

Title

Specialist dementia nursing models and impacts: A systematic review

Authors

Pat Brown^{1*}

Alexandra Burton²

Jordan Ayden³

Karen Harrison Dening⁴

Juanita Hoe⁵

Claudia Cooper⁶

Affiliations

¹Division of Psychiatry, University of London, London, UK & Dementia UK, London, UK

²Research Department of Behavioural Science and Health, University of London, London, UK

³Division of Psychiatry, University of London, London, UK

⁴School of Health & Life Sciences, De Montfort University, Leicester, Leicestershire & Dementia UK, London

⁵Geller Institute of Ageing and Memory (GIAM), University of West London, London, UK

⁶Centre for Psychiatry and Mental Health, Wolfson Institute of Population Health, Queen Mary University of London, London, UK

Corresponding author:

Pat Brown, UCL Division of Psychiatry, 6th Floor Wing A, Maple House, 149 Tottenham Court Road, London W1T7BN

Twitter: @AdmiralNursePat

email: pat.brown.20@ucl.ac.uk

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 shared 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 led to 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 and usual care on donepezil discontinuation rates [22*] and between high intensity (nurse) intervention and 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 difference 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 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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tool and managed 'medicare' claims data. Costs were measured over a two-year period. Intervention participants had fewer visits to the Emergency Department, shorter hospital stays, and were more likely to receive hospice support in the last six months of their life. No significant differences were found between groups for hospital or Intensive Care Unit stays.

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This study was an RCT which was carried out over a 7- month period where online self-management support was made available to family caregivers with the aim to help them to deal with behaviour changes in the relative with dementia whom they were caring for. The trial comprised of three arms: Arm 1: email contact with a specialist Dementia Nurse, Arm 2: Online training video & Arm 3: information via e-bulletin.. A mixed-model analysis compared the outcomes of the 3 intervention arms. The intervention: personal email contacts with a dementia nurse was compared with online interventions without email contact from the specialist nurse. Findings:78% (21/27) family caregivers had email contact with the specialist nurse, 80% (43/54) of family caregivers clicked on an online video, 37% clicked on an e-bulletin. Caregivers showed positive evaluations and satisfaction. Family caregivers in the major intervention involving email contacts showed no statistically significant differences in self-efficacy after the intervention compared with the minor intervention involving only e-bulletins (difference=0.02, $P=.99$).After adjustments, the medium intervention (involving videos and e-bulletins) showed a negative trend overtime (difference -4.21, $P=.09$) and at T1 (difference -4.71, $P=.07$) compared with the minor intervention involving only e-bulletins. No statistical differences found in the reported behaviour problems and the quality of the caregiver/PWD relationship.

29. Woods, R. T., Wills, W., Higginson, I. J., Hobbins, J., & Whitby, M. (2003). Support in the community for people with dementia and their carers: a comparative outcome study of specialist mental health service interventions. *Int J Geriatr Psychiatry*, 18(4), 298-307. <https://doi.org/10.1002/gps.822>
30. ** Gridley, K., Aspinall, F., Parker, G., Weatherly, H., Faria, R., Longo, F., & van den Berg, B. (2019). Health Services and Delivery Research. In *Specialist nursing support for unpaid carers of people with dementia: a mixed-methods feasibility study*. NIHR Journals Library. This study was undertaken to explore the effect/ impact, and cost of Admiral Nurse intervention compared to 'usual care' (without Admiral Nurse). Data from the

records of 24,825 clients who had been supported by Admiral Nurses was used for a secondary analysis. Questionnaires were obtained from 346 family carers of people with dementia, 158 people with dementia who were receiving services from Admiral Nurses, and 188 who were not in areas supported by Admiral Nurse services. Next they undertook a qualitative study that involved 35 carers of people with dementia (18 in receipt of Admiral Nursing services, and 17 without an Admiral Nurse). Alongside this the study gathered data from 22 focus groups, 13 individual interviews of family carers, and professionals (n=20). They found that carers reported that ongoing support, expertise, and meaningful relationships contributed to feeling supported. Carers surveyed receiving support from AN were older and provided more care than carers not in receipt of AN. Outcomes and costs did not differ significantly between groups.

31. Longo, F., Faria, R., Parker, G., Gridley, K., Aspinal, F., Van den Berg, B., & Weatherly, H. (2019). Investigating the economic case of a service to support carers of people with dementia: A cross-sectional survey-based feasibility study in England. *Health & Social Care in the Community*, 27(5), e734-e743. <https://doi.org/10.1111/hsc.12799>
32. Gridley, K., & Parker, G. (2021). Specialist nursing case management support for carers of people with dementia: A qualitative study comparing experiences of carers with and without Admiral Nursing. *Health Soc Care Community*. <https://doi.org/10.1111/hsc.13437>
33. Quinn, C., Clare, L., McGuinness, T., & Woods, R. T. (2013). Negotiating the balance: the triadic relationship between spousal caregivers, people with dementia and Admiral Nurses. *Dementia (London)*, 12(5), 588-605. <https://doi.org/10.1177/1471301212437780>
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36. Weatherhead, I., Eades, L., Harrison Denning, K., & Weidner, W. (2020). Admiral Nurses delivering workplace clinics for family carers: Innovative practice. *Dementia*, 19(2), 472-478. <https://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=med17&AN=28449594>
37. Thompson, R. (2010). Realising the potential: developing life story work in practice. *Foundation of Nursing Studies: Developing Practice Improving Care Dissemination Series*, 5(5), 1-4.

<https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,shib&db=jh&AN=105182002&site=ehost-live&scope=site&custid=s8454451>

38. Evans, S. C., Harrison-Dening, K., & Read, K. (2018). Towards the end of life: An in-depth exploration of the role of Admiral Nursing in dementia care (Innovative practice). *Dementia (London)*, 17(2), 244-251. <https://doi.org/10.1177/1471301216636485>
39. Harrison Dening, K., Crowther, J., & Adnan, S. (2020). An Admiral Nursing and hospice partnership in end-of-life care: Innovative practice. *Dementia (14713012)*, 19(7), 2484-2493. <https://doi.org/10.1177/1471301218806427>

Figure 1: PRISMA diagram of study selection (adapted from Moher et al., 2009)

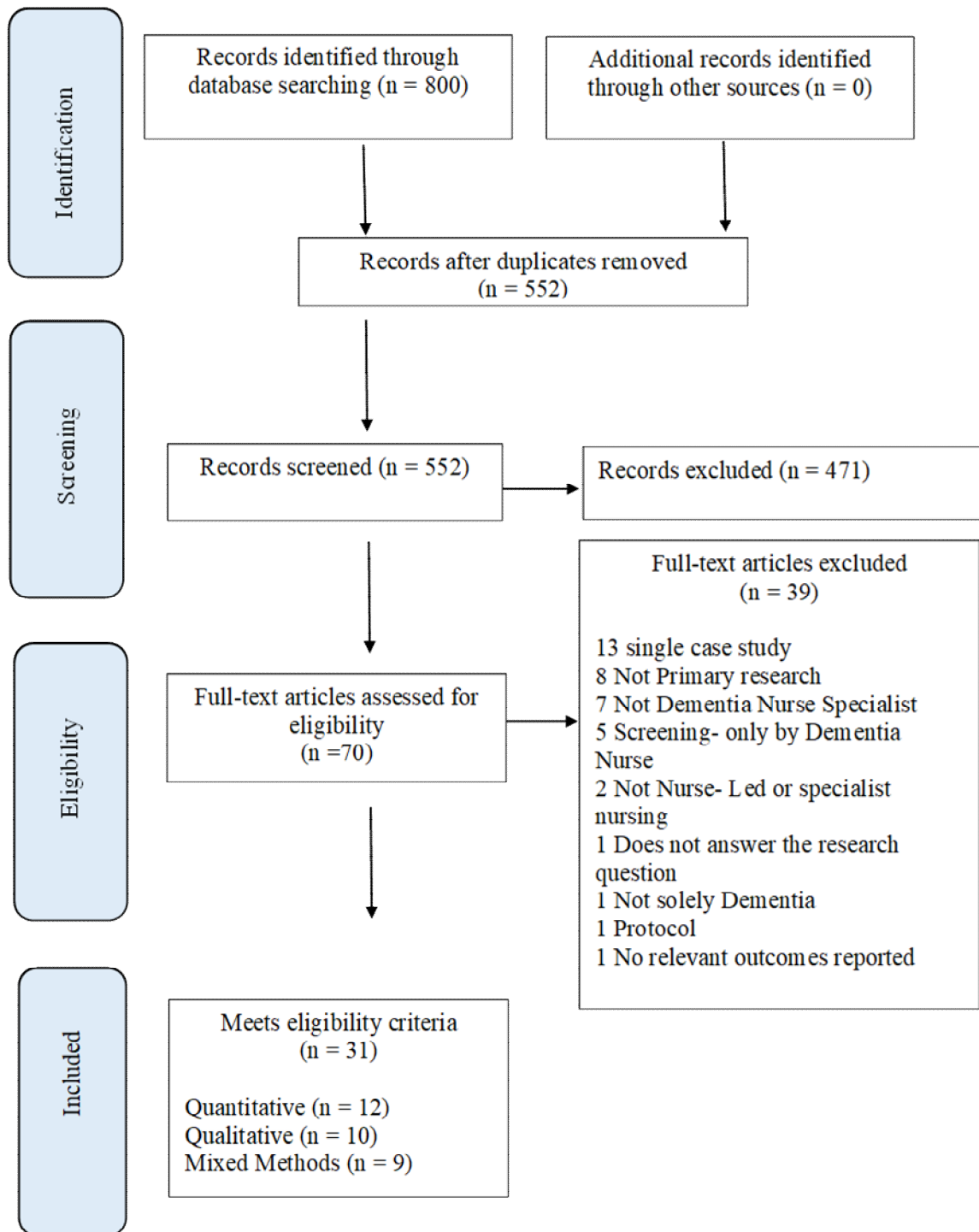


TABLE 1. Admiral Nursing studies

Study Citations are indicated in the order they appear in the text by [1]	Population, Setting, & Sample size	Study type	Aims of the study	Findings/ Outcome	Quality Rating Mixed Methods Assessment Tool Domains				
					1	2	3	4	5
Community settings									
Gridley et al 2019, 2021; Longo et al, 2019 [30,32,31]	24,825 client records from Admiral Nursing administrative data; Questionnaires: 346 family carers, 158 (46%) AN service- users and 188 (54%) from non-AN areas; Qualitative study: 35 carers of people with dementia (18 in receipt of AN services & 17 without AN); in focus groups (n=22) and individual interviews (n=13); 20 professionals also completed interviews	Secondary analysis of data; mixed methods questionnaires and qualitative study	Explore the effect of AN compared with usual care, on: Adult Social Care Outcomes Toolkit for Carers; EuroQol-5, Caregiver Self-Efficacy for Managing Dementia Scale; and to compare costs	Carers reported that ongoing support, expertise, and meaningful relationships contributed to feeling supported. Carers surveyed receiving support from AN were older and provided more care than carers not in receipt of AN. Outcomes and costs did not differ significantly between groups.	Y	Y	Y	Y	Y
(Maio et al., 2016) [35]	207/685 Family carers receiving Admiral Nurse community services in three areas of England.	Service Evaluation. Questionnaires	To elicit views and levels of satisfaction with services	Respondents found AN knowledge (82%), skills (83%) rapport (97%) and support for dyad needs (86%) helpful; 31%, 34% and 25% reported unhelpful in supporting activities/ stimulation, medication advice and care coordination. 5+ AN contacts and female gender predicted satisfaction.	Y	Y	Y	N	Y
(Quinn et al., 2013) [33]	6 dyads (People with dementia & their Carer) and 3 AN providing care from Northwest England	Individual interviews with each participant	To explore how triads work together	The study explored how relationship is balanced and highlight the need to explore all perspectives of the triad to better understand the working relationships.	Y	Y	Y	Y	Y
(Tierney et al., 2019) [34]	19 family carers receiving AN services, purposively recruited in one area of England	Qualitative interviews	- To explore the input of Admiral Nurses (AN) in relation to becoming and being a carer for a person with dementia.	Overarching concept of "the unity–division paradox" highlights complex interchange within caring dyad and external supporters. Such interactions can make carers feel part of a larger network (unity) but also as if they are on their own, fighting on behalf of the person with dementia (division).	Y	Y	Y	Y	Y
(Weatherhead et al., 2020) [36]	64 appointments offered by three AN over 4 days at HM Revenue and Customs Liverpool and Newcastle offices; 57 carers of people with dementia were seen	Mixed methods questionnaires	To explore feasibility of AN workplace clinics	Service satisfaction was rated as excellent by 69%; 87% said they would use the service again	Y	Y	Y	N	N
(Woods et al., 2003) UK [29]	104 carers of people with dementia (43 receiving AN service; 61 receiving usual care comparison services) in the London/North Thames Region	Two group quantitative comparison over 8 months	To compare outcomes for carers receiving AN with usual care	No significant differences between groups on the primary outcome measure at follow-up, the General Health Questionnaire (GHQ) or its sub-scales, apart from anxiety and insomnia, where outcome favoured AN group (p=0.038).	Y	Y	Y	Y	Y

Care homes, long-term palliative care and hospital settings									
(Evans et al., 2018) [38]	Four patient/carer dyads, where person with dementia was at end of life, recruited by one Admiral Nurses from her client list, West Midland AN service.	Nurse completed outcome measures and reflective diary over one year	To explore how Admiral Nursing can support families towards the end of life and pilot a range of standardised measures.	Majority of the chosen validated measures were reported to be inappropriate for use in this study; themes were identified about family carer experience and impact on AN.	Y	N	N	Y	N
(Harrison Denning et al., 2020) [39]	50 referrals to a pilot community palliative care AN service, run collaboratively with a Yorkshire hospice	Referral rates and Admiral Nurse caseload numbers; carer satisfaction	To evaluate the AN input to a Specialist Community Palliative Care Team, aiming to reduce inappropriate hospital admissions; support preferred place of death and advance care plans	All people referred to the Admiral Nurse were offered the opportunity to engage in discussions about their preferred place of death. 10/12 deaths in sample were in their preferred place of death: other 2 in acute care. Only 5 carers completed satisfaction rating – rated high	Y	Y	N	N	Y
(Thompson, 2010) [37]	7 Admiral Nurses worked with staff from 6 in-patient acute/ continuing care wards from two mental health trusts over one year to introduce life story work as an intervention	Recorded no. life story books developed, staff questionnaire, AN reflection, client feedback	To evaluate the introduction of life story work for people with dementia and their families	24 Life story books developed; where work was successfully implemented, staff achieved improved understanding of patients, relatives, and family carers.	Y	Y	N	N	N
Studies that evaluated training or developed competency frameworks									
(Harrison Denning et al., 2019) [27]	75 Admiral Nurses (AN) who had attended a master class in end-of-life care during 2017 and 2018.	Training Needs Analysis. Questionnaire	To explore the knowledge, skills, and levels of confidence to facilitate Advanced Care Plans	Specific AN training needs were identified that would help to build AN confidence and skills in end-of-life care for people with dementia	Y	Y	Y	Y	Y
(Carter et al., 2018) [26]	Admiral Nurses: national online survey, completed by 75/130 current in post; 4 telephone interviews and focus groups (n=27). Focus group: 3 people with dementia & 2 family carers recruited from experts by experience group	Mixed methods survey and qualitative interviews/ focus groups	To explore views of current Admiral Nurse Competency Framework (ANCF) and report on the process utilised to develop a refreshed version of the ANCF as a resource for practice.	6 Competencies were identified and 3 levels of specialism (Specialist, Enhanced specialist, and Advanced specialist)	Y	Y	Y	Y	Y
(Dewing & Traynor, 2005) [25]	All 11 Admiral Nurse (AN) Teams (each with 2-3 nurses) operating in 2000-3 were observed; undisclosed number of nurses, clients, managers commissioners took part.	Action research	To develop a competency framework.	13 themes were identified and 8 AN core- competencies developed	Y	Y	N	N	N

TABLE 2a. Non-Admiral Nursing studies: Clinics, Medical Centres & Day Hospital settings

Study	Population, Setting, & Sample size	Study type	Aims of the study	Findings/ Outcome	Quality Rating Mixed Methods Assessment Tool Domains				
					1	2	3	4	5
Studies reporting on the UCLA Dementia Care Managers (DCM) program (community hospital)									
(i). Jennings et al., 2016 [12]	(i) From July 2012- July 2014, Nurse practitioner notes of 797 participants who were enrolled on the UCLA, Alzheimer's and Dementia Care programme who had received Dementia Care Manager (DCM) intervention from 5 DCM's.	(i) Quantitative descriptive statistics: DCM notes were mapped against 17 dementia quality indicators (QI's)	(i.) Assess the quality of care delivered by DCM Nurse practitioners across 17 dementia QI domains, using the Assessing Care of Vulnerable Elders (ACOVE-3)21 and Physician Consortium for Performance Improvement (PCPI)	(i.) 92% of eligible QI's were passed. The UCLA ADC program achieved high Quality of Care provision for assessment, screening, and counselling. More variability in adherence was found with treatment associated Quality indicators.	Y	Y	Y	Y	Y
(ii.) Jennings et al.,2018 [13]	(ii) 101 people with dementia (PWD) and their caregivers; 5 nurse practitioner dementia care managers, (DCM) all from UCLA Dementia Care programme.	(ii) DCMs led 101 dyads of PWD and their caregivers in goal specification using a 5-category goal attainment scale. Goal attainment was measured at 6 and 12 months. Structured interviews with dyads and focus groups with DCMs were conducted.	(ii) Specification of a personalized health goal and action plan using goal attainment scaling (GAS) measurements during a clinical care visit.	(ii) 84% of non-medical (participant) goals identified.47% related to quality of life, and 29% were caregiver support goals. 88% of participants felt that the goal they set was meaningful. 85% found the process helpful in planning for future care. 74% of dyads had achieved or exceeded their expected level of goal attainment at 6 months. DCM experienced improved understanding of what was most important to the patient and were able to set expectations about disease progression and care needs.	Y	Y	Y	Y	Y
(iii.) Jennings et al., 2020 [15]	(iii) 856 people with dementia:3,139 people with dementia not enrolled in the program.	(iii) Intervention & comparison patients were followed (January 2012 to June 2016). Analysis of costs compared with PWD not in the program using fee for service (FFS) measurement tool and Medicare claims data.	(iii) To understand the impact of dementia co-management on costs of acute care, long -term care and hospice utilization. Program enrolees service utilisation was examined and compared with PWD not in the program using Fee-for-service (FFS) measurement tool and managed Medicare claims data.	(iii) Intervention participants had fewer ED visits, shorter hospital stays and were less likely to be admitted to long term care. Participants were more likely to receive hospice support in the last 6 months of their life. No significant differences between groups were found for hospital or ICU stays.	Y	N	Y	Y	Y

<p>(iv.) Reuben et al.,2020 [14]</p>	<p>(iv) From a cohort of 1,091who entered the programme from July 2012- December 2014, 554 people with dementia and 447 caregivers' outcomes were measured after 1-year. An unspecified number of Nurse practitioner dementia care managers (DCM)delivered the intervention.</p>	<p>(iv)Quantitative Observational, baseline, and 1 year after intervention measures were taken using validated rating tools to rate cognitive and physical function, and care giver burden and stress before and after the intervention.</p>	<p>(iv)Examine the clinical outcomes of ADC program to identify sub-groups who were more likely to benefit. Using Mini-Mental State Examination (MMSE), Functional Activities Questionnaire (ADL's & IADL, Cornell Scale for Depression in Dementia, & Neuropsychiatric Inventory Questionnaire (NPI-Q) Severity. Caregiver measures: Modified Caregiver Strain Index, the Patient Health Questionnaire-9, NPI-Q Distress, and the Dementia Burden Scale-Caregiver)</p>	<p>(iv) At year 1, PWD improved on all scales, except MMSE and functional status measures. 314/543 (58%) of patients, 282/447 (63%) of caregivers, and 376/501 (75%) of patients or caregivers demonstrated clinical benefit on all scales. Male caregiver sex, higher baseline caregiver burden, and caring for patients with less baseline depression symptoms was associated with caregiver improvement.</p>	<p>Y</p>	<p>Y</p>	<p>Y</p>	<p>Y</p>	<p>Y</p>
<p>(v) Evertson et al., 2021 USA [16]</p>	<p>(v) Of 1,091 dyads enrolled in the ADC programme, 151 caregivers were identified as not benefitting, based on the PLWD and caregiver clinical outcomes at 1 year. Those who did not benefit were the focus of this paper/analysis.</p>	<p>(v) Mixed methods. The 151 caregivers were randomised, then purposefully sampled. 40 were randomly selected to be interviewed, and 12 (30%) agreed. 111 were surveyed and 41 (36%) responded.</p>	<p>(v) Explore why some participants of the ADC programme did not benefit from the programme to determine what could be changed in this and other similar dementia management programs to increase the percentage who benefit. Lack of benefit was defined by scores on validated measures of the person living with dementia's behavioural symptoms and caregiver strain, distress, and depression.</p>	<p>(v) Seven themes of potential reasons for lack of clinical benefit among dyads: behavioural interventions that were no longer effective, Location of services, costs, lack of respite care, & technology were barriers to accessing services. Other themes related to needing more intensive support or counselling than could be provided. Recommendations about safety, support groups, and adult day care, did not seem to fit the caregivers' perceived current needs/ inappropriate for the PLWD's stage of dementia. 85% of caregivers reported that the programme was beneficial despite not showing clinical benefit as participants had in paper by Reuben et al, (2020).</p>	<p>N</p>	<p>Y</p>	<p>Y</p>	<p>Y</p>	<p>Y</p>

Other clinic or day care-based studies

Barton et al., 2014 USA [17]	66 recipients of a USA specialist Nurse-Led Behavioural Management clinic where patients and caregivers were referred because of the patient's behavioural symptom and/or the caregiver was having difficulty coping with the behaviour(s). 1 Nurse Practitioner (NP) and 1 Clinical Nurse Specialist (CNS) for the caregiver.	Qualitative Service Evaluation undertaken by recipients of the nurse – led behaviour management clinic. Evaluations were completed 1 month after intervention: strategies, individualized education, and specific caregiver support by NP & CNS.	The aim of the project was to implement a Nurse- Led (advanced practice nurse (APN) and CNS) clinic to support the management of problematic dementia-related behaviours.	The most common reasons for referral to the clinic were centred around personal care, agitated and/or 'combative' behaviour, and caregiver stress. Evaluation findings suggested that referrers and the PWD caregiver found the clinic appointment was helpful in targeting and managing behavioural symptoms. Interventions were reported anecdotally by evaluation respondents, to be positive, however the specific data as to the effect of the intervention was not stated.	Y	N	N	N	N
Greenbank et al 2020 UK [8]	85/115 (74%) people living with dementia and family carers receiving support from one 1 Advanced Nurse Practitioner (ANP) in an NHS memory clinic were surveyed and responded	Mixed Methods Service evaluation: 16-item questionnaire/ survey over 8-month period in 2018. Questions to service users on their treatment by the ANP, decision-making ability, credibility, and overall satisfaction with the service they received.	To evaluate service user and carer satisfaction with the Advanced Nurse Practitioner (ANP) role within an NHS Trust Memory Service/team.	73.9% of surveys were completed (85/115). Patients expressed significant satisfaction with the ANP, particularly in the areas of direct clinical practice (84%) and quality of care received (87%). Patients and families reported high satisfaction levels with the service provided by the ANP.	Y	Y	Y	N	Y
Kim et al, 2021. Korea [22]	93 participants received expert nurse caregiver education group and 92 from caregiver 'no education' group.	Randomised control trial/study (RCT) with 1-year follow-up. Primary Endpoint: discontinuation rate of donepezil treatment. Secondary endpoint: the effect of education on compliance with donepezil treatment. Clinician rating scale (CRS) and visual analogue scale (VAS) were used to measure changes from baseline.	To assess the impact of a nurse-led education program for caregivers of newly diagnosed Alzheimer's disease patients who had been newly prescribed donepezil.	No significant difference on discontinuation of donepezil or adherence to treatment or compliance between caregiver education and non -education groups. The donepezil discontinuation rates at 1 year were 5.38% (5/93) and 6.52% (6/92) in the caregiver education and no-education groups, respectively ($p=0.742$). this may have been due to the low severity of cognitive impairment among the included population at baseline (Mean MMSE score of 21).	Y	Y	Y	N	Y

Rolfe & Phillips., 1997. UK [9]	Action research project with Advanced Nurse Practitioner (ANP) at a UK Day Hospital. 42 Health Care professionals (HCP) 16 carers and one patient were interviewed	Action research project over 18 months (3 phases): Phase 1: assessment of needs where 42 health care workers were interviewed., Phase 2: Process evaluation involving reflection and action of the ANP in post to refine the role, & Phase three: Role evaluation.: HCP from Phase 1 were sent questionnaires. 16 carers and one patient were also interviewed	To develop and refine a new role of Advanced Nurse Practitioner in dementia.	The authors/researchers cautioned that the findings were too specific to this group of individuals and therefore the results cannot be generalised to other settings. Reported benefits of the role included quick assessment, early intervention, easier accessibility, less bureaucracy, and noticeable service improvements	Y	Y	Y	Y	N
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TABLE 2b. Non-Admiral Nursing studies: Community settings including the person's own home

Study	Population, Setting, & Sample size	Study type	Aims of the study	Findings/ Outcome	Quality Rating Mixed Methods Assessment Tool Domains				
					1	2	3	4	5
Duane et al., 2015., Australia [24]	9 People over the age of 65 years, with a six-month history of cognitive and functional decline but no previous diagnosis of dementia and cognitive impairment in the absence of delirium. Carer and clinical nurse specialist. Setting not specified but implied to be community.	Qualitative – Evaluation, 12- month study period A range of Non-specified Interventions from the Clinical Nurse Consultant in Dementia.	-To evaluate the clinical nurse consultant (CNC) role with a speciality in dementia in relation to the provision of person-centred pre-diagnosis support in the community.	Themes derived from qualitative account suggests that the CNC model provided evidence of its benefit to people who are living with cognitive impairment and/or their carers, and families	Y	Y	Y	Y	Y
Fortinsky et al.,2014., USA [18]	21 dyads (people with dementia and their carer) received the Nurse Practitioner (NP) intervention, 10 dyads were controls. Setting: primary care practitioner sites in the community	Quantitative- 12- month study period. Measurement of intervention (NP- led care) outcomes were compared to the control group outcomes.	To test the value of employing a NP to augment Primary Care Practitioner care for new and recently diagnosed patients and their care givers	There were no statistically- significant between-group differences in any of the patient or family caregiver outcomes. (All values $p > 0.05$)	Y	Y	Y	Y	Y

(i) Huis in het Veld et al., 2019. [23]	81 family caregivers, 4 Specialist* Dementia Nurses. *(Bachelor's or master's degree in nursing and advanced training in dementia)	(i) Mixed methods process evaluation of online self-management support involving 3 arms of intervention (see RCT below)	(i) Process evaluation component of study of family caregivers' and nurses use of online self-management support, Ascertain (1) actual usage of online support by family caregivers (2) family caregivers' and (3) nurses' evaluation and satisfaction.	Variation was found in the extent that family caregivers made use of the various elements of the online self-management support. The distinction between the 3 intervention arms consequently becomes less, making it difficult to demonstrate effects.	Y	Y	Y	Y	Y
(ii) Huis in het Veld et al., 2020., Netherlands [28]		(ii) RCT 7- month period. Online self-management support provided to trial participants: Arm 1: email contact with a specialist Dementia Nurse, Arm 2: Online training video & Arm 3: e-bulletin. Measured at baseline and at 6 (T1) and 12 weeks (T2) after the baseline. A mixed-model analysis compared the outcomes of the 3 intervention arms.	(ii) To study the effects of an online self-management support intervention in helping family caregivers deal with behaviour changes of a relative with dementia. The intervention: personal email contacts with a dementia nurse compared with online interventions without email contact from the specialist nurse	(ii) 78% (21/27) family caregivers had email contact with the specialist nurse, 80% (43/54) of family caregivers clicked on an online video, 37% clicked on an e-bulletin. Caregivers showed positive evaluations and satisfaction. Family caregivers in the major intervention involving email contacts showed no statistically significant differences in self-efficacy after the intervention compared with the minor intervention involving only e-bulletins (difference -0.02, $P=.99$). After adjustments, the medium intervention (involving videos and e-bulletins) showed a negative trend overtime (difference -4.21, $P=.09$) and at T1 (difference -4.71, $P=.07$) compared with the minor intervention involving only e-bulletins. No statistical differences found in the reported behaviour problems and the quality of the caregiver/PWD relationship.	Y	Y	Y	Y	Y

TABLE 2c.: Non-Admiral Nursing studies: Inpatient and long-stay facilities

<u>Study</u>	<u>Population, Setting, & Sample size</u>	<u>Study type</u>	<u>Aims of the study</u>	<u>Findings/ Outcome</u>	<u>Quality Rating Mixed Methods Assessment Tool Domains</u>				
					1	2	3	4	5
Studies in inpatient settings									
Gilmore et al., 2021.USA [19]	40 people with dementia; 16 nurses & 5 nursing assistants in a general medicine hospital	Quantitative – 3- year study of a nurse-led prevention and management intervention for dementia related Behavioural Expressions (BE) The PROACTIVE treatment approach (Personalized Approach and Targeted Treatment Interventions). (N=40) between the years of 2017–2018 was compared to a historical matched comparison (N=40) who received care on the same unit prior to the first staff-wide training between the years of 2013 to 2016.	Design, implement and evaluate the feasibility, utility, and exploratory nurse & patient outcomes in relation to the PROACTIVE approach.	Patients receiving the PROACTIVE Treatment Approach (N = 40) had higher rates of acetaminophen use, and shorter lengths of stay (N = 40). Post – implementation the nursing staff and nursing assistants, reported greater confidence related to BE management compared to pre-implementation (16 nurses & 9 Nursing assistants)	Y	Y	Y	Y	Y
Handley et al., 2019 UK [11]	Two study sites, both general hospitals: Total of 66 participants were recruited to the study; 36 staff, 28 patients and 2 family members were recruited. which included 7 patients out of 19 with the capacity to consent and 21 out of 50 where a consultee process was used.	Quantitative- Nurse -led, 6 – month realist evaluation using context – mechanism-outcome configurations (CMOC) to observe care actions of staff across two sites (7-week study at each site) and patient outcomes from dementia care interventions. Interviews, non-participant observations, medical notes & document review, assessment of mood and behaviour using the Neuropsychiatric Inventory Questionnaire (NPI-Q). Data collection focused on the anticipated outcomes from the interventions.	Use the CMOC to test and evaluation dementia care intervention outcomes from two hospitals where each had different approaches to supporting patients with dementia. To explain the factors that support hospital staff to provide dementia sensitive care and with what outcomes for patients with dementia	Nurses in the study had difficulty defining their expertise, particularly where there were limited opportunities to differentiate their work from that of healthcare assistants'. Effective interactions reduced patient distress. Patients' experience of care was observed to be impacted by the value placed on dementia care by the ward, and whether this influenced how staff prioritised activities.	Y	Y	Y	Y	Y

Sampson 2011 UK [10]	PHASE ONE: Interviews with 20 carers of patients with severe dementia & 21 health professionals. PHASE TWO: 33 people with dementia and carers (22 intervention arm; 11 in the control arm). Hospital in -patient ward	Quantitative- 6- month study period Exploratory RCT. Qualitative data was used to design the intervention which was a nurse -led palliative care patient assessment which informed an Advanced Care Plan (ACP) discussion with the carer, Carer was offered the opportunity to write an ACP for the person with dementia. Outcome measures included the Kessler Distress Scale, Decision Satisfaction Inventory, Client Satisfaction Questionnaire and the Euroqol-5D, measured at baseline, 6 weeks, 6 months, and three months after bereavement.	To design and pilot a palliative care and advance care plan (ACP) intervention delivered by a senior nurse experienced in dementia & palliative care training	7/20 carers made ACPs. despite intensive support from the nurse specialist. The care planning discussion was well received. There were methodological challenges where the acute hospital environment made recruitment difficult.	Y	Y	N	Y	Y
Studies in care homes/ long term care settings									
Hirt et al., 2021 Switzerland [21]	6 dyads of nursing home managers and nursing experts from six nursing homes (n = 12).	Qualitative descriptive study using individual interviews of participant nurses and managers who work within long term care settings. Used qualitative vignettes as a useful stimulus to generate narrations to study peoples' perceptions and beliefs	To describe the opinions and experiences of nursing experts and managers working within long- term care settings to identify barriers and facilitators to the implementation of nurse-led interventions in long term dementia care.	Seven themes reflecting facilitators and barriers to implementing nurse-led interventions in long-term dementia care were identified: A common attitude and cohesion within the organization», Commitment on several levels is required: A needs-oriented implementation.	Y	Y	Y	Y	Y
Perry et al., 2005., Canada [20]	8 care home residents with dementia. Two nurse-facilitators.	Qualitative. Audio recordings were made of a social group conversation where the group was led by Nurses using Nurse-Led Conversational interventions. Two nurse-researchers met the group for 10 weeks with sessions lasting from 30-50 minutes. Recorded communications were analysed, coded, and defined.	To describe the communication strategies used by expert nurses in communicating with residents in long-term care facilities who have a diagnosis of advanced dementia. To assess the effectiveness of strategies that are used to support conversations in social settings with this client group.	6 types of interaction were identified: Discourse markers, limited engagement, expanded response, Personalised response. Self- Initiated participation, and disconnected participation. Findings demonstrate that people with advanced dementia can be effectively supported to interact in a social setting, with support from nurses who can employ specific conversational strategies.	Y	Y	Y	Y	Y

