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Review Article

Care Planning for Community-Dwelling People with Dementia: A Systematic Scoping Review

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People with dementia and their care partners report a lack of support, treatment, and information, fragmented services, and a lack of inclusion in decisions about their care. Care planning may address these issues; however, there is scarce literature on the process or benefits of care planning for people with dementia. This review describes the literature on care planning for community-dwelling people with dementia and their care partners. A systematic scoping methodology was followed to identify the research questions, identify relevant documents, select relevant documents, chart the data, and collate, summarise, and report the results. 31 full-text documents published between 2010 and May 2020 were identified and reviewed. Seven were guidelines, seven were expert opinion pieces, 11 were intervention studies, and six were descriptive studies. The topics and process of care planning varied depending on the service context (e.g., memory clinic, home care, and primary care). Care planning was presented as a component of case management in 15 papers. Six of the 11 intervention studies reported positive outcomes, one showed no improvement, and one did not evaluate outcomes for people with dementia or their care partners. Of the six with positive outcomes, four evaluated care planning in the context of care management. There is limited evidence that care planning alone improves outcomes for people with dementia and their care partners. It is unclear whether it may have benefits when combined with care management.

1. Introduction

Care planning is the process by which professionals and care recipients discuss, agree, and review an action plan to achieve the goals or behaviour change of most relevance and concern to the recipient, and a care plan is the written document produced through the care planning process [1]. The UK's National Institute for Health and Care Excellence (NICE) guideline on supporting people with dementia and their care partners in health and social care (National Collaborating Centre for Mental Health [2], Australian Clinical Dementia Guidelines [3], Scotland's National Dementia Strategy 2017–2020 [4], and the Dementia Strategy for Canada all recommend that a care or support plan be developed for every person with dementia [5]. Care planning is intended to improve outcomes for patients/care recipients in health and social care by facilitating participation and shared decision-making, supporting self-management, behaviour change, and coordinating treatments [1].

The care planning process should be a multidisciplinary, solution and action-focused collaboration, including goal setting discussion with the person at the centre of the care plan and, if relevant, their care partner, based on their current and/or future needs and wishes [6]. Care planning is an integral part of case management and care coordination [7, 8] as well as chronic disease management [9]. Crucial components of care planning are defining and aligning medical care and treatment with patient goals, optimising the management of chronic disease, and a centralised single record of care [10].

There is mixed evidence for the benefits of care planning in different populations. A Cochrane systematic review of 19 studies (pooled $n = 10{,}856$) found that personalised care planning for adults with long-term health conditions results in small improvements in physical and psychological health along with people's capability to self-manage their condition compared to usual care and that the impact is greater when the intervention is more comprehensive, more intensive, and better integrated into routine care [6]. However, this review did not include people living with dementia. Reviews in other patient groups reported less positive results. A systematic review and meta-analysis of survivorship care plans for people in cancer remission suggests that care plans do not improve survivors' patient-reported outcomes [11]. A systematic review of integrated care interventions for frail older people, of which shared care plans were a key component in combination with case management, reported that most studies did not improve daily function, health, or quality of life [12]. We did not identify any literature reviews on whether there are benefits to care planning for people with dementia.

People with dementia and care partners have reported that they do not receive sufficient support, treatment, and information around diagnosis [13, 14] and find service systems fragmented and difficult to navigate [15]. These issues partly arise from the lack of integration and coordination between health and social care services [16, 17]. In addition, people with dementia often feel they are not included in decision-making about their own care [18].

There is substantial literature around advance care planning for people with dementia, which documents goals and preferences for future care, particularly end-of-life [19]. A recent umbrella review of 19 reviews (163 unique studies) of the effectiveness of advance care planning for people living with dementia found overall improved outcomes [20]. However, there is less literature about care planning earlier in the course of dementia, including the information that should be in care plans, the care planning process, and barriers and facilitators to care planning.

Care planning might contribute to improving the experiences of care and support for people with dementia, as care planning involves setting person-centred goals, provision of information and discussion of options, promotion of self-management, and having a single, written coordinated plan.

This scoping review aims to explore and synthesise the literature on care planning for people with dementia living in the community. A scan of the literature indicated few high-quality studies; therefore, a scoping methodology was employed to give a broad overview of relevant literature with less focus on the evaluation of quality [21, 22]. Specific review questions were as follows:

(1) What is included in a dementia care plan, and how is care planning for people with dementia currently undertaken?

(2) What evidence is there that care planning improves health and/or social outcomes for people with dementia and/or care partners?

(3) What are barriers and facilitators to care planning for people with dementia?

2. Materials and Methods

A systematic scoping review of the care planning literature for community-dwelling people with dementia was performed using the methodology defined by Arksey and O'Malley [21] and revised by Levac et al. [22]. A five-stage scoping study framework was used; stage one: identifying the research question; stage two: identifying relevant documents; stage three: selecting relevant documents; stage four: charting (or extracting) the data; stage five: collating, summarising, and reporting the results [21]. An optional sixth stage, consultation with key stakeholders, was not undertaken [21].

2.1. Literature Search

2.1.1. Search Strategy Development. An initial limited search of Scopus was undertaken using the search terms "dementia or Alzheimer*" and "care plan*." The title, abstract, and index terms of eligible studies were examined to inform the main search. An academic librarian was consulted to improve search strategies.

2.1.2. Search Strategy

(1) Academic Literature. In May 2020, we searched Scopus, Medline, Embase, PsycInfo, CINAHL, and Cochrane databases using the title, abstract, and keywords searches. Search limiters were set to obtain articles published within the last ten years to obtain the most recent results and written in English. An updated database and grey literature search was conducted in June 2022. See Table 1 for search details.

(2) Terms Used for Database Search. ("dementia OR Alzheimer") AND ("care plan*" "care-plan*" "action plan*" "action-plan*" "management plan*" "management-plan*" "management program*" "management-program*" "personal health plan*" "personal-health-plan*").

(3) Grey Literature. We used the Google and Google Advance search engines to search using the terms "dementia or Alzheimer*" "care plan*" (Table 1). Google search settings were adjusted, so we could search our local regions (Australia), USA, and UK. The Duck Duck Go search engine was also searched to minimize geographic search biases as this does not track Internet protocol (IP) addresses and yields global search results. The first 100 hits from Google Australia, USA, UK, and from Duck Duck Go were downloaded. PsycEXTRA (https://www.apa.org/psycextra/), NICE (https://www.nice.org.uk/), WHO Iris (https://apps.who.int/iris/), Trove (https://www.

Table 1

Literature search strategy-academic databases	
Database	Search terms
Scopus, Medline, Embase, PsycInfo, CINAHL, Cochrane review	Dementia OR Alzheimer* AND care plan* OR care-plan* action plan* OR action-plan* management plan* OR management-plan* management program* OR management-program* personal health plan* OR personal-health-plan*
Literature search strategy-grey literature	
Search engine and region	Search terms
Google “local region”	_“dementia_or_Alzheimer*”____“care_plan”
Google advance	_“dementia_or_Alzheimer*”____“care_plan”
Google USA	_“dementia_or_Alzheimer*”____“care_plan”_United States
Google UK	_“dementia_or_Alzheimer*”____“care_plan”_United Kingdom
DuckDuckGo	_“dementia_or_Alzheimer*”____“care_plan”_all regions
NICE	_“dementia_or_Alzheimer*”____“care_plan”
PsycEXTRA	_“dementia_or_Alzheimer*”____“care_plan”
WHO Iris	dementia (topic category)
Trove	_“dementia_or_Alzheimer*”____“care_plan”
APO	Dementia (topic category)
World Wide Science	_“dementia_or_Alzheimer*”____“care_plan”
Grey source	_“dementia_or_Alzheimer*”____“care_plan”

trove.nla.gov.au/), APO (https://www.apo.org.au/), World Wide Science (https://www.worldwidescience.org/), and GreySource Index (https://www.greynet.org/greysourceindex.html) were also searched (Table 1). The first 100 hits from both PsychEXTRA, NICE, and World Wide Science were downloaded.

2.1.3. Hand Search. The reference lists of included articles were hand searched.

2.1.4. Inclusion and Exclusion Criteria. Inclusion criteria were as follows:

(i) A community or primary care setting
(ii) That the content, process, or outcomes must relate to current care planning for dementia
(iii) Full papers including reviews, opinion pieces, or original research; English language; published between 2010 and June 2022 (inclusive) to capture contemporary care planning practices. Dates were selected to straddle major Australian Government policy changes enacted in 2015 to a consumer directed care focus for all aged care services in Australia [23] and to limit excessive search results, which can be problematic in scoping studies [21].

Exclusion criteria were as follows:

(i) Care planning was conducted in a nursing home or hospital setting
(ii) Related to future care planning such as advance care planning or directives
(iii) Care plans for delivery by one discipline, e.g., nursing or occupational therapy care
(iv) Non-English language
(v) Case studies with five or fewer cases
(vi) Outside our inclusion years

2.1.5. Screening of Search Results. All search results from academic databases were exported into EndNote citation software [24]. Duplicates for academic articles were removed using EndNote's comparison function and manually checked (LK). Two independent reviewers (LK and LFL) performed title and abstract screening, and ineligible articles were removed. Full texts were then obtained and read by two reviewers (LK and LFL) for eligibility. Where there was an initial disagreement between the two reviewers, a third reviewer (TJD) participated in the discussion to reach an agreement.

All grey literature results were combined in MS Excel, and duplicates were removed before being exported to EndNote. Grey literature results were screened by reading the URL and article title, and the full text of possibly eligible web pages or documents was downloaded and considered against inclusion criteria.

Methodological quality assessment was not undertaken as this scoping review is intended to provide an overview of all published records, regardless of quality [21, 22, 25].

2.2. Data Extraction and Synthesis. Quantitative data were extracted from papers using a standardized data extraction tool created for this review by one reviewer (TJD) and checked by a second reviewer (LFL). The extracted data were the author, date, geographic location, aims, design, sample characteristics, and findings.

Results pertaining to aims, methodology, efficacy or effectiveness, care planning techniques, facilitators, and barriers to care planning were summarized in tables and text. Thematic synthesis of facilitators and barriers was undertaken by two researchers (LFL and TJD).

3. Results

Our search of academic databases resulted in a combined total of 18,487 papers, from which 12,564 duplicates were removed, leaving 5,923 unique papers. From these, we excluded further 5,868 papers based on title and abstract screening, and 32 papers based on full-text screening, leaving 23 eligible papers from the academic search. The grey literature search yielded 1,960 unique papers, of which 23 full-text articles were screened and four were identified as eligible. Hand searching produced four additional eligible papers. A total of 31 papers were included in this review (Figure 1): 7 guidelines, 11 intervention studies, 6 descriptive studies, and 7 expert opinion pieces.

Seven guidelines were identified [2, 26–31]. Eleven intervention papers were identified, three of which studied care planning specifically [32–34], and eight where the intervention was case management including a substantial component of care planning [35–42]. Four of these intervention papers report on one study, Partners in Dementia Care (PDC) [35, 36, 39, 40].

There were six descriptive studies which predominantly used qualitative methods: a mixed methods study on the involvement of people with dementia in care planning that used surveys and interviews with social workers [18], a qualitative study on the experiences and views of staff on care planning for people with dementia [43], a qualitative study that reviewed care plans of people with dementia and observed home care worker delivery of the actual care [44], a qualitative study that interviewed home care workers about what they need in care plans [45], a qualitative study of the perceptions of nurse practitioners on their role in dementia care and care planning in general practice [46], and a paper describing a care pathway program that included care planning [47]. There were seven expert opinion pieces [48–54]. The main characteristics of these papers are included in Table 2.

3.1. What Are Current Care Planning Processes and What Is Included in Care Plans for People Living with Dementia in the Community?

3.1.1. Involvement of People with Dementia and Care Partners in Care Planning. Viewpoints varied concerning the involvement of people with dementia and care partners in care planning. Two papers described the minimal involvement of people with dementia and care partners in

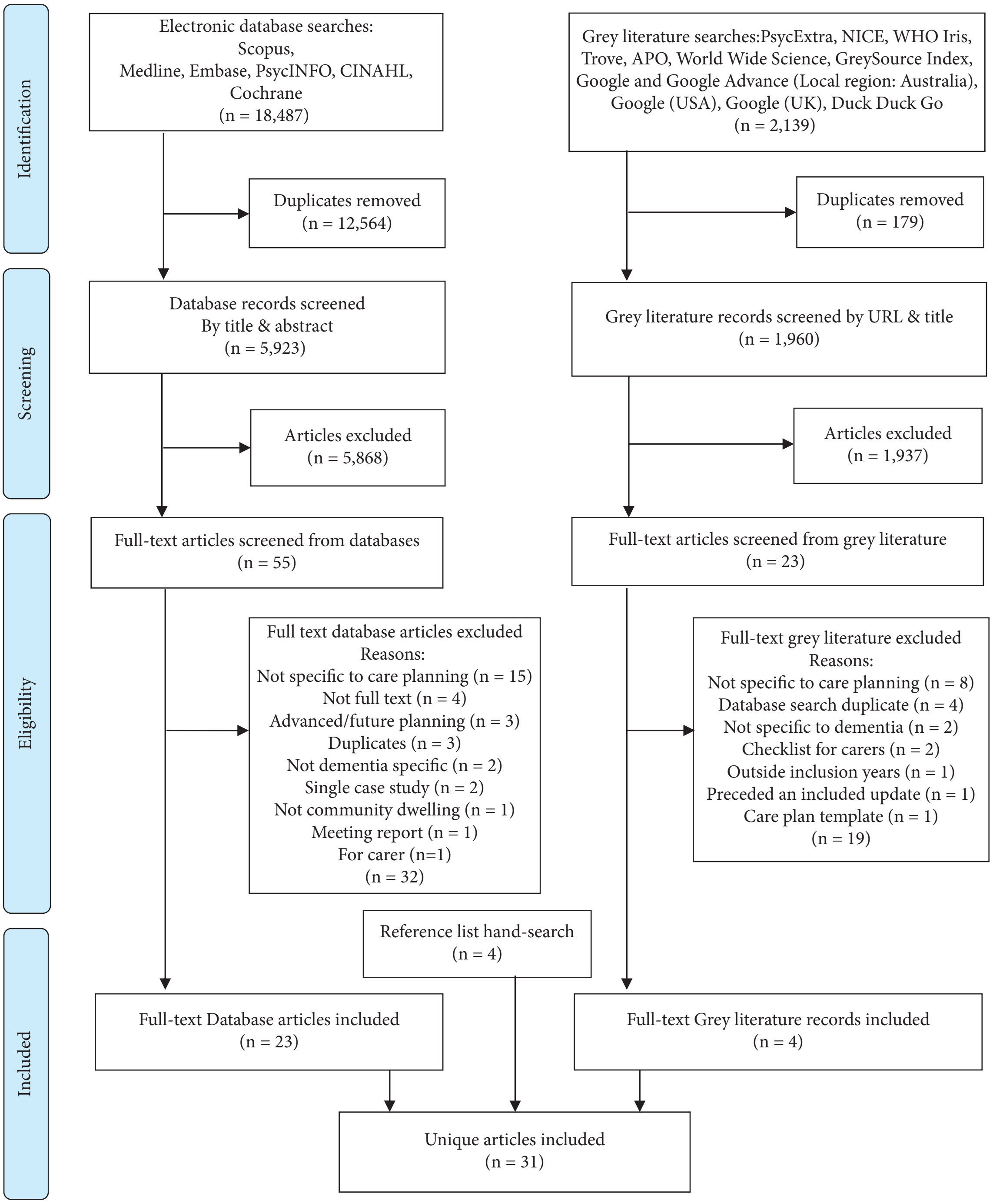

Figure 1: Flow diagram of the scoping review process and search results.

developing the care plan [42, 53]. Three studies discussed the involvement of care partners but had minimal focus on involving people with dementia [32, 37, 38]. The Partners in Dementia Care (PDC) study mentioned involving the person with dementia and their care partner in the development of the plan, yet they were unclear about how much involvement either person had [35, 36, 39]. Six papers suggested involving people with dementia when possible, depending on the level of cognition, understanding, and acceptance of the diagnosis, as well as care partners [2, 18, 30, 31, 49, 50], and one paper highlighted the importance of the involvement of people with dementia in constructing the care plan [34]. One challenge described was balancing the different values and preferences of the person with dementia and their care partner [29, 34, 54].

3.1.2. Beliefs about Dementia Underpinned Care Planning. There was variability in how dementia was conceptualised, and this underpinned how care planning was undertaken. Some papers have conceptualised dementia as an incurable disease against what fluctuations in health, medical, and

Table 2: Characteristics and key information from included papers.

First author (year)	Country	Aim	Setting, participants, sample, and follow-up	Content relating to care planning
		Expert opinion		
Brodaty (2013) [48]	Australia	To describe 14 practice points for general practitioners relating to different stages and types of dementia	Primary care	Management points include: implementing detailed care plan postdiagnosis and follow-up regularly Issues: work, driving, finances and legal responsibilities; dementia friendly environment; medication when appropriate, neuropsychiatric symptoms, and comorbidities Refer to appropriate support: community, respite, residential care; monitor carers' distress, and coping ability
Cheffey (2013) [49]	UK	Applies mental health service principles of active client involvement to older adults with dementia	Health and social care	Focus on positive attitude, enabling choice, decision–making, and supporting self-management for PWD and care to improve quality of life; stability and maintaining identity is important to PWD; the word "recovery" may be a barrier to acceptance of this approach in dementia care, but overall mental health recovery principles apply
Moorhouse (2014) [50]	Canada	To provide practical advice for clinicians to implement strategies for care planning as part of routine dementia care	Specialist healthcare	Involve family members/carers in care-planning discussion about decision-making and applying directives; a dynamic and continuous evolving process aligned with patient healthcare needs; a decision-maker who adheres to patient values; care-planning discussion should be documented
Schneider (2010) [51]	USA	To critique [33]	Memory clinics	Communication between specialists with patients and their families is important for best quality of care; review care often; collaborate with other care providers including primary care practitioners, social workers, and nurse specialists
Unwin (2019) [52]	USA	To present a navigational framework and clinical tools for dementia diagnosis and care planning for primary care physicians	Primary care	Physician goals: to improve patient care and communication with caregivers; use dementia toolkits to build tailored care plans that focus on the patient's short-term and long-term needs and goals; some components can be performed by nonclinicians

Table 2: Continued.

First author (year)	Country	Aim	Setting, participants, sample, and follow-up	Content relating to care planning
Walker (2010) [53]	UK	To specify important principles for effective dementia care planning for home care	Home care	A care plan should accurately and sensitively identify patient needs; should be accessible to the right people at the right time; emphasise use of the APIE model (assess, plan, implement, and evaluate/review) to ensure all steps in the care planning process are followed; involve all care staff from the beginning, staff not involved from the start may not see the importance, leading to nonimplementation
Whitlatch (2013) [54]	USA	To discuss care planning strategies involving the person with dementia and their care partners	Social care	Care planning questions should be individualised and under conditions that maximize success for the person with dementia (PWD); PWD and their caregivers should be involved in structured discussion about their best interests, decision-making involvement, care values, and preferences for care; persons with early to moderate dementia and their caregivers are able to engage fully in this process and report positive outcomes
Guidelines				
Alzheimer's Association (2018) [26]	USA	To present the Alzheimer's Association Expert Task Force recommendations and tools for implementation of cognitive assessment and care planning services	Specialist and primary care	Establish or confirm a diagnosis for a new or existing patient with symptoms of cognitive impairment. Discuss the plan with PWD and/or caregiver. Care planning can be provided by physicians, nurse practitioners, clinical nurse specialists, and physician assistants. Care plans should be easily understood, indicate who is responsible for what steps; specify an initial follow-up schedule
Molony (2018) [27]	USA	To provide recommendations for assessment and care planning derived from a literature review	Health and social care	Prioritise information about individual preferences, needs, values, routines, sources of joy, and personal meaning. Relationship-based care and positive social environments should be supported by identifying care partners and assessing their needs for support, information, and resources

Table 2: Continued.

First author (year)	Country	Aim	Setting, participants, sample, and follow-up	Content relating to care planning
National Collaborating Centre for Mental Health (2007) [2]	UK	To improve standards of care, ensure patient-centred approach, and reduce variations in care delivery and quality across the National Health Service (UK)	Health and social care	Care management for people with dementia delivers improved outcomes for both the person and their caretaker; variability in the models tested/researched makes it difficult to identify the most effective models or the individual components that contribute to effectiveness; characteristics that may be important to efficacy include long-term contact with older people and their care givers, smaller caseloads, and access to a significant range of other resources
National Health Service (2017) [28]	UK	To highlight the key characteristics of a PCSP (personalised care and support planning) for dementia and is aimed at primary care and commissioners who provide PCSP reviews as part of the quality outcomes framework (QOF) incentive scheme in primary care	Primary care	Primary care providers, care givers, and people with dementia should be involved. People with dementia should be central to developing and agreeing to their care plan and deciding who should be involved; focus on person with dementia's (PWD) needs, what is important to them, their wider health, and wellbeing; outcomes/goals should be agreed in partnership with relevant professionals; sharable plan to review formally and informally
Pierce (2010) [29]	USA	To provide guidelines for case managers in developing effective, individualised care plans for clients with progressive dementia in a home setting	Home care	Focus on nursing diagnosis and holistic and collaborative approach with healthcare providers. Professional case management should use best practice fundamentals, comprehensive and collaborative assessment, and communication between nursing, research, medical providers, and families to create individualised care plans
Victorian Department of Health (2012) [30]	Australia	To provide dementia-specific information and practical guidance for assessors from home and community care assessment services to improve assessment, care planning, and service provision for people with possible dementia and their caretakers	Home care	HACC (home and community care) assessor, GP, caretaker, person with dementia should be involved in writing the care plan. A goal setting and problem solving approach; build on strengths, maximize autonomy, encourage involvement in personal care and household tasks, balance safety with autonomy, highlight preferences and dignity, preserve home environment and independence, and respect decisions; sharing of assessment and care plans when transitioning between care providers

Table 2: Continued.

First author (year)	Country	Aim	Setting, participants, sample, and follow-up	Content relating to care planning
Victorian Department of Health (2013) [31]	Australia	To provide evidence-based and best practice standards, criteria, and guidelines for the operation and delivery of high-quality cognitive dementia and memory services (CDAMS) clinics	Memory clinic	Cognitive dementia and memory services (CDAMS) are responsible for initial care planning and short-term care plan implementation but not case management after diagnosis. Multidisciplinary case conferences should be used to develop the care plan. The care plan should be communicated with the general practitioner and other service providers
Intervention studies				
Bass (2013) [35]	USA	To test the effectiveness of partners in dementia care (PDC) on caregiver outcomes, with a larger, more representative sample and a refined PDC protocol than used in prior research	Health and social care caregivers of veterans with dementia $n = 486$ at the baseline $n = 394$ at 6 months n = 324 at 12 months	Significant improvements in unmet needs, role captivity, physical health strain, depression, caregiver support service use, and number of informal helpers, at 6 months; in unmet needs and relationship strain at 12 months. Most beneficial effects after 6 months and maintained for the length of the study. Study was not randomised within sites; therefore, intervention and comparison groups may have differed at the baseline
Bass (2014) [36]	USA	To test the effectiveness of partners in dementia care (PDC), a care coordination program integrating healthcare, community services, and support for veterans with dementia	Health and social care veterans with dementia $n = 333$ at the baseline $n = 263$ 6 months $n = 194$, 12 months	Significant improvements in unmet needs, relationship strain, and depression at 6 months. Some nonsignificant improvement in embarrassment about memory problems. At 12 months, further significant reductions in unmet needs and embarrassment about memory problems. Participant attrition was significantly more likely to be participants from a minority group, more impaired in personal care, and more isolated at the baseline. 34.4% of veterans were too impaired to be interviewed at the baseline. Results, therefore, may not be representative of severely impaired, more vulnerable of disadvantaged veterans
Chodosh (2012) [38]	USA	To analyse whether types of providers and frequency of encounters are associated with higher quality of care within a coordinated dementia care management (CM) program for patients and caregivers	Health and social care medicare recipients with dementia, their careers and care managers $n = 238$ Followed over 18 months	Unclear what was included in the care plan or which specific healthcare practitioners were involved in the planning, outcome measures depended on care manager's documentation. People with dementia and their caregivers were encouraged to participate in care planning

Table 2: Continued.

First author (year)	Country	Aim	Setting, participants, sample, and follow-up	Content relating to care planning
Chodosh (2015) [37]	USA	To compare the effectiveness and costs of telephone-only vs. in-person plus telephone support to deliver an evidence-based, coordinated care management program for dementia	Health and social care Latino PWD/caregiver dyads $n = 151$ (dyads) 6 months 12 months	Care planning was part of a larger case management strategy. Only 50% of participants completed a formal initial assessment. The intervention included a minimum of seven contacts primarily in-person or via telephone or mail. There were significantly more contacts for the telephone group (30.6) than the in-person group (22.3) ($p = 0.003$). Overall, the dementia care quality improved regardless of the delivery method
Gaugler (2016) [32]	USA	To investigate how caregivers perceive the clarity and ease of use of care to plan; how/why users perceive care to plan may assist in enhancing caregiving situations	Social care, online program caregivers of PWD $n = 30$ no follow-up	Unclear who is involved in the writing of the care plan other than caregivers and counsellors. The study focused on prototyping and testing an online tool called "care to plan" to support caregivers; caregivers found it easy to understand, and it was functional; positive perception of counsellor involvement. Barriers: need for additional features such as video instruction for caregivers; prototype had more barriers to use than the beta-version of the program. By describing, identifying, and prioritising support, care to plan (CtP) could help improve the care planning process for dementia caregivers
Judge (2011) [39]	USA	To provide a detailed description of a telephone-based care coordination intervention, partners in dementia care (PDC), for veterans with dementia and their family caregivers	Health and social care veterans with dementia: $n = 93$ caregivers: $n = 90$ 12 months	The person with dementia was not always included in care planning. The study addressed important nonmedical care issues, such as understanding VA benefits, accessing community resources, and addressing caregiver strain. The program is feasible; further research needs to look at psychosocial and service utilization outcomes. Minor barriers to implementation: establishing protocols for sharing client information between partner organisations and rules surrounding confidentiality

Table 2: Continued.

First author (year)	Country	Aim	Setting, participants, sample, and follow-up	Content relating to care planning
Morgan (2015) [40]	USA	To examine whether partners in dementia care (PDC) reduced direct veterans' health administration (VHA) healthcare costs compared with usual care	Health and social care veterans with dementia/caregiver dyads $n = 434$ dyads 12 months prebaseline 6, 12 months	No significant difference between prebaseline and postbaseline log costs. Significant predictors of change in cost: greater impairment at the baseline was negatively associated with change in cost, greater function impairment at the baseline was positively associated with change in cost, and the VHA service priority group (where one is highest priority and eight is lowest priority); groups two to six had greater cost increases than groups seven and above. The strongest predictor of total cost was prebaseline total cost
Nourhashemi (2010) [33]	France	To test the effectiveness of a comprehensive care plan specifically targeting reduced functional decline in people living with mild to moderate Alzheimer's disease compared with usual care in memory clinics	Memory clinics people with Alzheimer's disease $n = 1131$ 12, 24 months	No clear involvement of the person with dementia, family, or caregivers in the care planning process. No difference or positive effect was found on functional decline between treatment and control groups in patients with mild to moderate Alzheimer's disease. Future research should focus on more direct involvement of general practitioners
Orsulic-Jeras (2019) [34]	USA	To describe a counselling-based care-planning intervention, SHARE (support, health, activities, resources, and education), for care dyads in early-stage dementia	Social care people with early-stage dementia; setting unclear 4 months n = 40 (dyads)	Difficult to determine if SHARE leads to positive outcomes for people with dementia or their care givers, no long-termfollow-up to determine if care plans were used and updated. Highlights a structured and systematic approach to care planning. Early-stage supportive strategies such as rapport building and initiating care-related discussions with care dyads may lead to better outcomes in decision-making. Anticipating barriers and addressing possible solutions in care planning discussion is mentioned but not evaluated in this study
Reuben (2013) [41]	USA	To describe the clinical and operational aspects of the UCLA Alzheimer's and Dementia Care program and its experience with the first 150 individuals	Health and social care people with dementia and care givers $n = 150$	Most common recommendations for initial care plans: referral to support groups (73%) and Alzheimer's association safe return (73%), care giver training (45%), and medication adjustment (41%). People with dementia, caretakers, and physicians received the program well

Table 2: Continued.

First author (year)	Country	Aim	Setting, participants, sample, and follow-up	Content relating to care planning
Tan (2014) [42]	USA	To develop and implement a dementia care plan that offers training and support to caregivers, manages care transitions, and facilitates access to community-based services	Health and social care community-based patients with dementia and caretakers $n = 519$ no follow-up	Unclear who is involved in the writing of the care plan; gaps in dementia care: lack of support and training for caregivers, poor care transitions, and inconsistent access to community-based services; may inform policy and care management codes, serve as a national model for how dementia and other chronic diseases can be managed in partnership with primary care practices
Descriptive studies				
Brown (2021) [44]	UK	To explore how care plans are compared with observations of home care received by people with dementia	Social care people with dementia $n = 16$ home care workers $n = 17$ 100 hours of observations	Care plans contain useful information but do not always have specific information to support person-centred care tailored to client's needs and can be vague, incomplete, or out of date. There were inconsistencies between care plans and care that was delivered. Lack of documentation was sometimes associated with failures in person-centred care
Donnelly (2019) [18]	Ireland	To investigate older people's involvement in decision-making relating to care planning, focus on cognitive impairment and dementia	Health and social care social workers: $n = 38$ survey $n = 21$ interview older people: $n = 788$	55% of clients with dementia diagnosis were involved in care planning decisions; a lack of cognitive capacity, ageism, involvement of family, risk aversion, and time were barriers to involvement of people with dementia. Family members were assumed to be key decision-makers. Health and social care professional's dependence on family caretakers contributed to exclusion of older people from involvement in decision-making
Drummond (2017) [43]	UK	To investigate the experiences and views of staff in relation to care planning in dementia services in one National Health Service (NHS) provider	Healthcare nurses, social workers, occupational therapists, and psychologists from inpatient dementia assessment unit, dementia continuing care unit, and community mental health team $n = 11$	No mention of people with dementia or caretakers in care planning. Frontline staff should be involved in care planning, care planning documents must enable staff communication between themselves and others, and practice-based mentors could strengthen good practice in effective information sharing. Documentation of the care program approach was described as a barrier to achieving good practice by members of the community mental health team

Table 2: Continued.

First author (year)	Country	Aim	Setting, participants, sample, and follow-up	Content relating to care planning
Gibson (2021) [46]	Australia	To identify the nurse perceptions of their role in dementia care provision in primary care and barriers and enablers	Primary care nurses $n = 36$	General practice care plans are typically disease-focussed, but nurses rarely address cognition or dementia either in a separate care plan or with cognitive impairment considered across the care plans for other chronic conditions. Some nurses thought they might not be able to get accurate information from the person with dementia to care plan
Morhardt (2015) [47]	USA	To describe the conceptual design and implementation of the care pathway model for dementia (CARE-D)	Health and social care	The care pathway model for dementia (CARE-D) prescribes tailored care based on results from psychosocial and neuropsychological assessments. Focus on abilities and strengths, adapted over time as needs and abilities change. Psychosocial context is important. Consider: living situation, social supports, life stage, financial resources, individuals, and family's pre-existing coping strategies. Goals: enhance quality of life by maximizing independence and safety, identify helpful modifications to activities and the environment, and provide emotional support
Toteh Osakwe (2022) [45]	USA	To determine the information needs of home health aides providing care for people with dementia at home	Home care home health aides $n = 25$	It is difficult for aides to follow the instructions for medication management. Home health aides are given limited information about the person with dementia's care plan and are missing important clinical and social information. Information about behavioural and psychological symptoms of dementia is needed, not having it places aides at risk of abuse

service-oriented care planning decisions were set [49, 50]. Other care planning processes placed greater emphasis on personhood, emphasising person-centred care planning, and discussion on maintaining personal identity, empowerment, and self-efficacy and creating therapeutic optimism and hope [27, 30, 34]. This style of care planning focused on the maintenance of function, independence, and enhancing the quality of life [2, 27, 47].

3.1.3. Care Planning Often Occurs in the Context of Case Management and Care Coordination. The process of care planning depended on the setting and context. Fourteen papers described care planning in the context of case management or care coordination, and the health professionals in these roles (often a nurse or social worker) were seen as integral in care planning [2, 26, 27, 29, 30, 32, 33, 35–39, 41, 42]. When care plans were developed after a multidisciplinary assessment, it was suggested that a multidisciplinary team should be involved in that care planning [31, 47]. When care planning is for home care, it was suggested that home care workers have input [44, 45]. Comprehensive assessment as part of care planning was suggested in multiple papers [2, 26, 27, 29–31, 33, 35–39, 42, 47, 48, 52].

3.1.4. Care Plans Should be Reviewed Regularly. Reassessment and updating of care plans were recommended every 6–12 months with flexibility to review more often if changes in behaviour, cognition, or function occurred [2, 27, 42]. An advisory paper for general practitioners suggested that care plans should be reviewed every 3–6 months [48]. A protocol for a case management and care planning intervention included 6 monthly reviews [38]. When reviewing progress, this should be evaluated and recorded against the objectives in the original care plan [2]. Two papers described that suboptimal home care occurs when care plans are not up-to-date [44, 45].

3.2. Does Care Planning Improve Outcomes for People with Dementia or Care Partners? In this scoping review, we found limited evidence that care planning improves outcomes for people with dementia. In three intervention studies, care planning was evaluated independently of other interventions such as case management. A feasibility study of an online care planning tool facilitated by a counsellor found that it was acceptable and useful for care partners ($n = 40$); however, the study did not evaluate outcomes for people with dementia or care partners [32]. A French cluster randomised clinical trial of 1,131 community-dwelling older people living with Alzheimer's disease implemented care planning through memory clinics. The trial found that compared to usual care, twice-yearly care planning did not improve activities of daily living, risk of nursing home admission or mortality [33]. Schneider [51] suggested that this might have been due to challenges around implementation of the care plan but did not specify what these challenges were. The third study in this series reports on prepost interview outcomes for people with dementia and their care partners ($n = 40$ dyads) after seven sessions of care planning with a counsellor. The program was acceptable to people with dementia and care partners with reported improvements in communication, education, resources and services, support, satisfaction, and care planning. Drawbacks for the program were program/session length (too long or too short), time constraints, stressful conversations, program irrelevance, the level of involvement of the person with dementia, and dissatisfaction with the program [34].

In four intervention studies, planning was included as a substantial component of health and social care case management. The secondary analysis of the intervention arm of an 18-month case management trial of Alzheimer's disease Coordinated Care for San Diego Seniors (ACCESS) program ($n = 238$ dyads) reported increased interactions with healthcare organisation care managers, as well as care managers from community agency and primary care, increased quality of dementia care but did not present information specifically around the value of care planning [38]. The paper reporting the main findings of the study [55] was published outside our inclusion years and was not reviewed.

Another study of the same case management program (i.e., ACCESS) compared the delivery mode of care planning (home visits and phone calls or phone calls and mailouts) for the Latino community ($n = 151$ dyads). This study found that care quality improved significantly over time in both in-person and remote delivery conditions. In-person delivery was more expensive and did not produce additional improvements in care partner burden and behaviour of a person with dementia, retention, and healthcare utilization [37]. Another care management program modelled on the ACCESS program, the UCLA Alzheimer's and Dementia Care Program, involved a case manager partnered with the referring physician to create a care plan covering medical, behavioural, and psychosocial interventions with the aim of preventing unnecessary emergency department visits and hospitalisations. Evaluation of the first 519 participants with dementia found greater levels of satisfaction among care partners (52% response rate to the survey) and referring physicians (37% response rate). Satisfaction of a person with dementia was not reported [42]. It was unclear if every participant with dementia had a care partner, as only percentage response rates for care partners were reported.

The telephone-based Partners in Dementia Care (PDC) involved care coordination using a computerised tool for record sharing, care planning, and fidelity monitoring [39]. Veterans with dementia ($n = 93$) and care partners ($n = 90$) completed a 12-month study exploring a broad range of personal goals, identifying actions to get/give information, and access services and programs. Most actions were completed by care partners. Goals were written by the care coordinators, based on the priorities of the veterans with dementia and their care partners. Two follow-up papers from the same study reported significant improvements for care partners' ($n = 486$ at the baseline; $n = 394$ at 6 months; $n = 324$ at 12 months) unmet needs, depression, role captivity, physical health strain, support service use, and the number of informal helpers after 6 months [35]; significant improvements for veterans with dementia ($n = 333$ at the baseline; $n = 263$ at 6 months; $n = 194$ at 12 months) unmet needs, relationship strain, and depression after 6 months, with some nonsignificant improvements in embarrassment about memory problems [36]. Improvements were maintained after 12 months. It was unclear whether these improvements were the result of care planning specifically as this was not assessed independently of the care management program. An attrition analysis was conducted for Bass et al. [36] but not for Bass et al. [35]. The analysis revealed that attrition was more prevalent in those participants from a minority group who were more impaired in personal care and more isolated from others at baseline; therefore, the results may not be representative of the most vulnerable people living with dementia [36].

3.3. Design, Structure, and Suggested Content of Care Plans. We reviewed all papers for topics that were or should be included in a care plan. Topics recommended for inclusion varied by the context and purpose of the care plan. For instance, if the purpose of the healthcare plan was to prevent hospitalisations, then topics tended to be more around medical management, whereas if the purpose of the social care plan was to support access to services, then more psychosocial topics tended to be included. The program through which care planning was undertaken also impacted the included topics. For instance, care plans for caregiver support services included topics relevant to care support and stress, and care plans for social services included topics relating to supporting people with dementia at home. The previously mentioned philosophical underpinnings of the program also impacted the topics covered (e.g., whether the person's values or goals were included). A summary of topics identified for potential inclusion in care plans for people with dementia and care partners is shown in Table 3. There was variability regarding the areas of care planning included or emphasized across the papers.

Healthcare professionals preferred care plans that were easy to use in terms of content and functionality [32]. Healthcare professionals were reluctant to complete care plans that they viewed as repetitive in terms of content and as pointless paperwork [43].

Care plans need to be easily transferred between different care settings, such as home, community, and residential care, and consent for this should be requested when they are produced [2]. One study suggested that care plans be short as medical practitioners were unlikely to read lengthy plans, and long plans were also considered problematic for people living with dementia and care partners due to complexity [43]. One study used a web-based case management program [38]. While electronic records potentially save time by allowing teams to share information across locations, staff members were frustrated when electronic records were time-consuming to access and did not have the desired functionality (Drummond and Simpson).

Only two papers described care plan materials developed specifically for care partners [32, 33], and we identified no care plan materials specifically for people with dementia.

3.4. What Are Barriers and Facilitators to Care Planning for People with Dementia? Few papers included results concerning barriers and facilitators to care planning. Of those that did, barriers for healthcare professionals included difficulty in sharing client information between organisations [39] and a lack of system-level supports and incentives such as financial reimbursement for the time required to complete care planning and case management processes [18, 27, 32, 42, 52]. Other barriers to care planning included the acceptance of involving people with dementia in care planning due to risk aversion by family members and health and social care professionals and the time involved in creating and managing care plans [18, 46]. The need for additional video training features for care partners when using the online program Care to Plan was a barrier for care partners within this specific program [32].

People with dementia and care partners described barriers including planning being a source of emotional stress, being dissatisfied with the experience, irrelevant items in plans, and inflexible time frames allowed (too short, too long), and for some people with dementia, recalling previous planning sessions was difficult [34]. Training for healthcare professionals in care planning specifically with people with dementia was suggested to improve outcomes for people with dementia and their care partners, though we found no data to support this [56].

One paper from the Partners in Dementia Care study examined whether the program reduced healthcare costs compared with usual care and found that the program neither reduced nor increased direct Veterans Health Administration costs [40].

4. Discussion

National dementia strategies and clinical guidelines recommend care planning for people with dementia [2–5]. This review showed that there is limited evidence from intervention studies to support these recommendations, although expert opinion pieces suggest that a process of care planning and delivery of care using that plan is beneficial. This could be for several reasons. First, the process of care planning alone may be insufficient to change longer-term outcomes (i.e., treatment, health behaviour, or use of services), and care plans need to be implemented and potentially refined (e.g., through case management) for benefits to be experienced. Second, no studies have been conducted or used the appropriate methodology and outcome measures to demonstrate the benefits of care planning.

The review showed that care planning processes and topics were influenced by service undertaking care planning and what they provide (e.g., medical and psychosocial focus) and the broader health and social care context (i.e., the services available impacted the areas covered in the plan). This suggests that care planning can be highly contextual, and care plans have different goals (e.g., holistic medical management in a primary care plan, postdiagnostic referrals in a memory clinic plan, and planning and delivery of social services in a home care plan). Based on the current literature, it is unclear whether there are universal core topics that

Table 3: Considerations during care planning for people with dementia and their care partners.

Topics and description	Person with dementia	Care partner	Author (year)
Care planning processes			
Advance care plan and crisis plan	X		Brodaty (2013) [48] Cheffey (2013) [49] Chodosh (2012, 2015) [37, 38] Molony (2018) [27] Moorhouse (2014) [50] Unwin (2019) [52] Victorian Department of Health (2013) [31]
Daily maintenance plan	X		Cheffey (2013) [49]
Review care plan	X		NCCMH (2007) [2] Unwin (2019) [52] Victorian Department of Health (2013) [31]
When things decline	X		Cheffey (2013) [49]
Financial and legal	X	X	Bass (2013, 2014) [35, 36] Brodaty (2013) [48] Judge (2011) [39] Morhardt (2015) [47] NCCMH (2007) [2] Pierce (2010) [29] Victorian Department of Health (2013) [31]
Keep up to date	X		Brown (2021) [44]
Person with dementia/care partner involvement			
Endorsement of plan by person with dementia and care partner	X		NCCMH (2007) [2]
Named health and social care staff-specific responsibilities and who to go to for help	X		NCCMH (2007) [2]
Recommended support services	X	X	Bass (2013, 2014) [35, 36] Brodaty (2013) [48] Cheffey (2013) [49] Chodosh (2012, 2015) [37, 38] Judge (2011) [39] Molony (2018) [27] NCCMH (2007) [2] Orsulic-Jeras (2019) [34] Pierce (2010) [29] Unwin (2019) [52] Victorian Department of Health (2012) [30] Victorian Department of Health (2013) [31]
Lifestyle/activities			
Driving, safety to drive and medico-legal aspects	X		Brodaty (2013) [48] Chodosh (2012) [38] NCCMH (2007) [2] Unwin (2019) [52] Victorian Department of Health (2013) [31]
Exercise: physical and cognitive (CST, brain training)	X		Brodaty (2013) [48] Unwin (2019) [52] Victorian Department of Health (2013) [31]
Food, nutrition, weight gain or loss, and meals	X		Molony (2018) [27] Unwin (2019) [52]

Table 3: Continued.

Topics and description	Person with dementia	Care partner	Author (year)
Functional challenges	X		Bass (2014) [36] Cheffey (2013) [49] Chodosh (2015) [37] Judge (2011) [39] Molony (2018) [27] NCCMH (2007) [2] Orsulic-Jeras (2019) [34] Pierce (2010) [29] Unwin (2019) [52] Victorian Department of Health (2012) [30]
Living environment/situation	X		Bass (2014) [36] Brodaty (2013) [48] Molony (2018) [27] Morhardt (2015) [47] NCCMH (2007) [2] Victorian Department of Health (2012) [30] Toteh Osakwe (2022) [45]
Recreational activities	X		Molony (2018) [27] Morhardt (2015) Orsulic-Jeras (2019) [34] NCCMH (2007) [2]
Goals	X	X	Bass (2013, 2014) [35, 36] Judge (2011) [39] Molony (2018) [27] Unwin (2019) [52] Victorian Department of Health (2012) [30]
Personal history	X		Pierce (2010) [29] Molony (2018) [27] Morhardt (2015) [47] Victorian Department of Health (2012) [30] Brown (2021) [44] Toteh Osakwe (2022) [45]
Record of personal experience	X		Cheffey (2013) [49]
Family members and primary carer		X	Bass (2013, 2014) [35, 36] NCCMH (2007) [2]
Safety	X		Bass (2014) [36] Brodaty (2013) [35] Chodosh (2012, 2015) [37, 38] Judge (2011) [39] Molony (2018) [27] Orsulic-Jeras (2019) [34] Pierce (2010) [29] Unwin (2019) [52] Victorian Department of Health (2013) [31]
Sharing diagnosis: how to tell others	X		Cheffey (2013) [49]

Table 3: Continued.

Topics and description	Person with dementia	Care partner	Author (year)
Social support and engagement	X	X	Bass (2013, 2014) [35, 36] Brodaty (2013) [48] Chodosh (2015) [37] Judge (2011) [39] Morhardt (2015) [47] Pierce (2010) [29] Unwin (2019) [52] Victorian Department of Health (2012) [30]
Spiritual	X		Molony (2018) [27]
Values	X		Molony (2018) [27] Orsulic-Jeras (2019) [34]
Carer needs		X	Bass (2013) [35] Molony (2018) [27] Unwin (2019) [52] Victorian Department of Health (2013) [31]
Information and training			
Information about dementia	X	X	Bass (2013, 2014) [35, 36] Brodaty (2013) [48] Cheffey (2013) [49] Chodosh (2015) [37] Judge (2011) [39] NCCMH (2007) [2]
Local information sources: including libraries and advocacy organisations	X	X	Bass (2013, 2014) [35, 36] Judge (2011) [39] NCCMH (2007) [2] Victorian Department of Health (2012) [30] Victorian Department of Health (2013) [31]
Capacity to care: training about communication, problem solving, and behaviour management		X	Bass (2013) [35] Judge (2011) [39] NCCMH (2007) [2] Unwin (2019) [52]
Healthcare			
Behaviour: nonpharmacological interventions, including prevention	X		Bass (2014) [36] Brodaty (2013) [48] Chodosh (2012, 2015) [37, 38] Judge (2011) [39] Molony (2018) [27] NCCMH (2007) [2] Unwin (2019) [52] Toteh Osakwe (2022) [45] Victorian Department of Health (2013) [31]
Mental health needs mental health support for caretakers	X	X	Bass (2013) [35] Brodaty (2013) [48] Cheffey (2013) [49] Chodosh (2015) [37] Judge (2011) [39] Pierce (2010) [29] NCCMH (2007) [2]

Table 3: Continued.

Topics and description	Person with dementia	Care partner	Author (year)
Medication: cholinesterase inhibitors, memantine, and medications to avoid	X		Bass (2013, 2014) [35, 36] Brodaty (2013) [48] Chodosh (2015) [37] Judge (2011) [39] Pierce (2010) [29] NCCMH (2007) [2] Unwin (2019) [52] Toteh Osakwe (2022) [45] Victorian Department of Health (2013) [31]
Physical health needs	X	X	Bass (2013) [35] Brodaty (2013) [48] Cheffey (2013) [49] Judge (2011) [39] Molony (2018) [27] NCCMH (2007) [2] Unwin (2019) [52]
Strategies to manage cognitive challenges/memory difficulties	X		Brodaty (2013) [48] Cheffey (2013) [49] NCCMH (2007) [2] Unwin (2019) [52] Toteh Osakwe (2022) [45]

should be included in care plans for people with dementia, though arguably both health and psychosocial wellbeing should be considered irrespective of the service context.

National dementia clinical guidelines on care planning suggested that a range of healthcare professionals plan care, such as primary care physicians and general practitioners, nurse practitioners, organisation specific assessors, specialists, and physician's assistants [2, 26–30]. Only two papers clearly involved care planning by a multidisciplinary team [33, 47], and five papers explicitly involved a primary care physician or general practitioner in the writing of the care plan [26, 28, 30, 42, 52]. Most studies found in this review evaluated care planning that was conducted by a case manager or care coordinator, typically a nurse or social worker. Heterogeneity in the context, purpose, practitioners involved, structure, and implementation of care plans makes it difficult to determine which factors might contribute to positive outcomes. It is plausible that an important active ingredient in care planning in combination with case management is the close ongoing relationship the person with dementia and care has with a dementia care expert [57].

The development of an individualised care plan has been suggested as a process indicator of care quality [58]. Based on this review, the existence of a care plan alone may not be an ideal quality indicator, and the contributions of the nature of care planning processes and implementation of the care plan remain unclear.

This review scopes the broad literature on care planning for people living with dementia in the community. Limitations of the study are the search strategy and inclusion criteria due to the heterogeneity in terminology related to care planning across the literature; it is possible that relevant studies with a substantial element of care planning were overlooked because care planning was not mentioned in the abstract or key words. Future work could further broaden search terms to include support plans, which may be used in place of the care plan. Two reviewers independently decided whether the paper was related to care planning for people with dementia; however, this was a subjective judgment in papers when care planning is briefly mentioned. Only the first 100 hits were reviewed from the general Internet searches.

Rather than trying to evaluate care planning alone, future research might consider evaluating care planning and implementation together in different settings (e.g., primary or specialist care). The context of the care planning should be clearly described. Research might investigate what the optimal content and procedure for care planning and care plan implementation in different service contexts might be, and further research is also needed on how to include and support people with dementia in making decisions about their own care. Considerations of the context and goals of care planning should also inform the selection of outcomes in future research, including outcomes that are important to people with dementia and care. Future studies might also explore challenging aspects of care planning; for instance, goal setting can be difficult for people with dementia [59], as is balancing the goals of care partners and people with dementia [60].

5. Conclusion

While international guidelines recommend care planning for people with dementia, evidence from intervention studies that care planning alone improves outcomes is limited, though care planning in combination with case managing has promise. Guidelines may need to specify that care planning needs to be combined with case management or other implementation strategies. Future research should make a distinction between health, social care, and integrated care planning, test multidisciplinary involvement in care planning, and how to support people with dementia in care planning [61].

Data Availability

The quantitative and qualitative data supporting this review are from previously reported studies and datasets, which have been cited.

Additional Points

What is known about this topic?

(i) Guidelines suggest that care plans should be developed for people with dementia

(ii) Care plans are a core part of dementia case management and care coordination, particularly in home care services

What this paper adds?

(i) There was limited evidence relating to outcomes to support recommendations in national dementia guidelines that care plans should be developed for people with dementia

(ii) Heterogeneity in the context, purpose, practitioners involved, structure, and implementation of care plans makes it difficult to determine which factors might contribute to positive outcomes from care planning

(iii) A small number of studies suggest that care planning in combination with case management may increase access to services, decrease unmet needs of person with dementia and caretaker, increase satisfaction with services, and improve outcomes such as depression in person with dementia.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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Supplementary Materials

S1: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist. (*Supplementary Materials*)

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