










## REVIEW

# Healthcare interventions for older people with dementia and family caregivers in Europe: A scoping review

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## Abstract

**Aim:** This study aimed to examine the extent, range and variety of research in Europe describing healthcare interventions for older people with dementia (PwD) and family caregivers.

**Methods:** This was a scoping review and followed the PRISMA Scoping Review guideline. MEDLINE, CINAHL and Cochrane library databases were searched for studies published between 2010 and 2020. Studies reporting healthcare interventions in Europe for PwD over 65 years and their family caregivers were included.

**Results:** Twenty-one studies from six European countries were included. The types of healthcare intervention identified were categorized as follows: (1) family unit intervention (interventions for both PwD and their family caregiver), (2) individual intervention (separate interventions for PwD or family caregivers) and (3) family caregiver only intervention (interventions for family caregivers only but with outcomes for both PwD and family caregivers).

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**Conclusions:** This review provides insight into healthcare interventions for older PwD and family caregivers in Europe. More studies are needed that focus on the family as a unit of care in dementia.

#### KEYWORDS

dementia care, Europe, family care, family caregivers, family nursing, older people

#### Summary statement

What is already known about this topic?

- In Europe, the population is ageing, and the number of People with Dementia (PwD) who require long-term care and family support is increasing.
- A diagnosis of dementia is a 'family affair', as dementia is associated with physical, emotional and social costs for both PwD and their family caregivers, with impacts on family dynamics and functioning, even more so, when the PwD are older.

What this paper adds?

- This scoping review provides insight into the types of healthcare interventions targeting older PwD and family caregivers in Europe.
- It reveals that most studies ( $n = 19$ ; 90%) consider the family of PwD as the 'context of care' and not as a recipient of care. As a result, the focus of interventions is on the well-being and health of the PwD first and the family second, being seen as a resource for the care of the PwD.

Implications of the study

- The family plays a central role in long-term care of older PwD.
- A holistic approach to dementia care is needed that focuses on the health of family caregivers of PwD, in addition to the health of PwD.

## 1 | INTRODUCTION

Europe as a geographic region has the oldest population worldwide (United Nations, 2022), and it is estimated that the number of individuals aged 65 years and older will increase from 19% in 2016 to 29% in 2070 (European Commission & Directorate-General for Economic and Financial Affairs, 2018). Although increased longevity is a positive social achievement, it raises challenges due to the associated increase in chronic diseases, such as dementia and multimorbidity, in old age (Chrodis Plus, 2020; Deuschl et al., 2020). By 2050, the number of people with dementia (PwD) in Europe will have doubled to almost 19 million (Alzheimer Europe, 2019), placing increasing pressure on care and support services (Alzheimer Europe, 2020).

Dementia, among which Alzheimer's disease is the most common, affects memory, learning capacity, orientation, behaviour and activities of daily living, with all these deteriorating over time in accordance with disease progression (World Health Organization, WHO, & Alzheimer's Disease International, 2012). PwD require comprehensive support, depending on the stage of the disease. The majority of older PwD are cared for at home, supported by family caregivers (Pinquart & Sörensen, 2011; Seidel & Thyrian, 2019).

Family caregivers of PwD have to assume new roles and responsibilities (adaptability, organization and communication). As a result, the functioning of the family unit (i.e., communication, problem-solving, interactions and relationships between family members) is often disrupted (Brodaty et al., 2014; Cheng, 2017; Lindeza et al., 2020; Wright & Leahey, 2013). Therefore, dementia has implications for all members of the family. In addition to these changes, family caregivers are faced with trying to maintain the autonomy and dignity of the person with dementia while negotiating a care system of which they may have no knowledge (McCormack & McCance, 2006; Nolan et al., 2006).

For many family caregivers, caregiver burden has a significant impact on their quality of life (Lorito et al., 2021). This burden affects caregivers' physical, mental, social and financial well-being (Brennan et al., 2017; Cole et al., 2014). The care-related burden can be acute, cumulative and associated with the level of care dependency of the person living with dementia (O'Dwyer et al., 2017). Therefore, professional support must be individualized and address the needs of both PwD and their family caregivers (Lindeza et al., 2020).

This review is based on the assumptions of the Calgary Family Assessment Model (CFAM) and Calgary Family Intervention Model

(CFIM), a family-focused framework that emphasizes a systemic approach to family relations and strength-oriented ways to promote family health (Wright & Leahey, 2013). Based on these models, the family is seen as an interactional unit/system in which the focus of assessment and intervention is on the family structure, family relationships and family functioning (Wright & Leahey, 2013). In this review, the focus is also on the family as a system, including both the PwD and their families as a unit of care, as a 'client' who needs support to maintain family functioning and to promote family health and well-being.

The CFAM and CFIM have been widely used in family-focused care and in particular Family Systems Nursing (FSN), where they have been applied in families where a family member has been diagnosed with a chronic condition (Mileski et al., 2022; Ostlund & Persson, 2014). The FSN model has been found to be useful in various healthcare settings, including dementia care, for patients, family caregivers and healthcare professionals (Østergaard et al., 2021; Tasseron-Dries et al., 2021). Where FSN has been applied, nurses have reported having a closer and more authentic relationship with patients and their families (Voltelen et al., 2016). Families, on the other hand, have experienced an increased sense of family connectedness and reduced caregiver burden (Broekema et al., 2021).

The literature on healthcare interventions for older PwD and family caregivers is scarce (do Nascimento & Figueiredo, 2021). A literature search revealed no reviews of the types of healthcare interventions for older PwD and their family caregivers. Therefore, synthesizing the published evidence on family healthcare interventions in dementia would be of importance to clinical practitioners and policymakers. By healthcare interventions, we mean clinical interventions in which nurses, doctors, psychologists and social workers assess, diagnose and intervene with older PwD and their family caregivers (Mendes et al., 2015).

In this scoping review study, we focused on the geographic territory of Europe because the prevalence of dementia in this region is one of the highest in the world (Alzheimer Europe, 2019, 2020).

## 2 | METHODS

### 2.1 | Aim

This review aimed to examine the extent, range and variety of research in Europe describing healthcare interventions for older PwD and their family caregivers.

### 2.2 | Review question

What is the state of the evidence related to healthcare interventions to support PwD and their family caregivers in Europe?

### 2.3 | Design

A scoping review was conducted to determine the size and scope of the relevant literature. This type of review was considered most appropriate, as scoping reviews are recommended when a body of literature has not been broadly reviewed or a body of literature is suspected to be heterogeneous in terms of the methodologies applied (Tricco et al., 2018). The findings of a scoping review are summarized and synthesized regarding the extent, range and nature of the literature to inform research, practice and policy by mapping concepts, types of evidence and gaps in a defined field (Munn et al., 2018; Pollock et al., 2021). The PRISMA Scoping Reviews (PRISMA-ScR) checklist was used to facilitate complete and transparent reporting (Tricco et al., 2018).

This review was conducted by European researchers from the FAMily health in Europe-Research in Nursing group (FAME-RN) (García-Vivar et al., 2019).

### 2.4 | Search methods

First, to identify relevant publications, a librarian developed a search strategy for MEDLINE, CINAHL and Cochrane library databases (Table 1). The Population, Concept and Context (PCC) approach of Peters et al. (2020) for scoping reviews was applied in the search.

Four researchers (CGV, HK, ES, LI) performed the screening, selection and assessment of the publications. Zotero's web-based software platform was used to screen and select the articles for this review. The articles identified in the search of the three databases were divided between the four researchers. The researchers split into pairs and independently reviewed the assigned articles and decided whether the articles should be included, excluded or needed further discussion. The disputed articles were read by all four researchers and after discussion in online meetings, a final decision as to the inclusion or exclusion of the articles was reached by group consensus. Finally, a senior researcher extracted the main data of the included articles.

### 2.5 | Inclusion criteria

The inclusion criteria for the article are presented in Table 2. Articles were included if they were published between January 2010 and December 2020 in English. No limitation was placed on the study design.

### 2.6 | Data extraction and synthesis

A data charting form was developed in a matrix format. The form included the country of origin of the study; publication year; study design; number of participants; aims of the study, interventions and comparative interventions if any; and outcomes for the PwD and

TABLE 1 Search protocol, keywords and search strategy.

Medline	Cinahl	Cochrane library
1. Family nursing/	S1 (MH 'Family Nursing')	#1 (((('adult child*' or 'carer*' or 'caregiv*' or 'daughter*' or 'families' or 'family' or 'husband*' or 'next of kin' or 'relatives' or 'son' or 'sons' or 'spouse*' or 'wife' or 'wives') NEAR/5 ('clinical practice*' or 'community health' or 'counsel*' or 'educat*' or 'general practice*' or 'geriatric*' or 'health care' or 'healthcare' or 'health practice*' or 'health visit*' or 'home care' or 'intervention*' or 'medicine' or 'medical practice*' or 'nursing' or 'nurse*' or 'physician*' or 'primary care' or 'professional practice*' or 'program*' or 'psychol*' or 'psychotherap*' or 'rehabilitation' or 'social care' or 'social practice*' or 'social work*' or 'support*' or 'telenursing' or 'telemedicine' or 'therap*')));ti,ab,kw OR (((('family' or 'families') NEAR/2 ('center*' or 'focus*' or 'health*' or 'practice*')));ti,ab,kw
2. Professional-family relations/	S2 (MH 'Professional-Family Relations')	#2 ('adult child*' or 'carer*' or 'caregiver*' or 'daughter*' or 'husband*' or 'family' or 'families' or 'next of kin' or 'relatives' or 'son' or 'sons' or 'spous*' or 'wife' or 'wives');ti,ab,kw
3. exp Social support/	S3 (MH 'Counseling+')	#3 ('aged' or 'aging' or 'centenarians' or 'elder*' or 'nonagenarians' or 'octogenarians' or 'old' or 'older' or 'senior*');ti,ab,kw
4. exp Counseling/	S4 (MH 'Health Education')	#4 (alzheimer* or amnesia* or dementia* or demented);ti,ab,kw
5. Health education/	S5 (MH 'Health Care Delivery')	#5 (Europe or Andorra or Austria or Balkan or Belgium or France or Germany or Gibraltar or 'Great Britain' or England or Scotland or Wales or Greece or Ireland or Italy or Liechtenstein or Luxembourg or Monaco or Netherlands or 'Nordic countr*' or Portugal or Denmark or Finland or Iceland or Norway or 'San Marino' or Scandinavia* or Sweden or Spain or Switzerland or 'United Kingdom' or Albania or Baltic or Estonia or Latvia or Lithuania or Bosnia or Herzegovina or Bulgaria or Croatia or Czech or Hungary or Kosovo or Macedonia or Moldova or Montenegro or Poland or Belarus or Romania or Russia or Serbia or Slovakia or Slovenia or Ukraine) OR AB (Europe or Andorra or Austria or Balkan or Belgium or France or England or Scotland or Wales or Greece or Ireland or Italy or Liechtenstein or Luxembourg or Monaco or Netherlands or 'Nordic countr*' or Portugal or Denmark or Finland or Iceland or Norway or 'San Marino' or Scandinavia* or Sweden or Spain or Switzerland or 'United Kingdom' or Albania or Baltic or Estonia or Latvia or Lithuania or Bosnia or Herzegovina or Bulgaria or Croatia or Czech or Hungary or Kosovo or Macedonia or Moldova or Montenegro or Poland or Belarus or Romania or Russia or Serbia or Slovakia or Slovenia or Ukraine);ti,ab,kw
6. Delivery of health care/	S6 (MH 'Nursing Care+')	
7. Practice patterns, Physicians'/	S7 (MH 'Nurses+')	
8. Practice patterns, Nurses'/	S8 (MH 'Community Health Services')	
9. exp Nursing care/	S9 (MH 'Community Health Nursing+')	
10. exp Nurses/	S10 (MH 'Community Mental Health Services +')	
11. Nursing/	S11 (MH 'Home Health Care+')	
12. exp Nursing process/	S12 (MH 'Nursing Practice+')	
13. Community health services/	S13 (MH 'Medical Practice')	
14. exp Community health nursing/	S14 (MH 'Occupational Therapy Practice')	
15. Community mental health services/	S15 (MH 'Practice Patterns')	
16. Home care services/	S16 (MH 'Primary Health Care')	
17. Home health nursing/	S17 (MH 'Family Practice')	
18. Home care services, hospital-based/	S18 (MH 'Physicians-+')	
19. Home nursing/	S19 (MH 'Telehealth+')	
20. Primary health care/	S20 (MH 'Occupational Therapists')	
21. Health services for the aged/	S21 (MH 'Rehabilitation+')	
22. Family practice/	S22 (MH 'Social Work Practice')	
23. Exp physicians/	S23 (MH 'Social Workers')	
24. Exp telemedicine/	S24 (MH 'Psychotherapy+')	
25. Occupational therapists/	S25 (MH 'Psychologists')	
26. Cardiac rehabilitation/	S26 (MH 'Psychotherapists+')	
27. Occupational therapy/	S27 TI (((('adult child*' or carer* or caregiv* or daughter* or families or family or husband* or 'next of kin' or relatives or son or sons or spouse* or wife or wives) N5 ('clinical practice*' or 'community health' or counsel* or educat* or 'general practice*' or geriatric* or 'health care' or healthcare or 'health practice*' or 'health visit*' or 'home care' or intervention* or medicine or 'medical practice*' or nursing or nurse* or physician* or 'primary care' or 'professional practice*' or program* or psychol* or psychotherap* or rehabilitation or 'social care' or 'social practice*' or 'social work*' or support* or telenursing or telemedicine or therap*))) OR AB (((('adult child*' or carer* or caregiv* or daughter* or families or family or husband* or 'next of kin' or relatives or son or sons or spouse* or wife or wives) N5 ('clinical practice*' or 'community health' or counsel* or educat* or 'general practice*' or geriatric* or 'health care' or healthcare or 'health practice*' or 'health visit*' or 'home care' or intervention* or medicine or 'medical practice*' or nursing or nurse* or physician* or 'primary care' or 'professional practice*' or program* or psychol* or psychotherap* or rehabilitation or 'social care' or 'social practice*' or 'social work*' or support* or telenursing or telemedicine or therap*)))	
28. exp Rehabilitation/		
29. exp Social work/		
30. Social workers/		
31. exp Psychotherapy/		
32. ((adult child* or carer* or caregiv* or daughter* or families or family or husband* or next of kin or relatives or son or sons or spouse* or wife or wives) adj5 (clinical practice* or community health or counsel* or educat* or general practice* or geriatric* or health care or healthcare or health practice* or health visit* or home care or intervention* or medicine or medical practice* or nursing or nurse* or physician* or primary care or professional practice* or program* or psychol* or psychotherap* or rehabilitation or social care or social practice* or social work* or support* or telenursing or telemedicine or therap*));ti,ab,kf.		
33. ((family or families) adj2 (center* or focus* or health* or practice*));ti,ab,kf.		
34. or/1-33		
35. Caregivers/		
36. Family/		
37. Adult children/		
38. Spouses/		
39. (adult child* or carer* or caregiver* or daughter* or husband* or family or families or next of kin or relatives or son or sons or spous* or wife or wives).ti,ab,kf.		
40. or/35-39		
41. exp Aged/		

TABLE 1 (Continued)

Medline	Cinahl	Cochrane library
42. (aged or aging or centenarians or elder* or nonagenarians or octogenarians or old or older or senior*).ti,ab,kf.	S29 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28	#6 #1 AND #2 AND #3 AND #4 AND #5
43. or/41-42		
44. exp Dementia	S30 (MH 'Caregivers') OR MH ('Caregiver Burden')	
45. (alzheimer* or amentia* or dementia* or demented).ti,ab,kf.	S31 (MH 'Family')	
46. or/44-45	S32 (MH 'Adult Children')	
47. exp Europe/	S33 (MH 'Spouses')	
48. (Europe or Andorra or Austria or Balkan or Belgium or France or Germany or Gibraltar or Great Britain or England or Scotland or Wales or Greece or Ireland or Italy or Liechtenstein or Luxembourg or Monaco or Netherlands or Nordic countr* or Portugal or Denmark or Finland or Iceland or Norway or San Marino or Scandinavia* or Sweden or Spain or Switzerland or United Kingdom or Albania or Baltic or Estonia or Latvia or Lithuania or Bosnia or Herzegovina or Bulgaria or Croatia or Czech or Hungary or Kosovo or Macedonia or Moldova or Montenegro or Poland or Belarus or Romania or Russia or Serbia or Slovakia or Slovenia or Ukraine).ti,ab,kf.	S34 (MH 'Daughters')	
	S35 (MH 'Sons')	
	S36 TI ('adult child*' or carer* or caregiver* or daughter* or husband* or family or families or 'next of kin' or relatives or son or sons or spous* or wife or wives) OR AB ('adult child*' or carer* or caregiver* or daughter* or husband* or family or families or 'next of kin' or relatives or son or sons or spous* or wife or wives)	
49. or/47-48	S37 S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36	
50. 34 and 40 and 43 and 46 and 49	S38 (MH 'Aged+')	
51. Limit 50 to (Danish or English or French or Norwegian or Spanish or SWEDISH)	S39 TI (aged or aging or centenarians or elder* or nonagenarians or octogenarians or old or older or senior*) OR AB (aged or aging or centenarians or elder* or nonagenarians or octogenarians or old or older or senior*)	
52. Limit 51 to yr = '2008-current'	S40 S38 OR S39	
	S41 (MH 'Dementia+')	
	S42 TI (alzheimer* or amentia* or dementia* or demented) OR AB (alzheimer* or amentia* or dementia* or demented)	
	S43 S41 OR S42	
	S44 (MH 'Europe+')	
	S45 TI (Europe or Andorra or Austria or Balkan or Belgium or France or Germany or Gibraltar or 'Great Britain' or England or Scotland or Wales or Greece or Ireland or Italy or Liechtenstein or Luxembourg or Monaco or Netherlands or 'Nordic countr*' or Portugal or Denmark or Finland or Iceland or Norway or 'San Marino' or Scandinavia* or Sweden or Spain or Switzerland or 'United Kingdom' or Albania or Baltic or Estonia or Latvia or Lithuania or Bosnia or Herzegovina or Bulgaria or Croatia or Czech or Hungary or Kosovo or Macedonia or Moldova or Montenegro or Poland or Belarus or Romania or Russia or Serbia or Slovakia or Slovenia or Ukraine) OR AB (Europe or Andorra or Austria or Balkan or Belgium or France or Germany or Gibraltar or 'Great Britain' or England or Scotland or Wales or Greece or Ireland or Italy or Liechtenstein or Luxembourg or Monaco or Netherlands or 'Nordic countr*' or Portugal or Denmark or Finland or Iceland or Norway or 'San Marino' or Scandinavia* or Sweden or Spain or Switzerland or 'United Kingdom' or Albania or Baltic or Estonia or Latvia or Lithuania or Bosnia or Herzegovina	

(Continues)

TABLE 1 (Continued)

Medline	Cinahl	Cochrane library
	or Bulgaria or Croatia or Czech or Hungary or Kosovo or Macedonia or Moldova or Montenegro or Poland or Belarus or Romania or Russia or Serbia or Slovakia or Slovenia or Ukraine)	
	S46 S44 OR S45	
	S47 S29 AND S37 AND S40 AND S43 AND S46	
	S48 Limiters—Published Date: 20080101-20181231 Narrow by Language: Danish or English or French or Norwegian or Spanish or Swedish	

TABLE 2 Inclusion and exclusion criteria.

Papers were included if	Papers were excluded if
1. The study was conducted in Europe.	1. Focused on family members' without reporting an actual intervention of professionals.
2. Patients were diagnosed with dementia.	2. Study protocols and conference abstracts.
3. Patients mean age was 65 years or over.	3. Review articles and articles without abstract or retrievable text.
4. Clinical and/or education activities were described in any setting (hospital, community, home, etc.) and aimed on physical, psychological, social and environmental domain.	
5. Had to include a healthcare intervention delivered by healthcare professionals to patients and/or their family caregivers.	

family caregivers. Content analysis was used to analyse the data (Colquhoun et al., 2014), and themes were developed.

### 3 | RESULTS

#### 3.1 | Search outcome

The initial search yielded 1216 articles. After deleting duplicates, 1159 articles were included for screening. Of these, 815 articles were removed because they did not refer to family caregivers, next of kin or spouses; no intervention was described; the language was other than English; or the study did not take place in Europe. The remaining 344 studies were reviewed based on their titles and abstracts and, if necessary, the full text, to determine whether they satisfied the inclusion criteria. Of these 344 studies, 240 did not fulfil the inclusion criteria and were excluded. The remaining 104 studies were assessed, and 83 studies were excluded due to a lack of description of individual or family-focused interventions. Finally, 21 studies were included in the scoping review (Figure 1 and Table 3).

#### 3.2 | Characteristics of the studies

Sixteen studies used a randomized controlled trial design, of which five studies were pilot studies. One study was quasi-experimental, another was a cohort study, two were mixed-methods and one had adopted a qualitative approach (Table 3).

In total, 4032 patients and 4053 family caregivers participated in the 21 studies, which were conducted in seven European countries: Finland ( $n = 1$ ), France ( $n = 1$ ), Germany ( $n = 1$ ), the Netherlands ( $n = 5$ ), Spain ( $n = 1$ ), and the United Kingdom ( $n = 11$ ). One ( $n = 1$ ) study was multi-sited and conducted in Greece, Spain and the United Kingdom simultaneously (Torkamani et al., 2014) (Figure 2).

In terms of the study populations, the numbers of participants varied from 10–946 PwD and caregiver dyads. In 18 studies, the mean age of the PwD and their caregivers was 78.3 and 65.4 years, respectively. Most of the studies characterized the supporting person as a 'caregiver', 'informal caregiver' or 'family caregiver'. The second most commonly used term was 'carer' or 'family carer', with the terms 'family members', 'spouses' or 'relatives' seldom used.

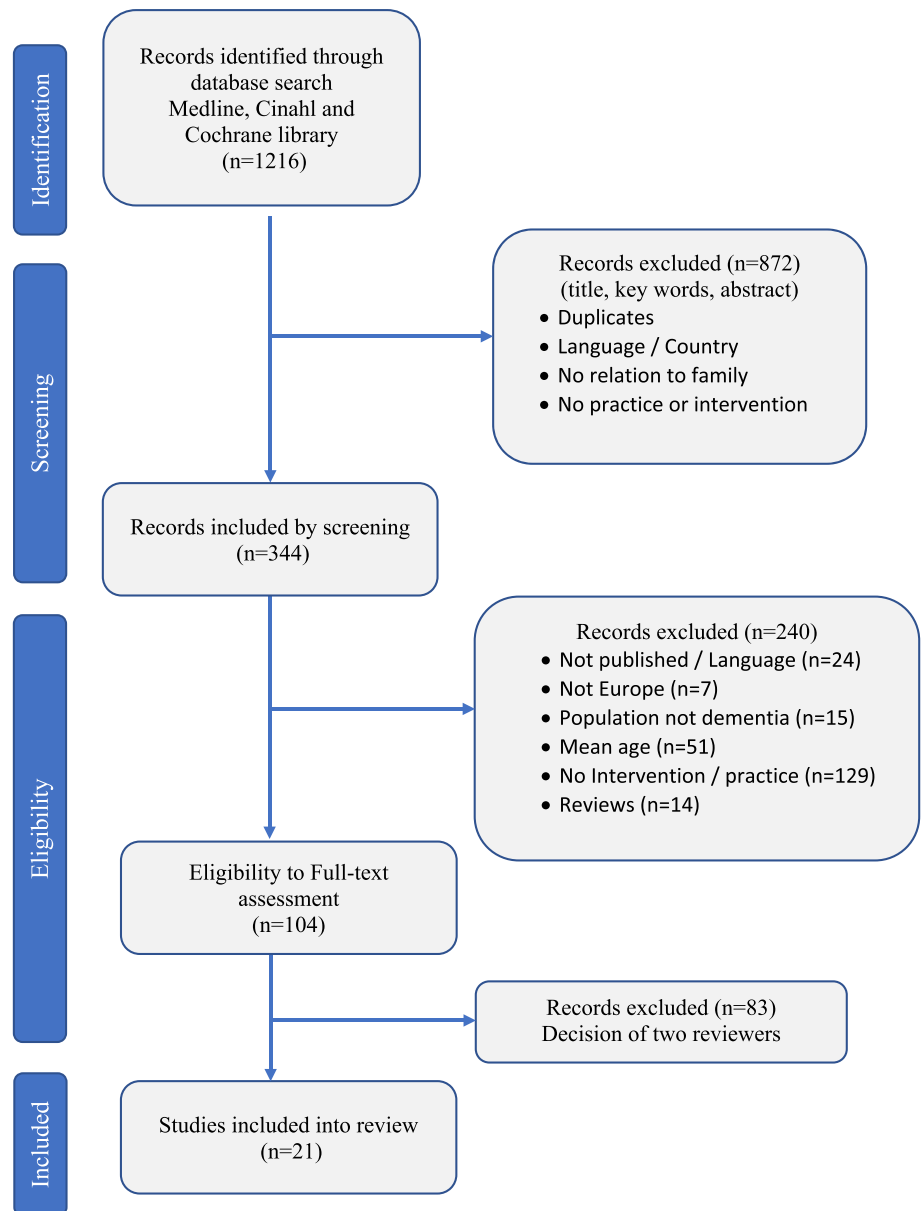
Ten studies reported the patients' stage of dementia, with the stage ranging from early to moderate and severe. All but two studies (Camic et al., 2016; Woods et al., 2012) used the Mini-Mental State Examination score to assess the level of dementia. Camic et al. (2016) used Addenbrooke's Cognitive Examination-Revised to assess the level of dementia, and Woods et al. (2012) used the Clinical Dementia Rating Scale.

#### 3.3 | Characteristics of the healthcare interventions for older PwD and their caregivers

Healthcare interventions for PwD and their caregivers are difficult to classify due to the diversity of interventions, target populations, modes of intervention delivery and levels of intervention delivery. In this review, we focused on the intervention level, with three categories of interventions: (1) family unit intervention (interventions for both PwD and their family caregiver), (2) individual intervention (separate interventions for PwD or family caregivers) and (3) family



**FIGURE 1** PRISMA flow diagram summarizing the screening process.



caregiver only intervention (interventions for family caregivers only but with outcomes for both PwD and family caregivers). In each of the three categories, the mode of delivery, the professionals involved, the type of intervention and the outcome measures assessed in the interventions are presented.

### 3.3.1 | Family unit intervention: Interventions for both PwD and their family caregiver

Eleven (52.3%) of the 21 studies included in this review described a family unit intervention for PwD and their family caregivers. Six studies (Clare et al., 2019; MacNeil Vroomen et al., 2015; Murphy & Oliver, 2013; Prick et al., 2015; Salva et al., 2011; Tyack et al., 2017) focused on interventions targeting both parties in the PwD dyad, and five studies (Barrado-Martin et al., 2019; Camic et al., 2016; Hamill

et al., 2012; Laakkonen et al., 2016; Woods et al., 2012) focused on interventions targeting several PwD dyads.

#### *Types of interventions and measured outcomes within the dyad*

The interventions within a dyad were performed by occupational therapists, nurses (Clare et al., 2019), case managers (MacNeil Vroomen et al., 2015), nursing and medical staff (Salva et al., 2011) and psychology students (Prick et al., 2015). Two studies did not specify the type of professional (Murphy & Oliver, 2013; Tyack et al., 2017). Three studies reported the lengths of the interventions, which lasted between 20 and 60 min (Clare et al., 2019; Prick et al., 2015; Tyack et al., 2017).

There was a diversity of approaches in the interventions within the dyad. Two studies involved a relationship-focused intervention, targeting the communication among PwD and their caregivers to improve the involvement of PwD in decisions relating to daily

TABLE 3 Characteristics of the included articles.

(Authors, year), Country	Design	Participants Age: M (SD) years Setting	Aim	Intervention	Outcome measurements
(Barrado-Martín et al., 2019) UK	RCT (pilot)	10 people with mild–moderate dementia Age >65 years 10 caregivers (living at home)	To investigate the feasibility and participants' acceptance of a Tai-Chi intervention, (presented as a falls prevention and balance improvement exercise) for people with dementia and their caregivers.	Group 1: Four classes (once a week) and practice at home for 20 min a day for 3 weeks as planned Group 2 Three classes (once a week) and an extension were not offered. One visit of the instructor in the second week at participants home	Feasibility of the intervention and participants' reaction to the intervention. (Effect was not measured)
(Camic et al., 2016) UK	Qualitative, grounded theory	12 people with mild–moderate dementia Age: 58–94 years 12 caregivers (living at home)	To understand how interventions with contemporary and traditional art might play a role in the lives of people with dementia.	8 weekly sessions with art viewing and art making. Each session lasted for 2 h: 1 h for art viewing and 1 h of art making	Fieldnotes Dyad interviews Intellectual stimulation Social relationship Changed perception
(Charlesworth et al., 2016) UK	Factorial pragmatic randomized trial	241 persons with dementia Age Int 1: 79.8 (8.2) years Int 2: 79.3 (7.5) years Int 3: 79.8 (8.4) years TAU: 79.5 (7.3) years 241 caregivers Int 1: 69.0 (10.5) years Int 2: 65.8 (12.4) years Int 3: 66.3 (11.8) years TAU: 66.8 (14.7 years) (living at home)	To evaluate usual care enhanced by peer support together or separately with reminiscence therapy	Treatment as usual (TAU) plus one-to-one peer support to family carers from experienced carers (Carer Supporter Programme; CSP) and group reminiscence therapy Remembering Yesterday, Caring Today (RYCT). 12 weekly meetings for people with dementia and carers, lasting for 2 hours each.	Data: Baseline, 5-, 12 months <b>Patient:</b> Quality of life (QoL-AD) Anxiety (HADS) Depression (HADS) Functional capacity (ADCS-ADL) Caregiver-patient relationship (QCPR) <b>Caregiver:</b> Quality of life (SF-12) Health related quality of life (EQ-5D) Anxiety (HADS) Depression (HADS) Loneliness Caregiver distress (NPI-D) Positive and negative affect (PANAS) Positive aspects of caring (cope-index) Personal growth (PGI) Caregiver-patient relationship (QCPR)
(Clare et al., 2019) UK	RCT multicenter	475 persons with dementia Age: 78.6 (7.1) years 475 caregivers Age 68.7 (13.1) years	To determine whether individual goal-oriented cognitive rehabilitation improves everyday functioning for people with mild-to-moderate dementia	Weekly cognitive rehabilitation sessions for 10 weeks within a 3-month period plus four maintenance sessions over the following 6 months. Sessions involved working collaboratively on up to three rehabilitation goals chosen by the participant.	<b>Patients:</b> Goal attainment Self-efficacy (GSES) Mood (HADS) Health related quality of life (DEMQOL) Memory (Rivermead Behavioral Memory Test) <b>Informal caregivers</b>



TABLE 3 (Continued)

(Authors, year), Country	Design	Participants Age: M (SD) years Setting	Aim	Intervention	Outcome measurements
(Cove et al., 2014) UK	RCT	72 people with mild– moderate dementia Age: Int 1: 75.4 (5.6) years Int 2: 76.8 (6.6) years TAU: 77.8 (7.5) years 72 caregivers Age: Int 1: 68.8 (10.4) years Int 2: 67.1 (11.3) years TAU: 70.4 (11.1) years (living at home)	To evaluate the effectiveness of cognitive stimulation therapy enhanced with a training programme for carers.	Intervention one: 14 group based weekly interventions lasting 45 minutes each, including cognitive stimulation training for people with dementia Intervention 2: 14 group based weekly interventions lasting 45 minutes each, including Cognitive stimulation training and training of informal carer.	<b>Outcome measurements</b> Stress (Relatives' Stress Scale) Quality of life (WHOQOL-BREF, EQ- 5D) Health related quality of life  Data: Baseline, 2 weeks after intervention <b>Patients:</b> Cognition (MMSE, ADAS-Cog) Quality of life (QoL-AD) Quality of relationship with carer (QCPR)
(de Rotrou et al., 2011) France	RCT multicentre	141 people with mild– moderate dementia Age: 78.6 (6.3) years 167 caregivers Age: 65.0 (12.0) years (living at home)	To determine whether a psycho- educational programme (PEP) for primary caregivers in addition to standard anti-dementia drugs for patients improves caregivers' psychological condition and patients' activities of daily life	12 sessions including groups of 6–10 caregivers for 3 months. Weekly sessions lasted 2 h and focused on education, problem-solving techniques and emotion-centred coping strategies, management of patient's behaviour, communication skills, crisis management, resource information and practical advice	<b>Data:</b> Baseline, 3-, 6 months <b>Patients:</b> Functional status (DAD) Cognitive status (ADAS-Cog) Behavioural disorders (NP) <b>Caregivers:</b> Depressive symptoms (MADRS) Caregiver burden (ZBI) Sense of competence (SCQ) Disease understanding (VAS) Coping ability (VAS)
(Dopp et al., 2015) Netherlands	RCT Cluster	71 patients with mild– moderate dementia Age: Int.: 77.3 (6.6) years TAU: 78.1 (5.7) years 71 caregivers Int: 69.0 (12.0) years TAU: 68.8 (11.1) years (living at home)	To evaluate the effectiveness of a training package to implement a community occupational therapy programme for people with dementia and their caregiver (COTID)	A postgraduate course for occupational therapists with an additional training package, including outreach visits, regional meetings, and access to a reporting system for professionals. CODIT: 10 1 h sessions over 5 weeks focusing on both patients and caregivers	<b>Data:</b> Baseline, 6-, 12 months <b>Patients:</b> Quality of life (DQOL) Daily functioning (AMPS, IDDD) Performance of daily activities (COPM) <b>Caregivers:</b> Quality of life (DQOL) Performance of daily activities (COPM) Sense of competence (SCQ)

(Continues)

TABLE 3 (Continued)

(Authors, year), Country	Design	Participants Age: M (SD) years Setting	Aim	Intervention	Outcome measurements
(Hamill et al., 2012) UK	RCT (pilot)	11 patients with moderate to advanced dementia Age: 75–96 years 7 caregivers Age: 61–88 years (living at home)	To explore the effects of a circle dance group therapy on people with severe dementia and their caregivers.	10 sessions of 'circle dance' weekly, for 45 min each.	<b>Patients:</b> Cognition (MMSE) Quality of life in Alzheimer disease (QoL-AD) <b>Caregivers:</b> General health (GHQ-12)
(Joling et al., 2013) Netherlands	RT	192 patients with dementia Age: Int: 72.8 (9.1) years TAU: 76.6 (8.3) years 192 caregivers Age: Int: 67.8 (9.8) years TAU: 71.2 (10.7) years (living at home)	To evaluate the effect and cost- effectiveness of a family meeting intervention for family caregivers of patients with dementia	Six sessions for the patient-caregiver dyad within a year. (one session every 2–3 months). (Total of 6.5 h). This includes one individual preparation session, followed by four structured meetings that included their relatives and/or friends (family meetings), and one additional individual evaluation session. The family meeting intervention included psycho-social interventions, problem solving techniques, mobilizing the social network.	<b>Baseline, 6-, 9-, 12 months</b> <b>Patient:</b> Quality of life (SF-12) <b>Caregivers:</b> Quality of life (SF-12) Symptoms of depression (MINI) Anxiety (MINI) <b>Both:</b> Cost Quality -adjusted life years
(Kurz et al., 2010) Germany	RCT multicentre	292 persons with moderate dementia Age: Int: 75.8 (8.0) years TAU: 76.1 (7.9) years 292 caregivers Age: Int: 62.6 (11.5) years TAU: 62.0 (13.4) years (living at home)	To evaluate the efficacy of a practical, easily implemented, educational intervention in group format for caregivers of persons with dementia	The educational programme was focusing on information about Alzheimer's disease. The caregiver intervention consisted of seven bi-weekly group sessions of 90 min duration each. The programme was complemented by 6 bi-monthly refresher meetings. Total duration of the intervention 15 months.	<b>Data: Baseline, 5 months</b> <b>Patients:</b> Cognition (MMSE) Behavioural disturbances (NPI) Activities of daily living (ADCS-ADL) <b>Caregivers:</b> Depression (MADRS) Quality of life (SF-36) Caregiver-time (RUD-light) Satisfaction with the intervention (PSQ)
(Laakkonen et al., 2016) Finland	RCT	136 patients with dementia Age: Int: 77.3 (6.2) years TAU: 76.6 (6.3) years 136 caregivers Age: Int: 75.9 (5.7) years TAU: 73.8 (7.4) years (living at home)	To investigate the effect of self- management-rehabilitation groups on health-related quality of life, the cognition of patients and the costs of health as well as social services.	10 dyads (carers and patients) participated in 4 h-group-sessions once a week, for 8 weeks. Sessions were facilitated by specially trained professionals and based on a psychosocial group rehabilitation model and on self-management supporting principles.	<b>Data: Baseline, 3, 9, 12, 24 months</b> <b>Patients:</b> Quality of life (EQ-15D) Cognition (VF, CDT) <b>Caregivers:</b> Quality of life (RAND-36) Sense of competence (SCQ) Mastery (PMS) Cost of health and social services (24 months)

TABLE 3 (Continued)

(Authors, year), Country	Design	Participants Age: M (SD) years Setting	Aim	Intervention	Outcome measurements
(MacNeil Vroomen et al., 2015) Netherlands	Prospective cohort study	521 patients with dementia Age: 79.8 (7.9) years 521 caregivers Age 64.6 (12.5) years (living at home)	To evaluate the effect of two types of implemented case management compared with no case management on patients and caregivers.	Patients and carers were offered case management within one care organization (intensive case management ICM (ICMM), case management that includes multiple organizations within one region (linkage models, LMs), or no access to case management at all (control).	Data: Baseline, 6, 12, 18, 24 months <b>Patients:</b> Neuropsychiatric symptoms (NPI) Institutionalization Quality of life (QOL-AD) Care and support (CANE) Activities of daily living (KATZ-6, KATZ 15 ADL and IADL items) <b>Caregivers:</b> Psychological health (GHQ-12), Quality of life (equation 5D) Loneliness (Jong-Gierveld Loneliness Scale) Burden (CarerQOL)
(Murphy & Oliver, 2013) UK	Mixed method	18 patients with dementia Age 77 (60–86) years 18 caregivers Age 69 (44–89) years (living at home)	To explore whether communication symbols (Talking Mats) could help people with dementia and family carers feel more involved in decisions about managing their daily living	Three visits took place. Couples discussed in a session four topics using the communication symbols: Personal care; getting around; housework; activities.	<b>Patients:</b> Feeling of involvement in the discussion Satisfaction with the discussion <b>Caregivers:</b> Feeling of involvement in the discussion Satisfaction with the discussion
(Prick et al., 2015) Netherlands	Mixed-method	111 patients with dementia Age: 77 (7.5) years 111 informal caregivers Age: 72 (10.1) years (living at home)	To investigate the effects of a dyadic intervention, (including exercise and support) on caregivers.	8 visits: Four weekly home visits the first month, biweekly during months 2 and 3. 1 h per session. Combination of physical exercise and support (psycho-education, communication skills training, and planning of pleasant activities) for both, the person with dementia and the caregiver.	Data: Baseline, 3–6 months <b>Patient:</b> Behavioural problems assessed by caregiver (RMBPC) <b>Caregivers:</b> Mood (CES-D) Burden (SPICC) General health (single item scale) Salivary cortisol level
(Quinn et al., 2016) UK	RCT (pilot)	24 patients with early-stage dementia Age: Int: 75.2 (8.7) years TAU: 76.1 (8.5) years 24 caregivers Age: Int: 67.0 (15.0) years	To explore the feasibility of a self- management intervention for people with early-stage dementia	Eight weekly group sessions 90 min each Self-management interventions including: For person with dementia Content of sessions: Enjoying favourite activities and interests.	Data: Baseline, 3-, 6-months <b>Patients:</b> Cognition (ACE-III) Self-efficacy (GSES) Anxiety (HADS) Depression (HADS) Quality of life (EQ-5D-3L)

(Continues)

TABLE 3 (Continued)

(Authors, year), Country	Design	Participants Age: M (SD) years Setting	Aim	Intervention	Outcome measurements
(Salva et al., 2011) Spain	RCT multicentre	946 people with dementia Age: Int: 79.4 (7.0) years TAU: 78.6 (7.5) years 946 informal caregivers Age: Int: 58.0 (13.0) years TAU: 62.0 (14.0) years (day care centres)	To assess the effect of a health and nutrition programme (NutriAlz) on daily functioning.	The intervention was a teaching and training intervention (health and nutrition programme) with a standardized protocol for feeding and nutrition.  Four educational sessions were provided to families: Presentation of the nutritional support programme, lifestyle habits, eating behaviour problems, general review and problem solving in creation of menus.	Data: Baseline, 6-, 12-months <b>Patient:</b> Anthropometry Cognition (MMSE) Dementia (CDR) Behavioural problems (NPI) Eating behaviour (EBS) Autonomy and Activities of daily living (ADL/IADL) Improvement in nutritional status (Mini Nutritional Assessment, MNA) Depression (Cornell score) <b>Caregivers:</b> Caregiver burden (ZBI) Cost (RUD)
(Spijker et al., 2013) Netherlands	RCT	125 people with dementia Age: Int 1: 77.1 (8.0) years Int 2: 80.8 (6.5) years 125 caregivers Age: Int1: 58.9 (13.0) years Int2: 56.0 (13.2) years	To evaluate the influence of adherence to the Systematic Care Program for Dementia (SCPD) on patient and caregiver outcomes.	<b>Training of professionals:</b> Training programme of professionals in the systematic assessment and interpretation of caregiver problems and strategies do deal with deficiencies.  Comparison of 3 groups: Professionals adhering; not adhering; usual care	Data: Baseline, 12-months Adherence of professionals to the protocol <b>Patient</b> Behavioural problems (NPI) <b>Caregivers:</b> Sense of competence (SCQ) Depression (CES-D) Distress (NPI)
(Subramaniam et al., 2014) UK	RCT (pilot)	24 people with dementia Age: 86.5 (6.5) years 23 informal caregivers	To evaluate the effect of different pathways for developing a life story book for people with dementia	Life review group: 12 individual life review sessions with patients to co-create a life story book. (1 h each).	Data: Baseline, 12-, 18-weeks <b>Patients:</b> Dementia (CDR)

TABLE 3 (Continued)

(Authors, year), Country	Design	Participants Age: M (SD) years Setting	Aim	Intervention	Outcome measurements
(Torkamani et al., 2014) UK, Greece, Spain	RCT (pilot)	60 people with mild- moderate dementia Age: 78.0 (6.9) years 60 caregivers Age: 60.7 (13.9) years (living at home)	To evaluate a technology platform (ALADDIN) for assisted living of people with dementia and their carers	The platform offers educational material about dementia to carers and provides the opportunity to contact other carers and clinicians. It also facilitates remote monitoring of people with dementia and their carers by clinicians. Enable speedy delivery of appropriate intervention.	<b>Data:</b> Baseline, 3-, 6-months <b>Patients</b> Cognition (MMSE) Cognition, attention (DRS2) Activities, habits (BDRS) Memory (CDRS) Distress (MBPC) Depression (GDS) Functional disability (BI) Daily activities (LADL) Co-morbidity (CCI) Behavioural problems (NPI) <b>Caregivers</b> Quality of life (EQ-5D, QOLS) Burden (ZBI) Depression (BDI) Depression (BDI, ZUNG)
(Tyack et al., 2017) UK	Quasi-experimental mixed method	12 people with dementia Age: 75 years 12 caregivers Age: 66 years (living at home)	To explore the effect of art-based interventions on well-being of people with dementia and their caregivers.	Stimulation of thoughts through 100 images on a touch screen device. Images were divided into objects, paintings and photography. Participants were asked to look at images at home. At least 5 sessions were observed for each dyad, lasting M = 20 minutes each.	<b>Data:</b> Baseline, after intervention <b>Patients:</b> Quality of life (QOL-AD) wellbeing, wellness, interestness (VAS) Experiences of the intervention (interviews) <b>Caregivers:</b> Quality of life (QOL-AD) wellbeing, wellness, interestness (VAS) Experiences of the intervention (interviews)

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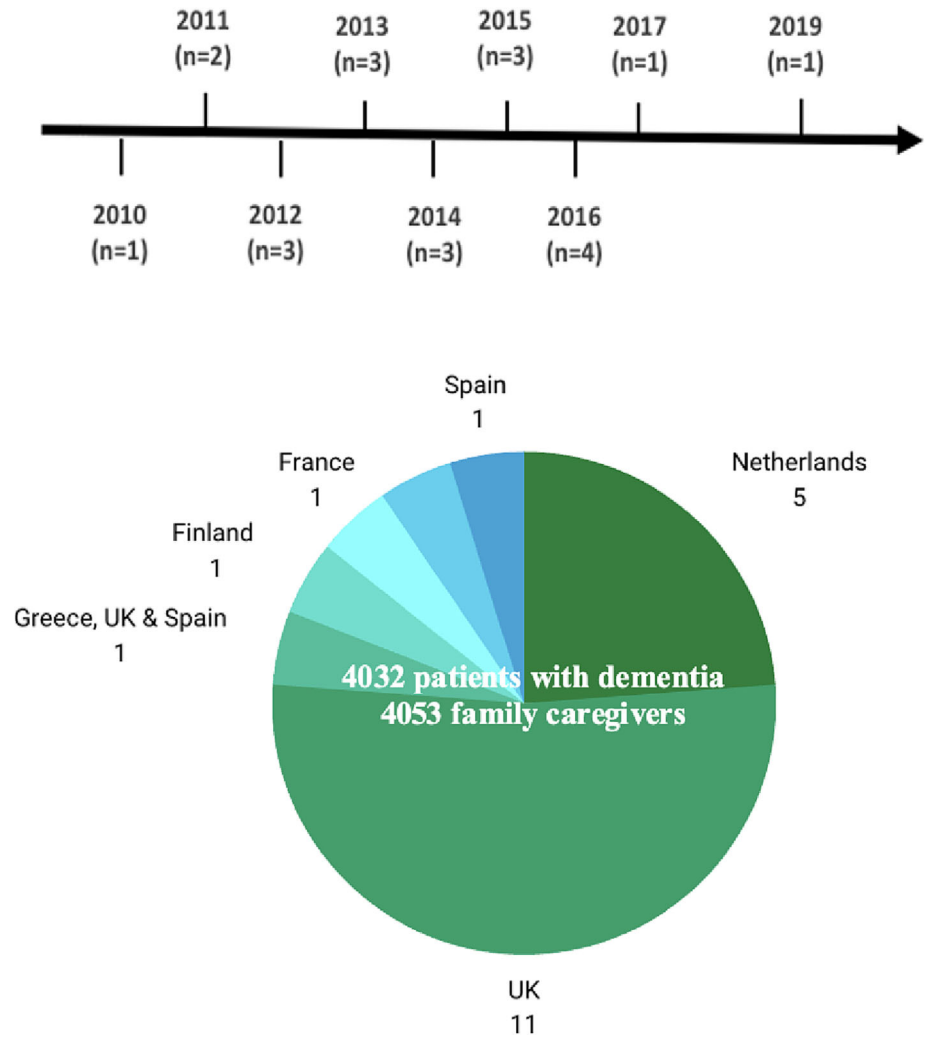
TABLE 3 (Continued)

(Authors, year), Country	Design	Participants Age: M (SD) years Setting	Aim	Intervention	Outcome measurements
(Woods et al., 2012) UK	RCT	488 people with mild-moderate dementia Age: Int: 78.4 (7.4) years TAU: 78.4 (5.8) years 488 caregivers Age: Int: 70.47 (12.0) TAU: 70.3 (11.7) years (living at home)	To assess the effectiveness and cost-effectiveness of joint reminiscence groups for people with dementia and their family caregivers	12 weekly reminiscence group sessions followed by monthly maintenance sessions for a further 7 months. The sessions followed a treatment manual. Up to 12 dyads were invited to attend each group.	Data: Baseline, 3–10-months <b>Patients:</b> Quality of life (QOL-AD) Autobiographical memory (AMIF, AMIM) Activities of daily living (BADLS) Anxiety (CSDD, RAID) Quality patient/relative relationship (QICPR) Service use Costs <b>Caregivers:</b> Quality of life (EQ-5D) Psychological distress (GHQ-28) Anxiety (GHQ-28) Depression (HADS) Stress (RSS) Quality patient/relative relationship (QICPR) Service use Costs

Abbreviations: ACE-III, Addenbrooke's Cognitive Examination-III; ADAS-Cog, Alzheimer's Disease Assessment Scale – Cognition; ADCS-ADL, Alzheimer's disease Cooperative Study – Activities of Daily Living Inventory; ADL, Activities of Daily Living; ADQ, Approaches to Dementia Questionnaire; AMIF, Autobiographical Memory Interview Factual; AMIM, Autobiographical Memory Interview Memory; AMPS, Assessment of Motor and Process Skills; BADLS, Bristol Activity of Daily Living Scale; BDI, Beck Depression Inventory; BDRS, Blessed Dementia Rating Scale; BI, Barthel Index; Cope-Index, Carer of Older People in Europe Index; CANE, Camberell Assessment of Needs for the Elderly; CarerQOL, Care related Quality of Life of Informal Caregivers; CCI, Charlson's Comorbidity Index; CDR, Clinical Dementia Rating; CDRS, Clinical Dementia Rating Scale; CDT, Clock Drawing Test; CES-D, Self-assessment questionnaire for depressive symptoms, Dutch version; COPM, Canadian Occupational Performance Measure; CORE-OM, Clinical Outcome in Routine Evaluation-Outcome Measure; CSDD, Cornell Scale for Depression in Dementia; DAD, Disability Assessment Scale for Dementia; DEMQOL, Dementia specific health related Quality of Life; DQOL, Dementia Quality of Life Instrument; DR22, Mattis Dementia Rating Scale 2; EBS, Eating behaviour scale; EQ-5D / EQ-5D-3L/EQ-15D, Health related quality of life; GDS, Geriatric Depression Scale; GDS-12R, Geriatric Depression Scale (Residential); GHQ-12 / GHQ-28, General health Questionnaire, –12/ –28; GSES, General Self-Efficacy Scale; HADS, Hospital Anxiety and Depression Scale; IADL, Instrumental Activities of Daily Living; ICECAP, Capability Index for Older People; IDDD, Interview for Deterioration of Daily Activities in Dementia; KATZ-6, Katz Activities of Daily Living –6; LADL, Lawton Activities of Daily Living; MBPC, Revised Memory and Behavior Problems Checklist; MINI, Short Diagnostic Interview for DSM-IV mental disorder; MMSE, Mini Mental Status Examination; MNA, Mini nutritional assessment; MADRS, Montgomery and Asberg Depression Rating Scale; NPI/NPI-D, Neuropsychiatric Inventory Questionnaire; PANAS, Positive and Negative Affect Schedule; PGI, Personal Growth Index; PMS, Pearl In Mastery Scale; PSQ, Participant Satisfaction Questionnaire; QICPR, Quality of Caregiver-Patient Relationship; QOLS, Quality of Life Scale; QOL-AD, Quality of Life – Alzheimer's Disease Scale; RAID, Rating Anxiety in Dementia; RAND-36, 36-Item Health Survey; RMBPC, Revised Memory and Behavior Problem Checklist; RSS, Relatives' Stress Scale; RUD/RUD-light, Resource Utilization in Dementia, /-short form; SCQ, Sense of Competence Questionnaire; SF-12, UK Short Form-12 Health survey; SF-36, Short Form Health Survey-36; SPICC, Perceived Stress Caused by informal caregiving; VAS, Visual Analog Scale; VF, Verbal Fluency; WHOQOL-BREF, WHO Quality of Life – Bref; ZBI, Zarit Burden Interview; ZUNG, Zung Depression Self Rating Scale.



**FIGURE 2** Characteristics of studies ( $n = 21$ ): years of publication and number of studies by countries.



activities of living (Murphy & Oliver, 2013) or to generate discussions between PwD and their caregivers (Tyack et al., 2017). Four of the six studies adopted a psycho-educational approach to the dyad. Clare et al. (2019) focused on cognitive rehabilitation, MacNeil Vroomen et al. (2015) focused on the provision of advice and information about health and available social services, Prick et al. (2015) focused on skills training and planning of pleasant activities and Salva et al. (2011) focused on lifestyle changes.

The measured outcomes of these six studies targeting dyad interventions were heterogeneous and included caregiver burden or stress (Clare et al., 2019; MacNeil Vroomen et al., 2015; Prick et al., 2015; Salva et al., 2011), quality of life of the caregivers and/or PwD (Clare et al., 2019; MacNeil Vroomen et al., 2015; Tyack et al., 2017), caregivers' mood (MacNeil Vroomen et al., 2015; Prick et al., 2015) and mood and depression among PwD (Clare et al., 2019; Salva et al., 2011). Other measured outcomes were behaviours and neuropsychiatric symptoms of PwD (MacNeil Vroomen et al., 2015; Prick et al., 2015; Salva et al., 2011) and the performance of activities of daily living and instrumental activities of daily living (MacNeil Vroomen et al., 2015; Salva et al., 2011).

#### *Types of interventions and measured outcomes within several dyads*

In the five studies that described *joint PwD-caregiver interventions in groups* of several dyads, the interventions were offered by Tai-Chi instructors (Barrado-Martin et al., 2019), art educators (Camic et al., 2016), nurses and psychologists (Hamill et al., 2012) or a combination of nurses, occupational therapists and physiotherapists (Laakkonen et al., 2016). In one study, no information was given about the specific type of healthcare professional providing the intervention (Woods et al., 2012). Two studies reported the lengths of the interventions, which lasted between 45 and 240 min (Hamill et al., 2012; Laakkonen et al., 2016).

There was a diversity of approaches in the interventions in several of the dyads. The relationship-focused interventions aimed to support the intervention of PwD and their caregivers to live a meaningful life. These interventions included Tai-Chi classes (Barrado-Martin et al., 2019) and shared art viewing and discussing by the dyads, as well as art-making (Camic et al., 2016), circle dancing for people with decreased motor capabilities (Hamill et al., 2012) and problem solving training aimed at empowering spouses of PwD (Laakkonen et al., 2016). One intervention included several activities,

including art, cooking, a physical reenactment of memories, singing and oral reminiscence (Woods et al., 2012).

The measured outcomes of the five studies that focused on group interventions to several dyads were heterogenous and included the following: caregivers' quality of life (Hamill et al., 2012) and the quality of life of both the PwD and their caregivers (Laakkonen et al., 2016; Woods et al., 2012), a sense of competence and mastery of everyday life (Laakkonen et al., 2016; Spijker et al., 2013) and the PwD-caregiver relationship (Camic et al., 2016; Woods et al., 2012). In two studies, the outcome measures were the cost-effectiveness of the interventions (Laakkonen et al., 2016; Woods et al., 2012).

### 3.3.2 | Individual intervention: Separate intervention for PwD and their family caregivers

Five studies described separate interventions for PwD and their caregivers. The professionals who provided these interventions were nurses (Joling et al., 2013; Quinn et al., 2016), psychologists (Joling et al., 2013; Subramaniam et al., 2014) and social workers (Joling et al., 2013). One intervention was offered by volunteer carers (Charlesworth et al., 2016). The interventions for PwD lasted from 60–90 min, and those for caregivers lasted up to 180 min.

Caregivers were invited to attend workshops on their own (Charlesworth et al., 2016) or to attend a shared session with PwD at the start and the end of the intervention (Quinn et al., 2016). Although the caregivers were invited to participate in sessions on their own, PwD could attend a session if desired by the caregiver (Charlesworth et al., 2016; Joling et al., 2013).

The interventions focused on psycho-education (Joling et al., 2013), psycho-social activities (Charlesworth et al., 2016; Quinn et al., 2016) or modified cognitive stimulation therapy (Cove et al., 2014). One study created a life-story book with PwD participants (Subramaniam et al., 2014). The caregivers in this study provided the necessary materials (photos, etc.) for the sessions.

The measured outcomes of these interventions targeting PwD and their caregivers individually included the following: quality of life of PwD and caregivers (Charlesworth et al., 2016; Joling et al., 2013) or PwD only (Cove et al., 2014; Quinn et al., 2016; Subramaniam et al., 2014), depression and anxiety of PwD and caregivers (Joling et al., 2013; Quinn et al., 2016; Subramaniam et al., 2014) and quality of the PwD-caregiver relationship (Charlesworth et al., 2016; Cove et al., 2014; Subramaniam et al., 2014).

### 3.3.3 | Interventions for the family caregiver only but with outcomes for both the PwD and their family caregivers

Three studies described interventions for caregivers only but measured the effects of these interventions on both the caregivers and PwD (de Rotrou et al., 2011; Kurz et al., 2010; Torkamani et al., 2014). Psychologists and social workers (Kurz et al., 2010),

technicians and clinicians (Torkamani et al., 2014) and psychologists, geriatricians, psychiatrists, social workers, speech therapists and occupational therapists (de Rotrou et al., 2011) composed the interprofessional teams in these interventions. The lengths of the interventions were reported in two studies and lasted from 90–120 min (de Rotrou et al., 2011; Kurz et al., 2010).

All three studies included a psycho-educational programme. In the study by Torkamani et al. (2014), caregivers were given an electronic device where information about the disease was combined with social networking, data collection about the health status of the person living with dementia and request for professional contact. The intervention by Kurz et al. (2010) included the provision of information about Alzheimer's disease and support opportunities, and the intervention by de Rotrou et al. (2011) provided this information, as well as information about problem-solving techniques, emotion-centred coping strategies and practical issues.

All three studies measured performance in activities of daily living, cognition and behaviour of PwD as an outcome. In addition, Torkamani et al. (2014) measured distress and depression as an intervention outcome. All three studies also measured depression as an outcome of caregivers interventions, combined with caregiver quality of life (de Rotrou et al., 2011), caregiver time spent on care needs (Kurz et al., 2010) and caregiver burden (Torkamani et al., 2014).

## 4 | DISCUSSION

To our knowledge, this is the first scoping review to examine health-care interventions in Europe for older PwD and their family caregivers. Our review revealed that there is a lack of focus on interventions targeting the family as a system or as the unit of care, including interventions targeting PwD and their family caregivers together, and a lack of focus on family relations, family functioning and family healing in routine clinical practice. The stage of dementia influences family functioning and the burden of caregivers (Kim et al., 2021). However, the studies included in this review did not use the same definition of the different stages of dementia and did not define or describe the impact of the dementia stage on the family unit. Thus, it was impossible to determine whether the interventions could be considered helpful for families caring for relatives in certain stages of dementia.

This review highlights that family caregivers are considered only in the context of the care provided to the PwD, rather than viewing the family as a 'client' and as a unit of care (Kaakinen et al., 2018). Although 11 studies in this scoping review included a family intervention with interventions targeting both PwD and their family caregivers together, only two studies mentioned some kind of family-focused intervention to improve family functioning and health. The family-focused intervention by Laakkonen et al. (2016) involved coordinated services that had been planned in collaboration with the families to respect autonomy, enhance the empowerment of the spouses and maintain their customary way of life. The intervention by Spijker et al.

(2013) focusing on the family involved modifying the homes of PwD, observing the abilities of PwD to perform daily activities of living and caregivers' supervision skills.

Our findings are not surprising, as the implementation of family-focused care, particularly FSN, is slow in all fields of nursing (Ostlund & Persson, 2014). Obstacles to FSN implementation have been found relating to feasibility, adoption and fidelity (Pusa et al., 2021). Besides, caring for PwD and their family caregivers from a family unit perspective is a complex process that requires professionals with specific qualifications and an optimal environment that is committed to a person- and family-focused approach to care (Duhamel, 2017). Despite these barriers and challenges, implementation of the FSN model and CFIM offers an important therapeutic approach in nursing practice, especially after the COVID-19 pandemic, which demonstrated the importance of family connections (Mileski et al., 2022).

When both managers and nurses share a commitment to FSN, participatory collaboration, that is, a shift from an individual approach to a systemic and relational approach, is feasible (Kläusler-Troxler et al., 2019). Using family conversations to explore the family structure, family roles and family functioning, including interactions and relationships within the family and adaptability, organization and communication (Wright & Leahey, 2013), are crucial elements for the effective implementation of FSN (Pusa et al., 2021). The use of family models to explore the above is also useful (Duhamel, 2017). Both the CFAM and CFIM have been found to be beneficial, particularly in dementia care (Tasseron-Dries et al., 2021). These models allow a deep understanding of the family's roles, functioning, illness beliefs and their strengths and weaknesses in coping with a person living with dementia (Esandi et al., 2018). However, in this review, none of the studies utilized a specific family framework/model. To reduce the lack of emphasis on family-focused care, as evidenced in this review, we recommend that leaders support healthcare managers to implement family-focused models of care that incorporate family function as a central component of interventions. In addition, collaborative partnerships between healthcare professionals, family caregivers and personal care workers who care for PwD at home are crucial to bring together diverse perspectives and integrated care.

We also strongly suggest investing in education and training on the effective use of family health conversations, as this has been shown to raise awareness and lead to better family functioning (Ahlberg et al., 2020). Family health conversations help to support healthy family functioning and make families feel closer by encouraging the family to talk more openly with each other to improve their understanding of the illness (Ahlberg et al., 2020; Østergaard et al., 2021). Moreover, the experiences of implementation of family nursing in clinical practice do not show a greater dedication of time although it does require family nursing training (Broekema et al., 2021; Mileski et al., 2022). There is a lack of studies on the cost-effectiveness of family-focused care in the long-term care. Thus, studies are needed to address this research gap.

This scoping review identified two main types of interventions for families of older PwD: psycho-educational and relationship

focused. The psycho-educational interventions educated PwD and family caregivers about the disease process and care requirements through the provision of skills building and information, leading to knowledge development (Table 1). The relationship-focused interventions aimed to enhance shared problem solving, conflict management and communication in the patient-caregiver dyad. According to family nurse researchers (Chesla, 2010; Mahrer Imhof & Bruylants, 2014), these two types of interventions have minimal impact on patients and family caregivers. In contrast, in family-focused dementia care, the focus is on coordinating the work and recommendations of an interdisciplinary team, including nurses (Oliva & Wexler, 2017), to address family functioning, which includes family beliefs and routines, family affectivity, family roles, family communication and problem-solving, and family cohesiveness (Wright & Leahey, 2013), all of which are essential elements in dementia care.

Furthermore, this review revealed the importance of the use of creative interventional approaches, such as Tai Chi (Barrado-Martin et al., 2019), dancing (Hamill et al., 2012) or performing art (Camic et al., 2016) when dementia progression adversely affects communication within the family. In such interventions, the family relationship and bond are increased, and the emphasis shifts from focusing solely on the disease to focusing on living a meaningful life. Stimulating non-verbal communication between family caregivers and PwD can be healing for family relations and communication. Our findings are consistent with those of another study on art therapy for dementia in which engagement in artistic activities promoted patients' attention, provided pleasure, improved symptoms and enhanced intrafamily communication (Chancellor et al., 2014). Creative interventions such as those above can be used to support the implementation of family-focused care in dementia.

Healthcare providers need to adopt a person-centred approach to patient care. Organizational commitment to allowing healthcare staff to engage in 'good' practice is pivotal to implementing family-focused care (McCormack & McCance, 2006). The core goals of person-centred care are autonomy and dignity. However, achieving these goals in practice is a challenge, particularly in the case of families of PwD (Nolan et al., 2006). Supporting PwD and the family as a unit requires special nursing training (Sunde et al., 2018).

This review focused on studies conducted in Europe. Many of the studies were conducted in the United Kingdom (52.3%). Three of the four regions of Europe were represented: Northern Europe (57.14%, United Kingdom and Finland), Western Europe (33.3%, France, Germany and the Netherlands) and Southern Europe (9.5%, Greece and Spain). No studies were conducted in Eastern Europe. This is not surprising given family health research remains a low priority in many countries in this region (Santoro et al., 2016). Research on healthcare interventions for older PwD and family caregivers is needed in Eastern and Southern Europe. Exploring dementia care in different socio-cultural contexts is important because the socio-cultural setting largely influences family dynamics and functioning.

## 4.1 | Strengths and limitations

We consider it a strength that we initially undertook a very broad search of the literature for this review, as we wanted to include studies from a broad range of healthcare professions. Moreover, the methodological steps of a scoping review can be prone to subjectivity. However, in this review, we performed the selection, extraction and analysis independently and resolved any disagreement by consensus.

Intrinsic limitations associated with the search strategy of our study have to be considered. First, we did not include grey literature and searched only for studies published in English. Restricting the review by language might have resulted in relevant studies written in other languages being overlooked. Likewise, it might have increased the number of included studies if we had searched for literature in databases related to social sciences. Second, many of the included studies originated from the United Kingdom, and therefore, the transferability of our findings to the European region might be limited.

## 5 | CONCLUSION

This review examined 21 studies from seven European countries. The majority of the studies ( $n = 19$ ; 90%) considered the family of PwD as a 'care resource' and not as a 'recipient of care'. Worldwide, the family is seen as a resource for providing care to PwD and not as a 'client' who needs support to maintain family functioning and family health. Thus, the focus of most interventions is on the health of PwD first and on the family well-being second. Therefore, there is a lack of family-focused interventions that address the family as a unit of care in which the emphasis is on assessing family structures, family roles and communication, and family cohesiveness and functioning when a family member is diagnosed with dementia.

As individuals live ever longer lives, families will increasingly become responsible for the care of older PwD. In this setting, there is a need for interventions targeting both individual and family needs. Considering the increasing number of people living with dementia worldwide, and particularly in Europe, and the impact of the disease on family functioning, healthcare services and professionals need to shift from a traditionally disease-centred approach to a family-focused approach, viewing 'the family as the unit' of care.

### AUTHORSHIP STATEMENT

All authors are involved in conception and design of the work, critical revision of the article and final approval of the version to be published. CGV, HK, ES, and LI performed the data collection and analysis and drafted the article.

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### CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

### DATA AVAILABILITY STATEMENT

Data sharing is not applicable, as no new data were generated.

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