Article:

Giebel, C. orcid.org/0000-0002-0746-0566, Reilly, S., Gabbay, M. et al. (5 more authors) (2023) Dementia care navigation: a systematic review on different service types and their prevalence. International Journal of Geriatric Psychiatry, 38 (8). e5977. ISSN 0885-6230

https://doi.org/10.1002/gps.5977

Received: 17 January 2023 | Accepted: 12 July 2023

DOI: 10.1002/gps.5977

REVIEW ARTICLE

International Journal of Geriatric Psychiatry WILEY

Dementia care navigation: A systematic review on different service types and their prevalence

Clarissa Giebel[1,2] | Siobhan Reilly[3] | Mark Gabbay[1,2] | Julie Dickinson[2] | Hilary Tetlow[2] | Hayley Hogan[4] | Alys Griffiths[1] | Claudia Cooper[5]

[1]Department of Primary Care & Mental Health, University of Liverpool, Liverpool, UK

[2]NIHR Applied Research Collaboration North West Coast, Liverpool, UK

[3]Centre for Applied Dementia Studies, University of Bradford, Bradford, UK

[4]Alzheimer's Society, London, UK

[5]Centre of Psychiatry and Mental Health, Wolfson Institute of Population Health, Queen Mary University London, London, UK

Correspondence
Clarissa Giebel, University of Liverpool, Liverpool, UK.
Email: Clarissa.giebel@liverpool.ac.uk

Funding information
National Institute for Health and Care Research

Abstract

Background: Dementia Care Navigators (DCNs) are professionals without clinical training, who provide individualised emotional and practical support to people living with dementia, working alongside clinical services. Navigator services have been implemented but the service offered vary without a consistent overview provided. The aim of this narrative systematic review was to describe and compare existing service formats, and to synthesise evidence regarding their implementation and impacts.

Methods: The review was registered on PROSPERO [CRD42021292518]. Three electronic databases were searched and included studies reported on a DCN service, defined as a service in which non-clinically trained workers provide personalised advice and support to people with dementia and/or carers in the community. Two independent reviewers screened abstracts and titles and read through full papers for inclusion. Risk of bias was assessed using the Standard Quality Assessment QualSyst.

Results: We included 14 papers reporting on six studies. All services were US-based and only varied by integration and training provided. Studies reported different degrees of impact on service utilisation and on symptoms and mental well-being of people with dementia and their carers, with too little evidence to draw substantial/meaningful conclusions and studies employing different outcome measures. One study evidenced greater impacts on people with more advanced dementia compared to earlier stages.

Conclusions: DCN services have the potential to effectively provide non-clinical support to people with dementia and carers from the point of diagnosis. Further research from countries other than the USA, focusing on the impact on social care and social support service access and utilisation, and utilising similar established outcome measures are required.

KEYWORDS
dementia, dementia care navigator, service access, social care

Key points

- Evidence on the impact of Dementia Care Navigators (DCNs) is limited but shows promising benefits for people living with dementia and their carers.
- More research needs to be conducted in countries other than the US, where all evidence was reported, and with similar outcome measures to allow comparison.
- DCNs are a highly useful professional group without medical training, who can navigate people living with dementia and their carers to support and provide support themselves.

1 | INTRODUCTION

Across the globe, 55 million people are living with dementia, with numbers constantly rising.[1] Whilst receiving a diagnosis can be full of obstacles,[2] there are many barriers to living well with dementia and living well caring for someone with the condition.

Post-diagnostic support includes sign-posting to care services, and/or day care centres, respite care, peer-support groups, social activities, paid home care, as well as befrienders. Accessing these services helps in maintaining a good quality of life and remaining independent for longer.[3] Many people with dementia and unpaid carers do not receive the care they need however, and face different barriers in accessing and utilising care.[4–6] These inequalities are underpinned by geographical location, socio-economic deprivation, ethnicity, gender, and education. Living in rural areas can often entail reduced service availability or lack of adequate transport to services[7]; and services may not be suitable to people from minority ethnic backgrounds.[4] Some services may not be subsidised, which may hinder people from lower socio-economic backgrounds from accessing these. There are additional barriers faced by those living alone, without a carer helping with identifying and reaching services, as well as facing the new digital format of many support services.[8,9] Even if people with dementia and carers would have the suitable means and lived nearby, they may struggle accessing services due to lack of awareness.[10]

Care navigation is one way in which people with dementia and unpaid carers can be linked up with suitable care and support in their locality. Dementia Care Navigators are non-clinical staff working either within a clinical or non-clinical infrastructure providing coordinated person-centred care and support for people living with dementia and unpaid carers from the moment of the dementia diagnosis. They may provide a single point of contact who is in regular contact with the person with the condition, and the unpaid carer if available, and signpost people to suitable care and support services within their locality. These care and support services may involve both health and social care services, the latter of which can include paid home care, respite care, day care centres, and support groups. Specifically, as outlined in a report by Health Education England,[11] the following sectors are signposted to and linked up with: voluntary sector, community services, informal support networks, social services, general practice, and hospitals. It may also be possible for people with dementia and carers to contact the DCN with specific queries.

The role of the DCN can sometimes be integrated within other roles, all subject to variations in terminology and task differences. Case management approaches to dementia care for example, as evidenced in a Cochrane systematic review,[12] is similar in that it takes place in the community, not in long-term care. It focuses on the planning and co-ordination of care however, which a DCN is not necessarily involved with—instead, a DCN can provide education and navigate people to services. In addition, case managers can be social workers or nurses for example, and thus can be clinically qualified, unlike DCNs. The limited evidence reported on showcased potential benefit of case management for dementia, although more evidence was required.[12] Other existing roles include Admiral Nurses in the UK, and through their definition already differ by involving clinically trained nurses. Admiral Nurses are a named, clinically qualified individual, who provides more in-depth support, for example, with behavioural symptoms, and have been found to be very effective in providing nursing-based dementia care.[13]

Dementia Care Navigators in England are not available in all areas, as recent evidence indicates.[14,15] Research from the USA highlights the different aspects of a care navigator role, including providing emotional support, tailoring education and resources, and working closely with the clinical team.[16,17] To date, there appears to be little published evidence on DCN services across England, except one report.[18] The report highlighted patient and staff satisfaction and increased signposting and access to care of the DCN service piloted in primary care settings in Gateshead and Halton. To date, one systematic review[19] has explored different system navigation programmes for dementia, albeit focusing solely on outcomes, specifically admissions to long-term care, and has not provided a comparison of different service formats and how these may influence different community-based outcomes (such as everyday functioning, well-being, and health and social care service utilisation).

Therefore, with a lack of an overview, comparison, and evaluation of existing published DCN services, the aim of this novel mixed-method systematic review was to explore existing DCN services, to provide learning for the implementation of DCNs across different regions and countries.

2 | METHOD

This systematic review has been registered on PROSPERO before formal searches were undertaken [Ref: CRD42021292518]. We undertook fact-finding discussions with a range of DCN services in several countries to define the scope and focus of the review and associated terms.

2.1 | Population

We defined care navigators as non-clinical staff working either within a clinical or non-clinical infrastructure providing person-centred care and support for people living with dementia and unpaid carers from the moment of the dementia diagnosis. This is a distinct role from case managers. They may provide a regular single point of contact with the person living with dementia, and the unpaid carer if available, and signpost people to suitable care and support services within their locality. These care and support services may involve both health and social care services, the latter can include paid home care, respite care, day care centres, and support groups. Specifically, as outlined in a report by Health Education England,[11] the following sectors are signposted to and linked up with: voluntary sector, community services, informal support networks, social services, General practice, and hospitals. It may also be possible for people with dementia and carers to also contact the care navigator when they have specific queries.

2.2 | Inclusion/exclusion criteria

This mixed-method systematic review focused on quantitative and qualitative studies exploring different DCN service formats and their implementation reach. We included studies evaluating DCN services, however they were termed. This was defined as (a) non-clinical staff (b) providing emotional/practical support for people with dementia and unpaid carers, (c) with people with dementia and carers able to contact them directly, and the (d) role including elements of signposting. Studies were included from any country, were published in English or German, were published since 2000, and were a peer-reviewed paper. Studies were excluded if the DCN described did not meet the definition outlined or care navigators worked with groups other than dementia, were published in languages other than English or German and before 2000, and were an editorial, letter to the editor or similar non-primary data and peer-reviewed article.

2.3 | Search criteria

Three databases (Pubmed, Scopus, Web of Science) were searched using the following syntax: “(dementia) AND ((care navigat*) OR (care coordinat*))”.

2.4 | Study selection

Once duplicates were removed, two research team members (CG, AG) screened all abstracts. Where there were discrepancies in judgement, the abstracts were discussed individually until agreement was obtained. After abstract screening, both researchers read through all full text articles of to be included citations. Similarly, where discrepancies arose, these were resolved in discussion.

2.5 | Data extraction and synthesis

The following data were extracted by one research team member (CG) into a table: country, study methodology (qualitative, quantitative), DCN service details, frequency of contact and intervention, population cared for (people with dementia and/or carers), outcomes. Data were synthesised and grouped into different categories to enable comparison between the services themselves, and their impacts on service utilisation and the population cared for (including well-being and behavioural outcomes), and synthesised narratively. Dementia Care Navigator service components included training, mode of contact (face-to-face or remote), frequency of contact, and individual or team-based.

2.6 | Assessment of study bias

We assessed the quality of each included paper. For quantitative and qualitative studies, we used the QualSyst,[20] which includes 14 items for quantitative studies, and 10 items for qualitative studies. For mixed-methods studies, we used the Mixed Methods Appraisal tool.[21] All included studies were assessed by two research team members (HH, CG) independently. Any discrepancies between ratings were discussed jointly, and first- and final-round inter-rater agreements were calculated. Quality ratings did not influence study selection, but were used in guiding the discussion of findings and drawing conclusions.

2.7 | Public and stakeholder involvement

Two unpaid dementia carers have been involved as team members and helped synthesising the evidence and interpreting them in the context of their real-life experiences of dementia care.

3 | RESULTS

3.1 | Overview of included studies

Originally, we found 3401 citations (see Figure 1 for PRISMA Flowchart). After duplicates were removed, we screened 2109 titles and abstracts. We screened 42 full texts and included a total of 14 papers reporting on six DCN services.[17,23–35] All DCN studies were conducted in states across the USA. Different methodological approaches were used in the 14 papers, including mixed-method process evaluation,[29] Randomised Controlled Trial,[32,33] matched pair intervention-control,[23] and cost-effectiveness analysis.[35]

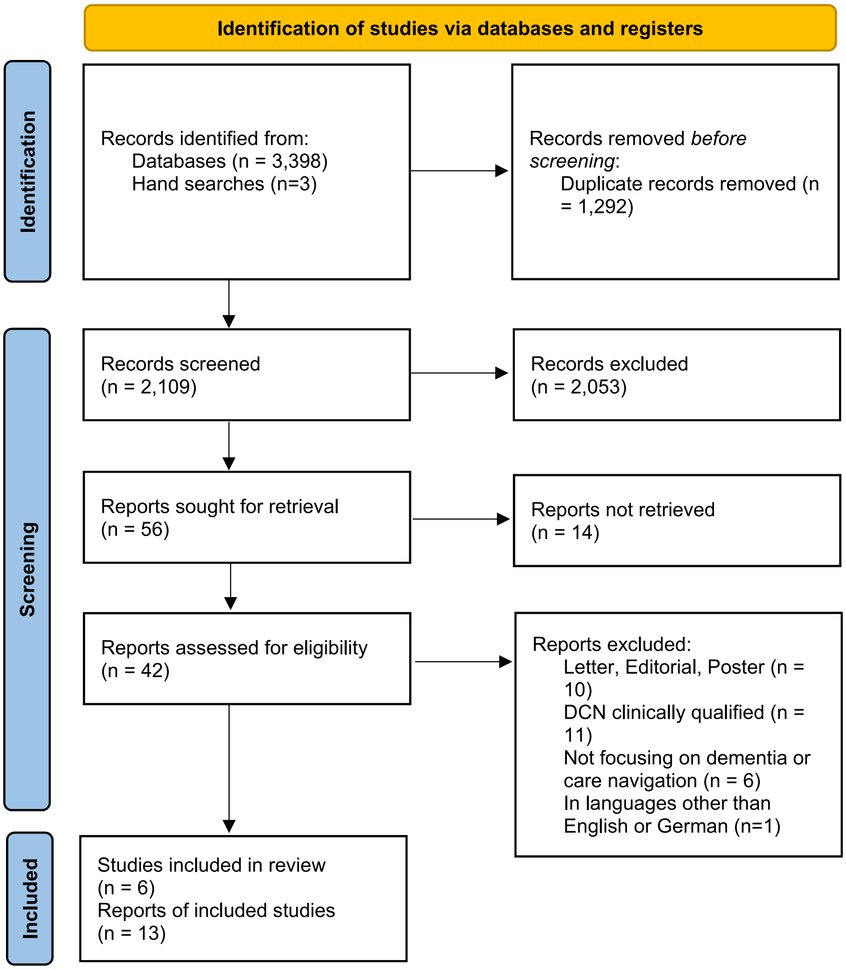

FIGURE 1 PRISMA Flowchart of study selection.[22]

Whilst some excluded studies did report on dementia care management, the care and navigation was provided by a nurse practitioner (i.e.[36]), and thus a clinically qualified person, as opposed to a non-clinically trained professional.

Studies reported on the following DCN services (also see Table 1 for more details): the telephone-based Care Ecosystem,[17,28,32–34] The Dementia Care Coordination Programme,[29] Maximising Independence at Home (MIND),[31,35] and Partners in Dementia Care for veterans with dementia and their family carers.[23–25] Studies also reported on a service for those from a Latin American background[26] and care coordinator assistants.[30] All service formats were similar in their approach and only varied to some degrees in terms of how care was delivered, whether the DCN was integrated into a wider team, the population group (some focused on ethnic minority dyads only).

Given the large number of papers reporting on the same DCN service, the following findings refer to a synthesis of each service, unless different papers reported varied results.

3.2 | Service delivery mode

Dementia Care Navigator services varied between providing in-person support only,[29] remote support only via telephone and/or email/post,[17] or a mixture.[23,30] Whilst Bass et al.[23] provided both remote and in-person support as part of their "Partners in Dementia" programme for veterans, the service was predominantly provided via telephone or email, with rare in-person meetings. There were no details as to whether the MIND DCN service[35] was provided in person only or has remote components of support as well. Some studies compared the effects of different types of service delivery.[26]

3.3 | Training and roles of the Dementia Care Navigators

The roles of the DCNs were very similar across the different services, also because they were part of the inclusion criteria and thus restricted to services run by non-clinical professionals, who did not require to have a degree or other professional qualification. Some studies noted the pre-requirements of DCNs, which were not academically focused, but concerning their interpersonal skills and/or experiences of working with people with dementia and unpaid carers. Dementia Care Navigators on the Care Ecosystem [32] for example, had to have strong communication skills, whilst Nowaskie et al.[30] outlined their DCNs (or care coordinator assistants) requiring to have core skills of caring and compassion as well as interpersonal and

TABLE 1 Characteristics of included studies.

Authors	Country	Study design	Date of intervention	DCN system	Team and roles	Intervention frequency and length	Recipients of care (n)	Outcomes
Bass et al.[23–25]	USA	Matched intervention and comparison site	*missing*	"Partners in dementia"	Care coordinators and assistants worked across health care and community sites. One half-time care coordinator and assistant based at veteran affairs site, and one half-time coordinator and assistant based at local Alzheimer's association site—both settings offering slightly different support (support with medical-related concerns vs. support with non-medical concerns). Initial assessment and action plan developed with veteran with dementia or dyad over first 4 weeks, with each person with dementia on average having 7 personal action steps.[23]	12 months	2013: 486 (6-month: 394; 12-month: 324) carers of veterans with dementia; 2014: 333 (6-month: 263; 12-month:194) veterans; 2015: 328 veterans	2013: Carer perception of unmet needs; carer strains, carer depression, support resources: Improvements across all measures after 6 months, more limited effects after 12 months. 2014: Reduced relationship strain, depression and unmet needs. 2015: Fewer hospital admissions and emergency department visits in treatment group veterans with more severe cognitive impairment and behavioural symptoms compared to comparison.
Bernstein et al.[17] Merrilees et al.[28] & Possin et al.[32,33] & Rosa et al.[34]	USA (California, Nebraska, Iowa)	Qualitative interviews and focus groups (Bernstein); mixed-methods (Merrilees); RCT[32,33]; cost-analysis (Rosa)	20/03/2015-28/02/2017	"The care ecosystem"	Care team included: Navigators, advanced practice nurses, a social worker, a pharmacist. Care team navigators unlicensed (not medically qualified) are single point of contact.	Monthly remote contacts for up to 1 year	Bernstein: 10 navigators; Merrilees: 3 case studies, but n (interviews and focus groups missing); Possin 2017 & 2019: 780 people with dementia and 780 carers;	Bernstein: Identifying care navigator approaches to address carer burden Merrilees: Improved self-efficacy but limited to 3 case studies; Possin (2019): Improved quality of life, reduced carer depression and

(Continues)

TABLE 1 (Continued)

Authors	Country	Study design	Date of intervention	DCN system	Team and roles	Intervention frequency and length	Recipients of care (n)	Outcomes
					Remote care for carer support, education, medications, advance care planning, behaviour symptom management		Rosa: 464 people with dementia	burden, reduced emergency department visits; Rosa: Reduced costs per participant per month ($75-$92)
Chodosh et al.[26]	USA (California)	Pre-post assessment (but only analysed for method of care delivery variations at each time point)	2007–2009	Dementia care management	Navigators were social workers with previous experience in Spanish-speaking populations. In-person home/community visits plus telephone and mail versus remote telephone and mail only. Navigators worked with the caregiver to prioritise problems, identify counselling and educational needs, and provide referrals.	12 months: Monthly contacts in the first 3 months; quarterly contacts thereafter	144 patient-caregiver dyads	Care quality improved regardless of which intervention; Caregiver burden, behavioural problems, retention, and health care utilisation did not differ between intervention arms with in-person arm costing more.
Nadash et al.[29]	USA (Massachusetts)	Mixed-methods process evaluation	Jun 2014 to May 2015	"The dementia care coordination programme"	Navigators were two full-time care consultants who provided education, symptom management strategies, advanced care planning, emotional support, and referral to community services.	Interviews and two surveys	14 interviews (9 staff and administrators, 6 referring health care providers); Survey 1 to 15 health care providers; Survey 2 o 136 unpaid carers	High stakeholder satisfaction

TABLE 1 (Continued)

Authors	Country	Study design	Date of intervention	DCN system	Team and roles	Intervention frequency and length	Recipients of care (n)	Outcomes
Cottingham et al.[27]; Nowaskie et al.[30]	USA	Case reports	*Missing*	Care coordination assistants	Care coordinator assistants supervised by a registered nurse and social worker; Person-centred approach with home visits and telephone consultations; Need to have core empathy, caring, and compassion skills;	No maximum length	People with dementia and unpaid carers, with study focusing on 119 quarterly case reports provided by 16 navigators.	Study outcome: DCN job satisfaction
Samus et al.[31]; Wilink et al.[35]	USA (Maryland)	Pre-post assessments	Enrolment between Mar 2015 and Oct 2016	"Maximising independence at home (MIND)"	Trained, non-clinical community workers with excellent communication and interpersonal skills, supported by multidisciplinary team (nurses, physicians including geriatric psychiatrists, occupational therapists); Traditional care management process (comprehensive assessment, individualised care planning, care plan implementation, monitoring impact, reassessment and revisiting care plan) for 13 broad care needs plus education, skills coaching, emotional support. At least one contact per month.	18 months	342 people with dementia and carers (medicare-medicaid dual beneficiaries vs. medicare-only beneficiaries)	Slower growth in inpatient and nursing home placement 5-year medicaid savings from MIND estimated at $7052 per person, a 1.12-fold return on investment

analytical skills. In Chodosh et al.'s[26] service, DCNs needed to be bilingual in English and Spanish, as the service was particularly targeted at people with dementia and carers from a Latin American background.

All services provided special training to the DCNs, including elements of communication skills, dementia care, and general skill building. Most services provided ongoing training and supervision, with some services providing weekly case study discussions (i.e., Care ecosystem;[35]) and supervision by nurses and social workers (i.e.[30]). In some services, DCNs were integrated into multi-disciplinary teams, so that complex issues could be discussed and fed back to the service users.[32,35]

As part of their role, DCNs met regularly with people with dementia and their carers to support them accessing services and provide general dementia education. The MIND in Dementia (MIND) service for example, provided four core elements[35]: needs assessment and care plan development, dementia education and skill building strategies, coordination, referral to services, care monitoring. The DCN roles of the Partners in Dementia service for veterans[23–25] were split between one DCN providing medical advice, such as with medication, and one DCN providing non-medical advice to access services and deal with dementia symptoms. Some services reported on conducting initial needs assessments, which were revisited half-way through or at the end.[26,35]

3.4 | Impact of care navigators on service access

Reports on the effects of DCN services on service access (including both health and social care) were primarily focusing on health care utilisation (five studies), with a more limited focus on some types of social support services. The veteran-specific service, Partners in Dementia Care,[23] showed decreases in hospital admissions and emergency department visits among those veterans with greater cognitive symptoms at 6 months (more advanced dementia), and those with more behavioural symptoms at baseline and 6 months. However, no significant association was reported. By contrast, Possin et al.[33] utilised a randomised control trial approach and showed significant reductions in emergency department visits for people with dementia who had accessed the DCN service, compared to those receiving usual care.

Chodosh et al.[26] evidenced no difference in impact of their service for Latin American people with dementia and unpaid carers on health care utilisation when comparing telephone only versus telephone and in-person care delivery. The authors solely compared differences at baseline, 6-month, and 12-month follow-ups, neglecting to compare baseline with follow-up data. According to the data evidenced in their paper, there appear to be reductions in carer burden over the study period for both methods—however, the authors fail to run suitable statistical tests on this, thus not allowing any conclusions to be drawn on the efficacy of their service. By contrast, the MIND DCN service[35] noted reduced spending (as noted via MediCaid) and spending redistributed to in-home services as opposed to inpatient and institutional long-term care services (first paper). In addition, the authors also noted a delay in time to transitions from home.[31]

3.5 | Impact of care navigators on people with dementia and unpaid carers

The included DCN services reported impacts on various outcomes, including quality of life, carer burden, depression, carer self-efficacy, unmet needs, and financial planning. Five similar DCN services focused on different impacts on the person living with dementia and their unpaid carer. Using a qualitative and quantitative approach, the Care Ecosystem model was explored for its impact on carer outcomes, including quality of life, carer burden and depression, and carer self-efficacy.[17,28,33] DCNs used strategies to reduce carer burden, by reducing carer guilt and frustration, trying to reduce carer depression, improving the dyadic relationship, and identifying strategies to support behaviours in people with dementia.[17] In addition, Merrilees et al.[28] reported three different categories of DCN approaches to address and improve carer self-efficacy: emotional, informational, and instrumental. These included activities such as psychosocial support (emotional), providing educational materials to communicate better with the person with dementia (informational), and identifying support groups and subsidised application pack for local nursing home (instrumental). Whilst these three different categories of approaches were considered beneficial in increasing carer self-efficacy, findings were based on three case studies, and thus three dyads of a person with dementia and their carer, only. This limits the representativeness of the findings, and is in contrast to their statements in the abstract that they conducted interviews and focus groups, whilst no sample size is provided. However, Possin et al.'s[33] randomized control trial involving 780 dyads showed significant improvements in quality of life and reductions in carer burden and depression by accessing a remote (telephone or online) DCN service for 12 months, and provides more rigorous data on the potential impacts of a DCN service.

Other evaluations of DCN service also showed positive impacts. The Dementia Care Coordination Programme was linked to reduced levels of carer burden and better financial planning. The MIND service was shown to improve self-reported quality of life, albeit no significant associations with changes in proxy-rated quality of life, neuropsychiatric symptoms, or depression.[31] When compared with usual care for veterans, the Partners in Dementia Care programme reported reduced depression, unmet needs, and relationship strains after 6 months compared to usual care. However, Bass et al.[24] compared the service with other sites as opposed to within sites as controls, thereby limiting the comparison. Focusing on carer outcomes, Bass et al.[24] reported reduced unmet needs and levels of depression, as well as two support resources easier accessed as a result of the DCN service. The authors failed to distinguish between the types of unmet needs explored (which included understanding dementia, daily living tasks, accessing veteran affairs and other services, legal and financial issues, organising family care, alternative living arrangements, emotional support, medications), making it unclear where the effects where noted. Some of those outcomes improved for all carers, whereas others only improved for those caring for someone with severe dementia. No other study has focused on the severity of dementia, so it is not possible to draw comparisons between the effects of DCN services based on severity.

Whilst some of those services reported no effects for some outcomes, or for different levels of dementia severity only, Chodosh et al.'s[26] intervention for people with dementia and carers from a Latin American Spanish-speaking background was not found to be effective. Compared to no intervention receipt, no differences were noted in carer burden or problem behaviour. One service type did not evaluate the impact of the service on people living with dementia or their unpaid carers, but focused on job satisfaction and team work[30] instead.

In summary, there is mixed evidence on the effectiveness of DCN services for people with dementia and their carers, albeit a number of studies indicating sizeable benefits to the population. Given the variation in methods, populations, and outcome measures, it was difficult to compare studies and their reported impacts.

3.6 | Quality assessments

Quality ratings for quantitative ($n = 7$), qualitative ($n = 2$) and mixed-methods studies ($n = 3$) are shown in Table 2, with inter-rater agreements (HH, CG) shown in Table 3. Samus et al.[31] is a protocol paper and was thus not rated. There was full inter-rater agreement for the few items on the mixed-methods studies. Quality overall was generally evaluated as good, although some quantitative studies had not included confounding variables in their analysis, whilst some were missing sufficient detail on study design and clearly stated aims.

4 | DISCUSSION

This systematic review is the first to compare existing published DCN services of non-clinically qualified professionals providing care navigation to people with dementia and their carers, and synthesises the evidence on different outcomes of dementia and service utilisation. Findings therefore advance a recent review[19] which focused solely on different outcomes and did not provide a framework for how effective DCN services are structured and run. This review provides novel insights into the different formats of DCN services, training requirements, engagement levels and formats that are currently reported on, and the fact that only DCN services in the US are published.

Despite the abundance of slightly different DCN service types, in one country alone, there seem to be clear components for each DCN, in addition to the definition used for study inclusion. Considering that all service types involved specific training for the DCNs, the overarching components of the services—including the role, setting, integration into existing care services, and service delivery components—could be adapted and modified, alongside the training, to different country settings. Considering findings from a recent Clinical Commissioning Group survey in England about care navigation[37] for example, which reported over 75 different titles for care navigation for adults aged 18+, it is perhaps less surprising that this review only identified US-based DCN services. Findings by Tierney et al.[37] suggest that there are further ongoing DCN services in England which have not been reported on in detail to date. Future research thus needs to evaluate existing DCN services in other countries outside the US, to allow a full realist evaluation across countries to assess what works, for whom, and how.

Whilst different DCN services were reported on from various angles, overall, there was limited evidence on the impact on service access. Specifically, evidence only showed some reductions in health care utilisation, including reduced hospital admissions and reduced healthcare costs, and some spending redistributions to in-home services compared to institutional long-term care and non-significant reductions in caregiving services. This limited evidence on delays to long-term care entry adds to literature on the link between for example, day care centre use and delays in long-term care entry.[38] However, evidence lacks long-term and adequately powered studies to provide an understanding of the link between community-based social care usage and long-term care, whilst the benefits of community-based social care availability on reduced health care utilisation has been evidenced.[39] Improving service access via DCN services also requires the DCNs to be well integrated into existing health and social care systems. This involves the General Practitioner or other medical professional delivering the dementia diagnosis to refer the person with dementia and their carer to the DCN service, and for services themselves to be integrated well to social care and support to refer to. Future DCN evaluations need to explore the impact on care utilisation to a greater degree than currently done to fill this gap in the literature, with early evidence from the USA providing indications of the potential success of DCNs.

These findings need to be considered in the context of a very specific healthcare funding system in the USA though, which varies greatly compared to other countries. The USA experiences growing inequalities in terms of health care access and usage, and related outcomes.[40] Included studies were not always specific on how the DCN services were funded and accessed, whilst one study in particular highlighted access to Medicaid recipients.[31,35] Medicaid is a Government-run, state-dependent support for health coverage for people in need, including eligible low-income earners, pregnant women, and older adults. Given the non-universal health coverage in the USA, some studies will have recruited participants who were able to afford health coverage and were thus eligible to receive a DCN. This already biases the representativeness of the sample, as in Germany or England for example, every resident is required to have health insurance, either via an insurance provider selected themselves (Germany) or via a national health service (England). Thus, in other countries with universal health coverage, every person with

TABLE 2 Quality ratings for quantitative, qualitative, and mixed-methods studies.

QualSyst—Quantitative studies

Item	Wilink	Rosa	Possin 2019	Chodosh	Bass 2013	Bass 2014	Bass 2015
Question/Objective	2	2	2	1	2	1	0
Study design	2	2	2	1	2	2	2
Methods of subject comparison	2	1	2	2	2	2	2
Subject and comparison group characteristics	2	1	2	2	2	2	2
Random allocation	0	2	2	2	2	2	2
Blinding of investigators	N/A	N/A	N/A	2	N/A	N/A	N/A
Blinding of subjects	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Outcomes well defined	2	2	2	2	2	2	2
Sample size appropriate	2	2	1	2	2	2	2
Analytic methods described	2	2	2	2	2	2	2
Estimate variance	2	2	2	2	2	2	2
Controlled for confounding	1	2	2	2	2	0	1
Results reported sufficiently	2	2	2	2	2	2	2
Conclusions supported by results	2	2	2	2	2	2	2

QualSyst—Qualitative studies

Item	Bernstein	Merrilees
Question/Objective	2	2
Study design	2	2
Context clear	2	2
Connection to theory	2	2
Sampling strategy	1	0
Data collection methods	2	1
Data analysis	2	1
Verification procedures	2	0
Conclusions supported by results	2	1
Reflexivity of account	1	1

Mixed methods appraisal tool - mixed methods studies

Item	Nadash	Nowaskie	Possin 2017
Adequate rationale	Yes	Yes	Yes
Research question	Yes	Yes	Yes
Outputs adequately interpreted	Yes	Yes	Yes
Divergences and inconsistencies addressed	Yes	Yes	Yes
Quality criteria	Yes	Yes	Yes

Note: This table shows the final agreed ratings. Details of inter-rater agreements are provided in Table 3. For the Qual Syst, the following ratings are used: (2) Yes; (1) Partial; (0) No; (N/A).

dementia would have been eligible to receive a DCN, regardless of their financial background.

In addition to service access, DCN services also reported various impacts on people living with dementia and their carers, including quality of life, carer self-efficacy, reduced unmet needs, and improved finance management. Whilst these findings are promising, studies were too varied in their outcome measures and foci to reliably state that DCNs impact on these areas, with Possin et al.'s[33] randomised controlled trial involving 780 dyads providing the strongest evidence on the efficacy of (remote) DCN support on quality of life, carer

TABLE 3 Inter-rater agreements for first and second round of ratings for quantitative and qualitative papers.

Item	Inter-rater agreement round 1 (%)	Inter-rater agreement round 2 (%)
Quantitative papers (n = 7)		
1	37.5	100
2	75	100
3	100	100
4	100	100
5	100	100
6	87.5	100
7	87.5	100
8	87.5	100
9	75	100
10	100	100
11	75	100
12	50	100
13	100	100
14	100	100
Qualitative papers (n = 2)		
Item		
1	100%	100%
2	100%	100%
3	100%	100%
4	100%	100%
5	50%	100%
6	50%	100%
7	50%	100%
8	100%	100%
9	50%	100%
10	100%	100%
Mixed-methods papers (n = 3)		
Item		
1	100%	
2	100%	
3	100%	
4	100%	
5	100%	

depression and burden. The evidence is promising and in line with existing research showcasing the positive impact of accessing social support services on the population group.[3,5,41] DCNs therefore appear to be beneficial to the lives of people with dementia and their carers, although more evidence needs to be collected on similar outcome measures, such as on quality of life, cognitive and everyday functioning, as well as behavioural symptomatology and mental well-being, to provide clearer conclusions on the service impacts.

There were some limitations to the review and to the evidence that need to be considered. The term DCN is predominantly used in England, albeit no published research exists as this systematic review shows. Therefore, different role descriptions were used with some of them meeting the DCN definition, whilst others were excluded as the professional was clinically trained or provided case management as opposed to care navigation (i.e.[42]). In addition, we searched three data bases and did not include grey literature.

Considering the included evidence, research only emerged from the USA, despite known similar programmes in other countries, such as England and the Netherlands.[5] The referred to cross-country comparison was not part of this review as it did not look at the effectiveness of a single DCN programme, but instead reported on how DCNs were perceived to be facilitators to social support services in the Netherlands, whilst sporadically provided and accessed in England. Future research thus needs to evaluate the effects of DCN services in other countries, with other health care systems, and with established valid and reliable outcome measures, such as on quality of life, cognition, everyday functioning, behavioural symptomatology, and carer well-being and burden, to ensure that the promising albeit limited findings from the USA are not country-specific and globally applicable. The lack of similar outcome measures across the studies was a notable limitation in drawing strong conclusions as to the efficacy of DCN services. Moreover, there was little evidence on the impact on social care and social support service utilisation, which is one of the key foci of the DCN role.

5 | CONCLUSIONS

There is limited published evidence into the existence and impacts of DCNs on the lives of people with dementia and their carers, including access to dementia-related health and social care. Current evidence is restricted to the USA and provides some mixed, albeit promising, evidence into the positive impacts on people affected by dementia, including improved quality of life, reduced carer burden, and reduced emergency department visits and delayed long-term care entry. Dementia Care Navigators therefore could provide a potentially cost-effective, non-clinically trained, avenue to improving the lives of people with dementia and their carers, and improve access to care. Dementia Care Navigators have the potential to address the severe inequalities in access to post-diagnostic care, as outlined in recent national from the UK Alzheimer's Society[43] and international reports from Alzheimer's Disease International,[1] and in times of a cost of living crisis and reduced social care funding for the most vulnerable in our Societies, can provide a valuable solution to tackling inequalities.

ACKNOWLEDGEMENTS

This is independent research funded by the National Institute for Health Research Applied Research Collaboration North West Coast. The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health Research or the Department of Health and Social Care.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Clarissa Giebel https://orcid.org/0000-0002-0746-0566

REFERENCES

1. Alzheimer Disease International (ADI). *World Alzheimer Report 2022 - Life after Diagnosis: Navigating Treatment, Care and Support*. England; 2022.
2. Parker M, Barlow S, Hoe J, Aitken L. Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia. *Int Psychogeriatri*. 2020;32(5):611-634. https://doi.org/10.1017/s1041610219002229
3. Samsi K, Cole L, Orellana K, Manthorpe J. Is it worth it? Carers' views and expectations of residential respite for people living with dementia during and beyond the COVID-19 pandemic. *IJGP*. 2022;37(2). https://doi.org/10.1002/gps.5680
4. Parveen S, Peltier C, Oyebode JR. Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise. *Health Soc Care Comm*. 2017;25(2):734-742. https://doi.org/10.1111/hsc.12363
5. Giebel C, Lord K, Cooper C, et al. A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers. *IJGP*. 2021;36(3):393-402. https://doi.org/10.1002/gps.5434
6. Watson J, Giebel C, Green M, Darlington-Pollock F, Akpan A. Use of routine and cohort data globally in exploring dementia care pathways and inequalities: a systematic review. *Int J Geriatr Psychiatr*. 2021;36(2):252-270. https://doi.org/10.1002/gps.5419
7. Bauer M, Fetherstonhaugh D, Blackberry I, Farmer J, Wilding C. Identifying support needs to improve rural dementia services for people with dementia and their carers: a consultation study in Victoria, Australia. *Aust J Rural Health*. 2019;27(1):22-27. https://doi.org/10.1111/ajr.12444
8. Chirico I, Giebel C, Lion K, et al. Use of technology by people with dementia and informal carers during the COVID-19 pandemic: a cross-country comparison. *Int J Geriatr Psychiatr*. 2022;37(9). https://doi.org/10.1002/gps.5801
9. Giebel C, Hanna K, Callaghan S, et al. Navigating the new normal: accessing community and institutionalised care for dementia during COVID-19. *Aging Ment Health*. 2022;26(5):905-910. https://doi.org/10.1080/13607863.2021.1914545
10. Nielsen TR, Nielsen DS, Waldemar G. Barriers in access to dementia care in minority ethnic groups in Denmark: a qualitative study. *Aging Ment Health*. 2021;25(8):1424-1432. https://doi.org/10.1080/13607863.2020.1787336
11. Health Education England. *Care Navigation: A Competency Framework*. Health Education England; 2016.
12. Reilly S, Miranda-Castillo C, Malouf R, et al. Case management approaches to home support for people with dementia. *Cochrane Database Syst Rev*. 2015. https://doi.org/10.1002/14651858.CD008345.pub2
13. Moore KJ, Crawley S, Cooper C, Sampson EL, Harrison-Denning K. How do Admiral Nurses and care home staff help people living with dementia and their family carers prepare for end-of-life? *IJGP*. 2020;35(4):405-413. https://doi.org/10.1002/gps.5256
14. Giebel C, Robertson S, Beaulen A, Zwakhalen S, Allen D, Verbeek H. Nobody knows where to even turn to": barriers in accessing and utilising dementia care services in England and The Netherlands. *Int J Environ Res Publ Health*. 2021;18(22):12233. https://doi.org/10.3390/ijerph182212233
15. Giebel C, Sutcliffe C, Darlington-Pollock F, et al. Health inequities in the care pathways for people living with young- and late-onset dementia: from pre-COVID-19 to early pandemic. *Int J Environ Res Publ Health*. 2021;18(2):686. https://doi.org/10.3390/ijerph18020686
16. Bernstein A, Harrison KL, Dulaney S, et al. The role of care navigators working with people with dementia and their caregivers. *J Alzheim Dis*. 2019;71(1):45-55. https://doi.org/10.3233/jad-180957
17. Bernstein A, Merrilees J, Dulaney S, et al. Using care navigation to address caregiver burden in dementia: a qualitative case study analysis. *Alzheimer's Dement*. 2020;6(1):e12010. https://doi.org/10.1002/trc2.12010
18. Deloitte. *The Primary Care Navigator Programme for Dementia: Benefits of Alternative Working Models*. Deloitte; 2017.
19. Kokorelias KM, Shiers-Hanley JE, Zoe L, Hitzig SL. A systematic review on navigation programs for persons living with dementia and their caregivers. *Gerontologist*. 2022. https://doi.org/10.1093/geront/gnac054
20. Kmet LM, Lee RC, Cook LS. *Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields*. Vol 13. Health Technology Assessment Initiative; 2004.
21. Hong QN, Pluye P, Fabregues S, et al. *Mixed Methods Appraisal Tool (MMAT)*. Canadian Intellectual Property Office; 2018.
22. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*. 2021;372:n71. https://doi.org/10.1136/bmj.n71
23. Bass DM, Judge KS, Snow AL, et al. Caregiver outcomes of partners in dementia care: effect of a care coordination program for veterans with dementia and their family members and friends. *J Am Geriatr Soc*. 2013;61(8):1377-1386. https://doi.org/10.1111/jgs.12362
24. Bass DM, Judge KS, Snow AL, et al. A controlled trial of Partners in Dementia Care: veteran outcomes after six and twelve months. *Alzheimer's Res & Ther*. 2014;6(1):9. https://doi.org/10.1186/alzrt242
25. Bass DM, Judge KS, Maslow K, et al. Impact of the care coordination program "Partners in Dementia Care" on veterans' hospital admissions and emergency department visits. *Alzheimer's Dement*. 2015;1:13-22. https://doi.org/10.1016/j.trci.2015.03.003
26. Chodosh J, Colaiaco BA, Connor KI, et al. Dementia care management in an underserved community: the comparative effectiveness of two different approaches. *J Aging Health*. 2015;27(5):864-893. https://doi.org/10.1177/0898264315569454
27. Cottingham AH, Alder C, Guerriero Austrom M, Johnson CS, Boustani MA, Litzelman DK. New workforce development in dementia care: screening for "caring": preliminary data. *J Am Geriatr Soc*. 2014;62(7):1364-1368. https://doi.org/10.1111/jgs.12886
28. Merrilees JJ, Bernstein A, Dulaney S, et al. The Care Ecosystem: promoting self-efficacy among dementia family caregivers. *Dementia*. 2020;19(6):1955-1973. https://doi.org/10.1177/1471301218814121
29. Nadash P, Silverstein NM, Porell F. The dementia care coordination program: engaging health systems in caregiver supports. *Dementia*. 2019;18(4):1273-1285. https://doi.org/10.1177/1471301217697466
30. Nowaskie D, Carvell CA, Alder CA, et al. Care coordinator assistants: job satisfaction and the importance of teamwork in delivering

person-centered dementia care. *Dementia*. 2020;19(5):1560-1572. https://doi.org/10.1177/1471301218802739

31. Samus QM, Davis K, Willink A, et al. Comprehensive home-based care coordination for vulnerable elders with dementia: maximizing Independence at Home-Plus - study protocol. *Int J Care Coord*. 2017; 20(4):123-134. https://doi.org/10.1177/2053434517744071
32. Possin KL, Merrilees J, Bonasera SJ, et al. Development of an adaptive, personalized, and scalable dementia care program: early findings from the Care Ecosystem. *PLoS Med*. 2017;14(3):e100226. https://doi.org/10.1371/journal.pmed.1002260
33. Possin KL, Merrilees JJ, Dulaney S, et al. Effect of collaborative dementia care via telephone and internet on quality of life, caregiver well-being, and health care use. *JAMA Intern Med*. 2019;179(12): 1658. https://doi.org/10.1001/jamainternmed.2019.4101
34. Rosa TD, Possin KL, Bernstein A, et al. Variations in costs of a collaborative care model for dementia. *J Am Geriatr Soc*. 2019; 67(12):2628-2633. https://doi.org/10.1111/jgs.16076
35. Willink A, Davis K, Johnston DM, et al. Cost-effective care coordination for people with dementia at home. *Innov Aging*. 2020;4(2):1-9. https://doi.org/10.1093/geroni/igz051
36. Reuben DB, Evertson L, Wenger NS, et al. The University of California at Los Angeles Alzheimer's and dementia Care Program for comprehensive, coordinated, patient-centered care: preliminary data. *J Am Geriatr Soc*. 2013;61(12):2214-2218. https://doi.org/10.1111/jgs.12562
37. Tierney S, Wong G, Mahtani KR. Current understanding and implementation of 'care navigation' across England: a cross-sectional study of NHS clinical commissioning groups. *Br J Gen Pract*. 2019; 69(687):e675-e681. https://doi.org/10.3399/bjgp19x705569
38. Rokstad AMM, Engedal K, Kirkevold O, Benth JS, Selbaek G. The impact of attending day care designed for home-dwelling people with dementia on nursing home admission: a 24-month controlled study. *BMC Health Serv Res*. 2018;18(1):864. https://doi.org/10.1186/s12913-018-3686-5
39. Allan S, Roland D, Malisauskaite G, et al. The influence of home care supply on delayed discharges from hospital in England. *BMC Health Serv Res*. 2021;21(1):1297. https://doi.org/10.1186/s12913-021-07206-5
40. Dickman SL, Himmelstein DU, Woolhandler S. Inequality and the health-care system in the USA. *LANCET (N AM ED)*. 2017;389(10077): 1431-1441. https://doi.org/10.1016/s0140-6736(17)30398-7
41. Orellana K, Manthorpe J, Tinker A. Day centres for older people: a systematically conducted scoping review of literature about their benefits, purposes and how they are perceived. *Ageing Soc*. 2020; 40(1):73-104. https://doi.org/10.1017/s0144686x18000843
42. Duru OK, Ettner SL, Vassar SD, et al. Cost evaluation of a coordinated care management intervention for dementia. *Am J Manag Care*. 2009;15(8):521-528.
43. Alzheimer's Society. *Left to Cope Alone: The Unmet Support Needs after a Dementia Diagnosis*. Alzheimer's Society; 2022.

How to cite this article: Giebel C., Reilly S., Gabbay M., et al. Dementia care navigation: a systematic review on different service types and their prevalence. *Int J Geriatr Psychiatry*. 2023;e5977. https://doi.org/10.1002/gps.5977