies that we reviewed are published in the English language, further limiting the review's generalisability, whilst additionally exposing gaps in knowledge regarding potential cultural or other influences that may affect the role and delivery of specialist dementia nursing.

CONCLUSION

We found only one framework defining specialist dementia nursing competencies, and limited evidence for effectiveness of specialist nursing dementia services, though families living with dementia valued it. No RCT has measured the impact of specialist

nursing on family carer and client outcomes relative to less specialist care, though preliminary findings from non-randomised studies suggest it may reduce emergency and inpatient service use, and qualitative studies suggest it may improve patient and carer experience. We only found evidence regarding specialist nursing from higher income countries; more evidence is required regarding whether specialist nursing might support better dementia care in lower and middle-income countries.

Key points

- The only skills and competency framework proposed to date for specialist nursing considers person-centred care, therapeutic skills, building triadic relationships, sharing knowledge, best practice, and critical reflective practice.
- Nurses with an advanced knowledge of dementia and specialist nursing interventions are highly valued by people with dementia and their families.
- There is no RCT evidence evaluating whether specialist nursing delivers better clinical outcomes for clients or family carers, relative to other models of care; we argue these are now needed.
- There is consistent evidence from one community and one inpatient study that specialist nursing services can reduce hospital bed usage, from non-randomised controlled studies.

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Conflicts of interest

Dementia UK is the charity who provides Admiral Nurses in the UK. The first author is an Admiral Nurse employed by the charity.

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