

## Review Article

# Mapping Collaboration and Coordination of Health and Care Services for Older People with Dementia: A Scoping Review

Johannes Österholm <sup>1</sup>, Åsa Larsson Ranada <sup>1</sup> and Ann-Charlotte Nedlund <sup>2</sup>

<sup>1</sup>Linköping University, Department of Health, Medicine and Caring Sciences, Division of Prevention, Rehabilitation and Community Medicine, Unit of Occupational Therapy, Linköping, Sweden

<sup>2</sup>Linköping University, Department of Health, Medicine and Caring Sciences, Division of Society and Health, Unit of Health Care Analysis, Linköping, Sweden

Correspondence should be addressed to Johannes Österholm; [johannes.h.osterholm@liu.se](mailto:johannes.h.osterholm@liu.se)

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Responsibility for health and care services for people with dementia is often divided between various professionals, agencies, and authorities, causing a fragmentation of care and an unclear division of responsibility between different stakeholders. In relation to this, collaboration and coordination of health and care services are often described as vital for catering to diverse needs and to provide adequate support. The aim of this scoping review was to map how different health and care agencies collaborate and coordinate services for older people with dementia. Joanna Briggs Institute's proposed methodology for scoping reviews was used, and systematic searches were carried out in six databases. A total of 59 articles published within the last 10 years were included based on certain eligibility criteria. The Research Pyramid was used to critically appraise these articles, suggesting that available research is of moderate quality. The descriptive content analysis of the articles revealed eight categories describing the characteristics of collaboration and coordination for people with dementia, as presented in previous articles. These characteristics are described in terms of different barriers, the function of the care coordinator, assessment and planning to provide services, interprofessional collaboration, information sharing, knowledge needed to navigate a complex health and care system and understanding of dementia, and personalisation of care. Engaging care coordinators with diverse competencies to address both medical and social care needs is essential, especially since people with dementia experience multiple and complex needs. It is also important to explain and visualise available services and when these services are suitable for implementation. Knowledge about dementia is necessary to empower people with dementia in everyday life situations.

## 1. Introduction

A commonly discussed issue, in countries around the world, is the fragmentation of health and care services for older people [1–3]. To address this fragmentation, there is an urgent need to shift the focus from health and care systems designed around diseases and institutions towards systems and practices designed for people and communities to achieve health and well-being in accordance with personal preferences and local prerequisites [4]. This shift in focus is acknowledged by the integrated care approach; “integrated services are health services that are managed and delivered so that people receive a continuum of health promotion,

disease prevention, diagnosis, treatment, disease management, rehabilitation, and palliative care services, coordinated across the different levels and sites of care within and beyond the health sector, and according to their needs throughout the life course” [5].

Collaboration and coordination are aspects often addressed and raised as vital to achieve and provide continuity and integrated and seamless care. As pointed out by The World Health Organisation (WHO) [5], collaboration entails activities that cuts across sectors, organisations, providing agencies, professional responsibilities, between providers and users, and other types of boundaries. Furthermore, coordination of care is described, by WHO, as “a

proactive approach to bring together care professionals and providers to meet the needs of service users to ensure that they receive integrated, person-focused care across various settings” [5]. Accordingly, collaboration and coordination of care can be regarded as related to the provision of services both within and across various agencies where the patients receive the continuum of health and care services according to their need. In WHO’s framework on the integration of care of older people [6], it is highlighted that actions are needed to integrate and implement care for older people at multiple levels: on the system level (e.g., financing health and care services, available services, accountability systems, guidelines, and regulations), the service level (e.g., coordination of services delivered by interdisciplinary providers), and the personal level (e.g., patients’ goals, providing service to maximise capacity, and functional abilities of the older person). Thereby, collaboration and coordination of health and care services can refer to services provided by different professionals with various disciplinary backgrounds, working either on the same or on diverse levels within the same or at different health or care agencies.

Dementia is an umbrella concept used for cognitive and behavioral symptoms associated with different progressive brain diseases affecting higher cognitive functions (such as Alzheimer’s disease, vascular dementia, and Lewy body dementia). Later stages of a dementia disease are often associated with multiple and complex health and care needs [7]. In the coming years, the number of people with dementia is expected to grow [6, 8]. Consequently, stress will be put on health, social care, and welfare systems regarding challenges in prioritising due to limited resources [9]. That is, care agencies must know how to use resources in a fair, appropriate, and effective way and to do what is most relevant for catering to the person’s health and care needs. Therefore, different care agencies, with various responsibilities, must collaborate and coordinate their services [10] to overcome the risk that people with dementia, and their carers, do not receive the formal support that they need or are entitled to [11]. Considering the widespread consensus on the significance of collaboration and coordination in achieving integrated care, the aim of this scoping review was to map how different health and care agencies collaborate and coordinate services for older people with dementia.

*1.1. Previous Research on Collaboration and Coordination regarding People with Dementia.* Previous research on coordination of health and care services for older people with dementia has primarily been conducted from the perspective of case management, also referred to as care management [12, 13]. Case management is a complex intervention used to identify various needs and to provide or coordinate medical and community services [14, 15]. A commonality of case management is that one key person coordinates and monitors all support and services provided to the service user [16]. The impact of case management is diverse and varies according to previous research [10, 17]. Probably this is because case management is implemented differently in various countries or contexts with different management

systems, funding policies, and cultural variations governing the process [10, 17]. In addition to this, the clinical setting has consequences for how case management is implemented [13]. For example, additional support such as cognitive stimulation, stress management, and psychological support might be provided at memory clinics but not provided at a primary care setting [13, 14, 18].

There are some previous reviews summarising the evidence on interventions aiming at coordinating health and care services for people with dementia [10, 12], but most reviews on collaboration and coordination of health and care services do not single out a specific target group. Røsvik and colleagues [12] mapped and examined research, in a scoping review, on how access to and use of formal community services could be improved through case management, monetary support, enhancing referral, and information sharing. In the process of coordinating health and care services for people with dementia, a variety of professions (e.g., social workers and nurses) or interprofessional teams are involved [10, 14, 15, 19, 20]. The disciplinary background of the professionals and their organisational affiliations have also been described to have consequences for what is pointed out as important in the process of coordinating care for people with dementia. Furthermore, interprofessional teams working collaboratively could result in more efficient primary, secondary, and tertiary care for people with dementia [10]. Information sharing between different agencies and different care providers with various disciplinary backgrounds has been identified as vital when coordinating services for people with dementia to provide appropriate support, especially in terms of communication between different agencies and professionals [14, 15, 19]. Less is known about the actual collaboration and coordination taking place between different agencies of professionals working together either at the same or at diverse levels in health, social care, and welfare system and what the consequences are for the individuals concerned and their significant others.

Even though there is a legal requirement in many countries for different care agencies and various professionals to collaborate and coordinate their services or activities [5], this does not seem to achieve the expected result—to create good, fair, accurate, and effective provision of care for older people [4, 5]. Therefore, more knowledge is needed on how different care agencies collaborate and coordinate health and care services for people with dementia.

## 2. Review Questions

The aim of this scoping review was to map how different health and care agencies collaborate and coordinate services for older people with dementia.

RQ1: what characterises collaboration and coordination between different care agencies regarding people with dementia?

RQ2: what are the outcomes reported following collaboration and coordination of health and care services for people with dementia?

RQ3: what are the experiences described by different agency representatives, service providers, service users, and significant others regarding collaboration and coordination of health and care services for people with dementia?

### 3. Materials and Methods

**3.1. Study Design.** A scoping review has been carried out following the methodology proposed by Joanna Briggs Institute (JBI) [21], reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) [21–23]. A protocol presenting the design of this scoping review in more detail has previously been published [24].

**3.2. Search Strategy.** An initial limited search [21] was conducted in PubMed and CINAHL to identify and determine search terms. The final search for this scoping review was then conducted in PubMed, CINAHL, Embase, PsycInfo, Scopus, and Web of Science using the search terms reported in Appendix A. The search terms and the combination of search terms were adjusted according to the instructions of each database. The final search was conducted on the 6th of April 2022.

Neither a citation search nor a reference list search was conducted. This was agreed upon among all authors, since the number of articles included was judged to be extensive and sufficient to address the aim and the research questions of this scoping review.

**3.3. Study Eligibility.** The inclusion criteria in this scoping review were that the studies should be empirical (conducted with qualitative, quantitative, or mixed methodology) and published in peer-reviewed journals in the English language. Study protocols, reviews, letters to editors, opinions, doctoral dissertations, and conference abstracts have been excluded. A 10-year limit, considering the publication date of articles, has also been applied (i.e., 2012 and forward) to include contemporary research in this scoping review.

**3.4. Search Outcome.** All potential studies were imported to an EndNote 20© library. EndNote 20© was utilised to identify and remove duplicates of articles. EndNote 20© was also employed to identify and exclude articles based on their publication years and type of publications (i.e., study protocols, reviews, letters to editors, opinions, doctoral dissertations, and conference abstracts). Inclusion of articles was then based on titles and abstract screening and full text reading (JHÖ and ÅLR). All included articles were then retrieved in full text and imported to an EndNote 20© library. A full text reading was conducted of all included articles at this stage to ensure that articles were relevant in accordance with the eligibility criteria of this scoping review (JHÖ and ÅLR). During the article selection process, disagreements in article inclusions were discussed among all authors until consensus was reached. The study selection

process is reported in a PRISMA flow diagram [25] (Figure 1). A list of articles excluded after full text reading can be obtained from the authors.

**3.5. Data Extraction Process.** Data of relevance for this scoping review's aim and research questions were extracted from the included articles. A Microsoft Excel© spreadsheet was used for organising the extracted data, including the following parameters: (1) basic characteristics of the included studies (author(s), year of publication, country of origin, aims/purposes, and methodology/method); (2) different stakeholders represented/presented in the study (i.e., from which perspective is collaboration and coordination studied, who are participating in the study); (3) intervention or model of collaboration or coordination; and (4) outcome or key findings of the intervention/model.

**3.6. Critical Appraisal.** All included articles were critically appraised (ÅLR) and then verified (AN and JHÖ), using the Research Pyramid Model, which allows articles with different study designs to be critically appraised [26]. The Research Pyramid Model is illustrated as a pyramid, where descriptive research forms the base of the pyramid, and the three sides represent experimental research, outcome research, and qualitative research. Each side and the base are divided into four levels used to appraise the evidence. Evidence grading, according to the JBI recommendations for scoping reviews, could either be based on the title, abstract, or full text of included studies [21]. The grading of the evidence has been based on the included articles' abstracts and is presented both in text and tabular form in the Findings section.

**3.7. Data Analysis and Synthesis.** A descriptive and inductive content analysis [27] was performed. This analytical approach was chosen because scoping reviews typically do not synthesise the results of the articles included [21]. The extracted data in the spreadsheet were coded independently by all authors. In this coding procedure, extracted data were labelled with a shorter sentence or a single word with the intention of shortening the extraction but keeping the principal content of these kinds of extraction. All codes of the extracted data were then discussed by all authors together. These codes were then compiled into categories of relevance for what characterises collaboration and coordination of health and care services for older people with dementia. Eight categories emerged and could be identified in the analysis. Discussions among all authors have occurred continuously throughout the analytical process. This procedure was chosen to ensure rigidity in the analysis, and that the findings emerged from the included articles and not a single author's preunderstanding of the studied topic at hand.

### 4. Ethical Considerations

Scoping review does not require approval from a human research ethics authority as it does not involve human participants.

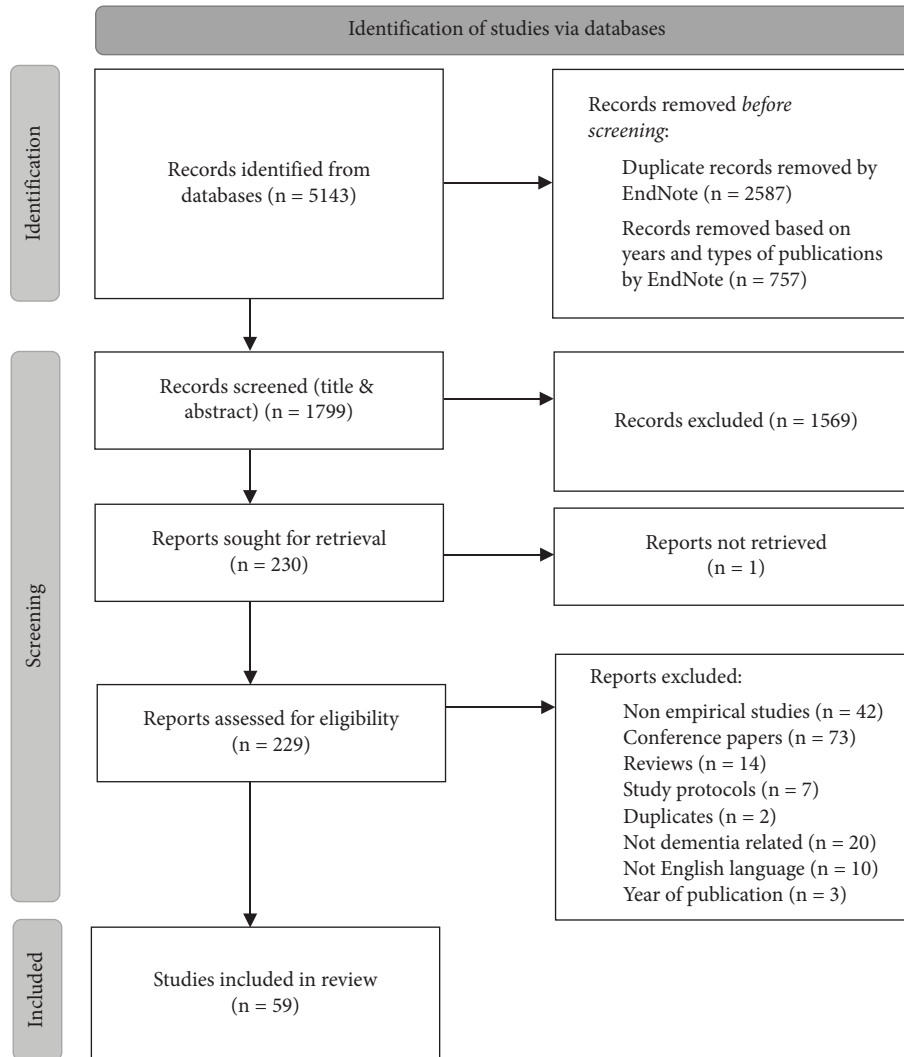


FIGURE 1: The identification, screening, and inclusion process present in a PRISMA flowchart.

## 5. Findings

In this section, we will present the *characteristics of the included studies*, the *grading of the evidence*, and what *characterises* collaboration and coordination for people with dementia. Based on the content analysis, we identified eight categories of what characterise *collaboration and coordination* for older people with dementia. These categories are presented in Section 5.3.

**5.1. Characteristics of the Included Articles.** In this scoping review, 59 articles were included. Of these articles, 27 had qualitative design, 20 quantitative design, and 12 mixed method design. The qualitative data were collected using interviews (21), focus group interviews (10), or observations (4). Seven (7) of the quantitative studies were randomised controlled trials. Twenty-seven of the articles included persons with dementia as participants (among these, eight studies included dyads). Health or social care professionals were participating in thirty-seven of the included articles. More characteristics and the main findings of the included articles are presented in Table 1.

Most of the articles included were conducted by researchers located in Western countries (27 in Europe and 23 in North America), with additional studies conducted in Asia (4) and Oceania (3). Additionally, a few articles were co-authored by researchers from Asia and Europe (1) and Oceania, North America, and Europe (1).

**5.2. Grading of the Evidence.** About half of the included studies ( $n = 29$ ) were categorised according to the Research Pyramid Model [26] as qualitative research (27 qualitative methods and two with a mixed method design), all at level 3 (group qualitative studies with less rigor). Thirteen (13) articles were categorised as outcome research, with ten (10) at level 3 (case-control studies, preexisting group comparisons) and three (3) at level 4 (one-group pre-post studies). Ten (10) articles were categorised as descriptive research, nine (9) at level 3 (multiple-case studies, normative studies, descriptive studies) and one at level 4 (individual case studies). The remaining seven articles were categorised as experimental research, five at level 3 (controlled clinical trials) and two at level 2 (individual blinded randomised

TABLE 1: Characteristics and main findings of the included articles.

Reference	Country	Aim	Method	Sample	Model/intervention	Key findings	Evidence
Abendstern et al. [79]	UK	To describe features of and approaches to care coordination practice and explore reasons for variations	Semi-structured interviews	13 non-statutory sector services	—	Non-statutory sector services provide innovative support. This complements and sometimes substitutes for services within the statutory sector.	Q3b
Amjad et al. [58]	US	To investigate the effects of MIND, a care coordination program on health services utilisation	In-person, self-report interviews	303 community dwelling adults with cognitive disorder	MIND	MIND had no impact on utilisation of acute care/inpatient services. MIND at home increased use of dementia-related outpatient medical care and non-medical supportive community services.	E2
Ashbourne et al. [60]	Canada	To study the care transition experiences of PWDs and their caregivers	Individual and dyad interviews	12 PWDs, 29 caregivers (12 dyad interviews)	—	A theoretical framework was outlined. Key themes: transition context, transition processes, and influencing factors. Transitions are situated within communities, influenced by perceptions and aims of participating actors.	Q3b
Bamford et al. [31]	UK	Based on normalisation process theory, to report and evaluate barriers to implement case management in England	Qualitative interviews, informal discussions, observations	6 PWDs, 10 carers, 9 case managers, 4 case managers/mentors, 2 research members, 6 general practitioners, 5 administrative practice staff, 2 community mental health team members, 3 voluntary sector workers, 2 commissioners/funders	Case management	There are barriers to implement case management: how to embed case managers in existing well-established community networks, protecting time for case management, case managers' inability to identify/act on emerging needs	Q3b
Bass et al. [53]	US	To test the effectiveness of Partners in Dementia Care (PDC)	Seven diverse caregiver outcomes	394 PWDs (veterans), 324 caregivers	PDC	Significant improvements in outcomes representing unmet needs, caregiver strains, and depression. PDC improves linkages between health care services and community services.	O3

TABLE 1: Continued.

Reference	Country	Aim	Method	Sample	Model/intervention	Key findings	Evidence
Brown et al. [52]	US	To examine if the effect of a dementia collaborative care management intervention varied depending on the educational attainment of the informal caregiver	22 dementia care indicators and self-reported caregiver education	392 dyads (PWDs and carers)	Collaborative care management	Collaborative care management was associated with smaller disparities in dementia care quality between caregivers with lower educational attainment and those with more education	E3
Chase et al. [32]	UK	This paper presents challenges in operationalising an integrated pathway from the service providers' perspective	Interviews, focus groups, observations, service attendance, performance metrics reviews	Practitioners	Integrated dementia care	There are several challenges for integrative dementia care such as interpractitioner prejudices, restrictive and competitive commissioning frameworks, and barriers to effective data sharing, with consequences such as practice overlap and failure to identify and respond to people's needs	Q3b
Chen et al. [78]	US	To assess if a care coordination and caregiver support intervention reduces the use of acute medical services for patients with Alzheimer's disease and their caregivers	Medical expenditures, emergency departments visit, inpatient admissions, inpatient discharge	101 PWDs, 63 caregivers	Memory program	Care coordination does not decrease overall acute health service use. Coordination of care improved clinical documentation of patients' memory impairment. Stress levels among caregivers may decrease.	O4
D'Souza et al. [51]	US	To describe the Caring for Older Adults and Caregivers at Home (COACH) program's operation, assess alignment of program components with quality measures, report characteristics of program participants	The dementia management quality measures	133 dyads (PWD and caregiver)	COACH	COACH is a home-based care coordination intervention for PWDs and their family caregivers that enhances care and is aligned with quality measures	D3

TABLE 1: Continued.

Reference	Country	Aim	Method	Sample	Model/intervention	Key findings	Evidence
Darlak et al. [54]	US	To describe engagement of veterans with dementia in PDC	Structured interviews	202 veterans with dementia	PDC	Most veterans had a minimum level of actual engagement in PDC. Higher levels of engagements were reported among younger veterans and those self-reporting more memory difficulties.	Q3b
Marcusson et al. [67]	France	To develop an understanding of the role played by case manager teams. To identify the value of interprofessional collaboration in multidisciplinary teams.	Focus groups	59 case managers (nurses, social workers, occupational therapists, psychologists)	—	Multidisciplinary teams consisting of case managers are central when implementing case management and when to develop a new role and a core interprofessional competency	Q3b
Faeo et al. [47]	Norway	To explore the coordinator's role and how coordinators may empower PWDs in decisions	In-depth and focus group interviews	6 dyads (PWD and carer), 3 carers, 2 coordinators and leaders	The LIVE@HomePath	Coordinators are perceived as a safety net, being a pathfinder and a source for emotional support and care	Q3b
Galvin et al. [83]	US	To test if early dementia detection and comprehensive care consultations would improve health outcomes for PWDs and family caregivers	The 12-item Zarit Burden Inventory and the Dementia Care Confidence Scale	244 community dwelling PWDs and family care givers	Project Learn MORE (Missouri Outreach and Referral Expanded)	Increased detection of cases of dementia in the community. Possible to connect PWDs and their families with appropriate services. Psychosocial interventions at an early phase may have a significant impact on improving patient- and family-centred outcomes.	O3
Amjad et al. [58]	UK	To understand differences between experiences of carers with and without support from admiral nurses	Focus groups, in-depth interviews	35 carers	Admiral nursing	Continuous support, expertise in dementia, and a meaningful relationship are key features for creating a relationship with carers	Q3b

TABLE 1: Continued.

Reference	Country	Aim	Method	Sample	Model/intervention	Key findings	Evidence
Ha et al. [29]	Singapore, Netherlands	To evaluate the process and extent of integration within Comprehensive, Accessible, Responsive, Individualised, Transdisciplinary, Accountable, and Seamless (CARITAS)	Questionnaires, observations, semi-structured interviews	Key stakeholders (13 questionnaires, 17 interviews, 14 observations)	CARITAS	Inspiring clinical leaders and tacit interdependencies among partners strengthened the network. The lack of structured documentation and a shared information-technology platform hindered functional integration.	Q3b
Ha et al. [41]	Singapore	To evaluate CARITAS' impact on patients and caregivers as well as its cost-effectiveness	The EQ-5D-3L, the Zarit Burden Interview, revised memory and behavior problems checklist	344 patients and caregivers	CARITAS	CARITAS reduced caregiver burden, improved PWDs' behavioral problems, and reduced depression and was comparable to pharmacological and non-pharmacological interventions for dementia. Cost-effectiveness found.	O3
Heckman et al. [30]	Canada	To understand physicians' and specialists' perspectives on primary care collaborative memory clinics (PCCMCs)	Telephone interviews	10 physicians, 10 specialists	PCCMCs	Challenges identified; lack of education, inadequate resources, a need for closer collaboration, lack of standardised electronic medical records	Q3b
Heinrich et al. [34]	Germany	To evaluate knowledge management strategies in dementia care networks	Single and group interviews	13 dementia care network coordinators, 68 health and social care professionals	Dementia care networks	Lack of time and lack of financial resources are barriers for implementing knowledge management structures and processes in DCN. Competition among various actors.	Q3b
Hirakawa et al. [35]	Japan	To identify barriers for cooperation and coordination among medical professionals, care managers, and medical social workers	Focus groups	4 directors of nursing service departments, 3 chief nurses, 4 medical social workers, 2 care managers	Community-based integrated dementia care	Dementia care teams in hospitals honoring decisions made by PWDs were important factors	Q3b
Bamford et al. [31]	UK	To adapt the PREVENT and test it in general practice	In-depth interviews, identify unmet needs, actions to meet needs	28 dyads (PWD + carer), 1 carer, 63 case managers	PREVENT	Case management provides a safety net and a therapeutic relationship	D3



TABLE 1: Continued.

Reference	Country	Aim	Method	Sample	Model/intervention	Key findings	Evidence
Jasper et al. [28]	UK	To identify practitioner's preferences as to the relative value of different service attributes of care coordination for older people in the English non-statutory sector	Discrete choice experiment survey	120 practitioners		Continuity of care and access to services outlined in the care plan were the most important service attributes. The length of time services were provided was important	D3
Kazawa et al. [61]	Japan	To explore the impact of providing dementia care during COVID-19 on caregivers involved in dementia care	Semi-structured interviews	46 family carers, care managers, staff	Collaboration	The process of aligning the perceptions of caregivers to the objectives and priorities of care for older people with dementia during the COVID-19 pandemic strengthened the relationships among caregivers	Q3b
Lee et al. [86]	Canada	To describe the implementation of PCCMCs and the impact of these on access to quality assessment and management of dementia within primary care	Surveys (online/paper-based), individual or group telephone interviews, charts	Surveys (55 PWDs, 34 caregivers), 27 physicians (surveys). Interviews (13 physicians, 13 nurses, 5 Alzheimer society representatives, 4 social workers, 2 mental health counsellors, 1 occupational therapist, 1 pharmacist, 1 care navigator	PCCMCs	Patients and caregivers were satisfied with received care. Family physicians reported increased capacity to manage dementia. PCCMC, led by family physicians, provides timely access to high-quality collaborative dementia care.	D3
Heckman et al. [30]	Canada	To describe the strategic implementation of the PCCMCs	Individual interviews	11 physicians, 12 allied health professionals, 9 initiative leaders	PCCMCs	PCCMCs facilitate earlier identification of dementia, increased capacity for dementia care, better patient and caregiver experience with care, improved continuity, integration and coordination and improved care, and system efficiencies	Q3b

TABLE 1: Continued.

Reference	Country	Aim	Method	Sample	Model/intervention	Key findings	Evidence
Lee et al. [33]	Canada	To explore collaborative relationships between family physicians and specialists caring for persons with memory concerns in PCCMCs	Survey	25 geriatricians, 3 geriatric psychiatrists	PCCMCs	Specialists and family physicians valued their collaboration but desired more time for collaboration. Structured relationship-building is needed (formalised processes, clear delineation of roles, responsibilities, and expectations)	D3
Lee et al. [66]	Canada	To describe key lessons learned in the development and implementation of PCCMCs	Individual telephone interviews, online surveys	139 health and social care professionals (physicians, reg. nurses, physicians' assistants, social workers, pharmacists, occupational therapists, Alzheimer society representatives, home and community care representatives, community responsive behavior team members, chaplains, and coordinators) answering 183 surveys and 40 interviews	PCCMCs	Interprofessional team-based models that facilitate cross- and intersectional partnership may facilitate access to care, improve quality of dementia care, and build community capacity for dementia care	D3
Leggett et al. [39]	US	To explore the process of caring for PWDs in various care settings across a tertiary care system	Interviews	49 stakeholders; clinicians (doctors, nurses), support staff (social workers, clinic directors, hospital security, hospital bed management), family members	—	Recommendations for better care: outpatient education, care management to link services, Internet-based training for providers, and re-use of attendants as senior life specialists	Q3b
Lertkratoke et al. [63]	Thailand	To examine the effectiveness of the Thai integrated care program for dementia	2 questionnaires, 6 instruments	19 PWDs, 19 caregivers	Thai integrated care program for dementia	The Thai integrated care program for dementia has the potential to maintain quality of life and reduce caregiver burden	O3

TABLE 1: Continued.

Reference	Country	Aim	Method	Sample	Model/intervention	Key findings	Evidence
Luckett et al. [75]	Australia, US, Germany	To explore the palliative care planning coordinators (PCPC) and health professional perceptions of the benefits of facilitated case conferencing and identify factors influencing implementation	Semi-structured interviews	11 PCPCs, 18 nurses, 8 allied health staff, 3 physicians	PCPC	This study addresses known barriers to case conferences causing difficulties to receive the required levels of nursing qualification, training, and time. Collaboration and relationships with health professionals are also prerequisites for success.	Q3b
Vroomen et al. [50]	Netherlands	To evaluate outcomes for PWDs and informal caregivers of intensive case management model (ICMM) and Linkage model (LM)	Interviews and questionnaires	521 dyads (PWD and carer)	ICMM and LM	ICMM positively affected caregivers' quality of life and the number of needs of the patient compared to people in LM and people without access to case management	O3
World Health Organisation [76]	Canada	To evaluate the usability of a care coordination application and its effectiveness at easing caregiver burden	4 instruments	4 caregivers	The family care coordination app	An initial part of understanding the usability of a care coordination application	D4
Mavandadi et al. [45]	US	To examine if a brief community-based telephone-delivered collaborative dementia care management program was associated with changes over time	Sociodemographic information, standardised assessments	75 caregivers	Telephone-delivered collaborative dementia care management program	Reduction in distress due to dementia-related symptoms and larger improvements in ability to cope and caregiving mastery among caregivers	E3
Mavandadi et al. [46]	US	To evaluate a brief community-based telephone-delivered collaborative dementia care management intervention	4 instruments/questionnaires	440 caregivers	Telephone-delivered collaborative dementia care management program	Reduction in caregivers' burden over time with care management. Dementia-related behaviors and distress among care givers were reduced.	O3
Moore et al. [73]	UK	To understand how the compassion intervention operated in nursing homes in different health economies	Interviews, assessments	9 PWDs, 4 family members, 28 health care professionals	The compassion intervention	Implementation of the compassion model was feasible to differing degrees across sites. The implementation depends on the context.	O3

TABLE 1: Continued.

Reference	Country	Aim	Method	Sample	Model/intervention	Key findings	Evidence
Nadash et al. [62]	US	To report on a process evaluation assessing the Dementia Care Coordination Program (DCCP) supporting families of persons with dementia (PWDs)	Interviews, focus groups, survey	Interviews: 5 Alzheimer's associations, 4 staff/administrators from health plan, 6 health care providers Survey: 15 physicians	DCCP	The studied health plan model of collaboration offers potential for early detection of potential clients	O3
Nordh and Nedlund [71]	Sweden	To explore the experiences of care managers involved in assessing the need for social services	Interviews	19 care managers		Care managers are constantly trying to find new strategies to manage their practical work situation and to include PWDs in decision making about social care services. The risk of using strategies is infringing on the person's right to self-determination.	Q3b
Oostra et al. [69]	Netherlands	To investigate how care integration in interprofessional primary dementia care networks matures and to identify factors associated with (un)successful maturation	Interviews, protocol	17 network of primary dementia care	The DementiaNet program	Participation of a GP, to know each other's expertise, having a competent leader, and a stable composition of participants are of importance	O3
Peeters et al. [42]	Netherlands	To study whether satisfaction with dementia case management and the development of caregiver burden depend on the organisational model	Survey	429 caregivers	Case management from first dementia symptoms or after diagnosis by specialist	The organisational features make little or no difference in caregiver burden or regarding the satisfaction of informal caregivers	D3
Phillipson et al. [38]	Australia	To explore the perspectives and practices of care planners and case managers through the consumer-directed care program	Semi-structured telephone interviews	16 planners and managers	Consumer-directed care	Managers aspire to support choice according to person-centred care. Capacity to support decision making was limited by capped care budgets, skills, and time needed in a market-based system. Decentralised systems and increased care budgets may improve decision making among PWDs.	Q3b

TABLE 1: Continued.

Reference	Country	Aim	Method	Sample	Model/intervention	Key findings	Evidence
Piercy et al. [40]	UK	To evaluate the implementation and the outcomes of an integrated service delivering post diagnosis To evaluate the implementation and outcomes of an integrated service delivering post-diagnosis is	Activity data, survey, focus groups, individual interviews	Patient data, 84/92 questionnaires, 2 focus groups (3 admiral nurses, 7 dementia advisors, 1 service administrator), 6 partner representatives	Admiral nurses or dementia advisors	Satisfaction with the service among carers was high. Individual caseloads ensured continuity of care. The integrated structure facilitated seamless transfer of caseloads. Challenges of managing large workloads and agreeing on division of responsibilities across the skill-mix of staff.	O4
Possin et al. [82]	US	To determine whether the care ecosystem is effective for PWDs, their caregivers, and payers beyond those achieved with usual care	Assessments	571 dyads (PWD and caregiver)	Care ecosystem	Telephone-based collaborative dementia care consisting of provision of education, support, and care coordination reduced emergency department visits and caregiver depression/burden and increased PWDs' quality of life	E2
Reinhoudt-den Boer et al. [80]	Netherlands	To explore what action strategies case managers use to handle conflicts in health care	Interviews, observations	19 case managers (10 observations)	Case management	Case managers use strategies when coordinating care and support for PWDs and their carers. Coproduction (compromises, use tricks to persuade to accept services), production (letting time go, ally with PWDs or carers, exercise control), and act in desperation (passing on responsibility, inaction rather than reduce crises)	Q3b
Renehan et al. [55]	Australia	To develop and describe an optimized key worker framework for PWDs and their families	Semi-structured interviews, systematic review, qualitative evaluation of key worker models	14 organisation managers, 19 key workers, 5 PWDs, 10 carers	Optimized key worker framework	The key worker framework includes four components: overarching philosophies, organisational context, role definition, and key worker competence	Q3B

TABLE 1: Continued.

Reference	Country	Aim	Method	Sample	Model/intervention	Key findings	Evidence
Risco et al. [84]	Spain	To identify barriers and facilitators in dementia care	Focus groups	25 health care professionals (physicians, nurses, and social workers), 20 caregivers, 15 PWDs	—	An important part of successful care coordination during dementia care is the family. Benefits for people with dementia and caregivers can be achieved with self-management strategies and case management.	Q3b
Robertshaw and Cross [68]	UK	To understand views and experiences of integrated health and social care	Open online course, discussion board posts	847 board posts from carers, families, health care professionals	—	Integrated care should be person-centred and holistic, involving a multidisciplinary team (health and social care practitioners), the patient, the family, and the wider community	D3
Rosa et al. [70]	US	To evaluate the direct costs of implementing a collaborative dementia care program	Micro-cost analysis	464 dyads	Collaborative dementia care program	The caseload of care teams navigators is an important driver of service cost	O4
Samus et al. [56]	US	To assess whether a dementia care coordination intervention delays time to transition from home and reduces unmet needs	Demographics, assessments	303 older community dwellings (110 intervention groups)	MIND	MIND delivered by non-clinical community workers led to delays in transition from home, reduced unmet needs, and improved self-reported QOL	E3
Scerri et al. [72]	Malta, UK	To explore the perceived challenges of nurse managers in acute hospitals and to identify possible solutions	Focus groups	16 nurse managers	—	Care coordination is described as a possible solution for improving direct quality of care for PWDs	Q3b
Steiner et al. [43]	Australia	To ensure that the region-specific needs of the memory clinic were considered	Semi-structured interviews	20 GPs, 78 seniors, 25 community health care workers	Multidisciplinary memory clinic	GP requires support to make diagnosis. Expectations of a memory clinic include diagnostic services, rapid referrals, case management, education, legal services, and culturally sensitive judgements.	Q3B

TABLE 1: Continued.

Reference	Country	Aim	Method	Sample	Model/intervention	Key findings	Evidence
Stephan et al. [44]	Germany, Ireland, Italy, Netherlands, Norway, Portugal, Sweden, UK	To explore barriers and facilitators of access to and utilisation of formal care	Focus groups	51 PWDs, 96 carers, 114 health care providers	—	Attitudes towards PWDs and their carers often serve as barriers. Formal care is avoided as long as possible since it is perceived as a threat to independence. A key contact to establish a consistent and trusting relationship.	Q3b
Stephan et al. [36]	Germany	To investigate perceptions of successful collaboration and to describe obstacles and facilitators	Focus groups	13 health care professionals, 17 informal carers	—	Constraints in the health care system may considerably hinder successful collaboration. A permanent contact person might facilitate access to professional support and improve collaboration.	Q3b
Tanner et al. [49]	US	To assess whether MIND reduces unmet caregiving needs and burden of caregivers	Demographics, assessments	289 care recipients, 278 caregivers	MIND	MIND at Home has a clinically meaningful impact on informal caregivers' time with care recipients	E3
Thyrian et al. [57]	Germany	To test the effectiveness and safety of dementia care management (DCM) in the treatment and care of PWDs	Computer- assisted interviews, assessments	407 PWDs, 86 GPs	DCM	DCM (by nurses) is an effective collaborative care model that improves patient and caregiver-related outcomes in dementia	E3
Tilburgs et al. [65]	Netherlands	To explore barriers and facilitators concerning advanced care planning (ACP)	Semi-structured interviews	10 GPs, 10 PWDs/ caregivers, 1 focus group with case managers/practice nurses	ACP	ACP requires trust between the GP, PWD, and caregiver. In ACP, both medical and non-medical concerns are addressed. GPs' availability and time restraints are barriers to ACP.	Q3b
Van Mierlo et al. [64]	Netherlands	To evaluate a transfer intervention to nursing homes	Interviews	5 community psychiatric nurses, 5 family carers, 12 nursing homes carers, 11 professional caregivers	Transfer intervention	The transfer intervention increased the awareness of nursing home staff about personal and behavioral characteristics of residents with dementia and supported caregivers in coping with the new situation	Q3b

TABLE 1: Continued.

Reference	Country	Aim	Method	Sample	Model/intervention	Key findings	Evidence
van Mierlo et al. [37]	Netherlands	To explore facilitators and barriers of the LM and the combined IM/joint agency model	Semi-structured interviews	22 stakeholders (project leaders, case managers, health insurers, municipalities, Alzheimer Netherlands)	LM and ICM	It is easier to implement the IM as a case manager due to less competitiveness. The model is more intricately linked to the expert group than case managers in the LM.	Q3b
Verbeek et al. [74]	UK, Netherlands	This study portrays teams in 2009 against which subsequent service provision may be compared	National postal survey	367 integrated community mental health teams	—	Care coordination between agencies was less prevalent than care coordinators supervising care provided by team members. In teams, there was an increase in non-medical staff and unqualified support staff. Less common was integrated work between health and social care and between primary care and secondary care.	D3
Waugh et al. [59]	UK	To report the adaptation of the PREVENT intervention to the setting of the English National Health Service	Co-design development meetings, nominal group techniques	12 multidisciplinary groups (occupational therapist, social worker, admiral nurse, family carers, consultant psychologist, GP, community psychiatric nurse, outreach worker from Alzheimer's society) and 11 older people	PREVENT	Generic skills and attributes for acting as case managers were described as interaction (with each other regularly) and mapping resources and to work proactively to identify resources to support PWDs and diminish risks associated with distress	Q3b
Willink et al. [85]	US	To examine the cost of providing care to older adults with dementia and their care partners	Cost of care management service	342 MIND recipients	MIND	MIND is a cost-effective coordination program for home-based dementia care. Trained non-clinical community workers form the primary contact, supported by a multidisciplinary team.	O3



controlled trials). Thus, 53 articles were on level 3, four on level 4, and two on level 2, suggesting that the evidence for the articles included must be deemed as moderate (see Table 2).

*5.3. Characteristics of Collaboration and Coordination for People with Dementia.* Various characteristics of collaboration and coordination of health and care services for older people with dementia were identified through the inductive and descriptive content analysis. These are presented in Table 3.

*5.3.1. Structural and Organisational Barriers Hindering Collaboration and Coordination.* Consistency and stability over time were identified as central aspects when coordinating health and care services for people with dementia [28]. There are several *structural barriers* presented in the included articles such as lack of structured documentation [29], lack of shared information-technology platforms between various organisations or agencies [29, 30], lack of clarity [31], difficulties in coordinating multiple schedules, inadequate infrastructural support, and insufficient communication among team members [32, 33]. Staffs' lack of skills, training, and limited time for reflection or feedback were also raised as structural barriers [31].

There are also *organisational barriers* described in the included articles, hindering collaboration and coordination of health and care services for older people with dementia. These include lack of sustainable funding and consistency [30, 33–35], lack of financial compensations for collaborative practices, lack of designated time [36, 37], restrictive commissioning frameworks, constraints in resources [32], competing priorities in everyday work [33], competition among various care agencies [34], a centralised care system [38], and blurry boundaries of responsibility in-between different organisations or agencies [39, 40]. Other organisational barriers consist of inflexible structures and services [36], limited availability of care places [39], and lack of service integration [41]. One article [42] showed that the organisational features did not affect care giver burden.

*5.3.2. Care Coordinator as a Function for Enhancing Collaboration and Coordination.* Many articles took their point of departure in a key person [43, 44], often referred to as a care coordinator, case manager, care manager, social worker, or admiral nurse (i.e., registered nurses who are specialised in dementia care), that served an important function for enhanced collaboration and coordination of services. Several tasks for the care coordinators were mentioned in the articles, such as making various organisations' responsibilities explicit, referring the person with dementia to the right care provider, giving recommendations on how to proceed, support in contacts, and creating a structure or a timeline for when certain tasks should be carried out or when support should be implemented [37, 45]. Furthermore, as part of their function, care coordinators advocate the necessity of services [46] and provide emotional support to the person with dementia [47, 48].

TABLE 2: Levels of evidence for included articles.

	Level 1	Level 2	Level 3	Level 4	Total
Descriptive research			9	1	10
Experimental research		2	5		7
Outcome research			10	3	13
Qualitative research			29		29
Total	0	2	53	4	59

When services were provided by different organisations or care agencies, the care coordinator's function was to link the person with dementia, in relation to their care needs, to relevant care providers [37, 49, 50]. On the contrary, imbedded, or integrated care coordinators within an organisation or a care agency were described to work intensively with the same patient over time, in close collaboration with other health care professionals at the same agency [40, 50].

In some articles, care coordinators with medical knowledge, working in a health care organisation, were addressing medical needs, while care coordinators within community services were responsible for catering to social care needs [51–56]. Care coordinators representing a medical discipline were presented as having additional working tasks, which might be prioritised over work related to coordination of care [50].

*5.3.3. Assessments and Planning to Provide Services in Relation to their Care Needs (Current).* Various assessments and interventions were prominent components of collaboration and coordination of health and care services for older people with dementia described in the articles. A structured assessment was depicted as important to ensure that care needs were not missed when coordinating services [52]. Computer-based systems [57] and standardised protocols provide a clear division of responsibility among all professionals [53, 54, 58] to address both medical and non-medical needs [53]. Standardised protocols were also used to ensure an equal distribution of services, to support the care coordinator in prioritising various patients [37], and to facilitate for care coordinators to be proactive in their work rather than acting on crises as the disease trajectory progresses [59].

Since dementia is a progressive condition, the assessment of the person's needs of care must be continuously updated, discussed, and reported back to the patient and their significant others to ensure that relevant support is still provided [49, 53, 54, 60–62]. Telephone [53, 54, 63] or e-mail contacts [53, 54] were described as being used to regularly follow up the patient's disease trajectory. Changes in health and care needs for people with dementia often occur swiftly, which is why there might be limited possibilities to plan services or support in advance [64]. At an early phase of the disease, coordination of different services might be easier than at later stages when the patient's condition has worsened [65]. There are examples of a delayed implementation of services with the consequence of having a crisis-driven process rather than a need-driven process [36, 44].

TABLE 3: Presentation of the identified categories.

Categories
Structural and organisational barriers hindering collaboration and coordination
Care coordinator as a function for enhancing collaboration and coordination
Assessments and planning to provide services in relation to their care needs (current)
Interprofessional collaboration to address multiple health and care needs
Communication as a means of sharing information and building relationships
Knowledge to navigate a complex health and care system
Knowledge and competencies about dementia
Personalisation of care, empowerment, and acknowledging agency

5.3.4. *Interprofessional Collaboration to Address Multiple Health and Care Needs.* Many articles took their point of departure in interprofessional collaboration and coordination of services for people with dementia [35, 39, 41, 66]. Diverse concepts were used among the included articles to refer to this such as multiprofessional, multidisciplinary, interdisciplinary, and interprofessional teams. Interprofessional teams were portrayed as a prerequisite for collaboration in dementia care [35, 39, 67] and for providing person-centred care [33, 68]. It was depicted that interprofessional teams provide a broader understanding of the patient's situation or condition for physicians [63, 66] or for care coordinators [51] that works as a support in decision making of how to proceed with a person's care needs. Various professional disciplines participate in interprofessional collaboration to provide services [66], bringing their professional competency to the team [67, 69, 70]. Different professionals representing various disciplines might have different understandings or assessments of a person's health and care needs (and responsibilities), as well as different ideas of how to proceed [71]. There are some hierarchies presented in the included articles associated with interprofessional collaboration among health professionals [65, 72]. For example, the main responsibility for a given care recipient is usually held by a general practitioner who sometimes cannot prioritise participating in interprofessional work, which is why the necessary mandate to make decisions may be missing [65, 69, 73].

Professionals partaking in interprofessional collaboration may be located at various agencies or within the same organisation or care agency [36]. Furthermore, team members tend to appreciate being part of an interprofessional team when coordinating care for people with dementia [51]. Still, little is known about interagency coordination in dementia care [74].

Case conferences, as part of interprofessional collaboration, facilitate the coordination of health and care services for people with dementia. At case conferences, key responsible professionals meet to discuss patients' needs, but also to share information about patients [75]. At these meetings, team members discuss, plan, and make collective assessments on the needs of people with dementia and on how and when to proceed [73].

5.3.5. *Communication as a Means of Sharing Information and Building Relationships.* Communication was identified as being relevant for the collaboration and coordination of health and care services for older people with dementia. An

aspect pointed out as of importance was *information sharing* between various organisations or care agencies [39, 51] to ensure that relevant support was administered by staff with the right competencies [39, 62], that knowledge about the patient was shared among all involved professionals [59], and that they work towards the same preferred (by the patient) outcome [51, 75]. One study also identified the importance of communication by using a mobile application for information sharing (about medication, contacts with health care professionals, or changes in the person's health condition) among significant others [76].

Another aspect relating to communication was the importance of *building relationships* such as creating an alliance with the person with dementia when coordinating services [36, 77], to signal an interest in the family's individual circumstances [48]. When interacting with the person concerned, health and care professionals should ensure that a relationship is developed to facilitate participation in the process of coordinating care [77] and to ensure person-centred care [60, 67, 72]. If the person living with dementia experiences an encounter with the professional or the use of a service negatively, further requests for support or the person's compliance with care plans could be affected negatively [44]. The use of visual prompts, but also reduction of external stimuli, was described as important to facilitate communication [59]. Facilitation of communication between lay persons and professionals might also be needed since professionals often use complex terms in their communication [78].

5.3.6. *Knowledge to Navigate a Complex Health and Care System.* When people with dementia or their significant others need support, they must navigate in a complex health and care system [43], often with limited knowledge and information about the system [47]. Professionals experience that when people with dementia or their significant others request support, they often do not know what to apply for or what services are available [44]. In relation to this, guidance and advice may be given by professionals with knowledge about the system on how to proceed [62, 79, 80] and how to support decision making among people with dementia [38]. Knowledge about the health and care system seems to some extent to be of greater importance than professional training (such as being a trained social worker or nurse) [59]. Still, the professional competencies associated with various disciplines have consequences as medical health care professionals and social workers address different forms of needs (i.e., medical, or social care needs) among people with dementia [51].

*5.3.7. Knowledge and Competencies about Dementia.* Knowledge and competencies related to dementia diseases and how to approach people with dementia, among both professionals and caregivers, were highlighted as important for the collaboration and coordination of health and care services for people with dementia. Special competencies and skills of professionals have been found to be important [55, 60] and necessary for providing accurate care and support [31, 48]. For example, specialist clinics were described as a resource to increase competencies among non-specialised clinics or practitioners by giving assistance in the care of patients with dementia [30, 81] or consultations for general practitioners from dementia specialists (such as geriatricians) [65]. Furthermore, nurses with specialist training in dementia, in identifying behavioral and psychological symptoms, increase the chance of use of dementia medications [57]. Other competencies depicted as being of importance were interpersonal skills when interacting with people with dementia and advocating that they accept relevant services [72]. These interactional skills also pertain to understanding the diagnosis, as well as how to adjust interaction in accordance with the person's needs [37, 72].

The dissemination of knowledge and skills based on the caregiver's preferences and choices has been identified as an important aspect of establishing regular and lasting contact between informal caregivers and professionals [45, 46, 58]. Training of informal caregivers [49] on how to manage dementia symptoms [62, 78] and how to manage stress and self-care strategies [78] was also presented as key in the included articles. The caregivers of the person with dementia could also be thought competencies such as coping skills, communication skills, behavioral management techniques, and problem-solving techniques [45, 47, 58]. Training informal caregivers the skills [73] of how to manage the care of, interact with, and understand people with dementia, reduces perceived caregiver burden [63, 82], depression [78, 82], and visits to the emergency department [82]. On the other hand, an increased understanding of dementia diseases and their consequences among informal caregivers may also increase perceived caregiver burden [83].

*5.3.8. Personalisation of Care, Empowerment, and Acknowledging Agency.* The aspects of enhancing participation in the decision-making processes and acknowledging the agency of persons with dementia were discussed in the articles included [47, 71]. In these articles, empowerment, inclusion, and participation in the process of coordinating care were described as goals [38, 47, 79], but none of the articles presented these as achieved outcomes. Acknowledging agency was also performed by advocacy [79] and by supporters/advisors through the mechanism of supported decision making [38].

The disease trajectory may have implications for the person's involvement in the process of coordinating services [54]. Younger patients, and those who reported memory difficulties themselves, exhibited a higher level of engagement in coordinating their care. Nevertheless, for people with dementia to remain motivated to receive or accept

support, it is crucial for the time between the decision to implement care and the actual implementation to be as short as possible to minimise the risk of them later declining support [28].

Significant others often advocate for support, frequently at an earlier stage of the disease trajectory than the person with dementia [44]. However, in the process of receiving formal support, significant others may experience a fear of losing control when allowing strangers into their personal space [44]. The role of the family has been emphasised [84], and family case conferences provide an opportunity for significant others to influence the organisation of care and share their understanding of the person with dementia. This understanding can then be taken into consideration when coordinating services [75].

Non-clinical community care coordinators engage in advocacy on behalf of or together with the person with dementia to access support or to address various difficulties encountered when using health and care services [79, 85]. Furthermore, care coordinators working from an office located at, for example, the Alzheimer's associations, were presented as accessible and easily reachable for people with dementia and their significant others. For care coordinators, splitting their time between an Alzheimer's association and a clinic made it possible to engage with those receiving services and also interact with professionals responsible for providing or organising health or care services, thereby advocating on behalf of the person with dementia [62, 66, 86].

## 6. Discussion

In this scoping review, we have mapped research about how different care agencies collaborate and coordinate health and care services for older people with dementia. Most of the articles included in this scoping review were conducted in either Europe or North America. Our grading of the evidence [26] suggests that available research about the topic at hand is moderate. Hence, there is a need for more extensive research with more robust research methodologies in countries with various health, social care, and welfare systems to further our understanding of collaboration and coordination of health and care services for people with dementia.

In the present scoping review, we identified that the care coordinator exercises a function for enhancing coordination of health and care services, but also in relation to facilitate collaboration among various professionals and lay persons when care services are implemented. The function of working as a care coordinator is administered by a key person such as nurses, social workers, or admiral nurses. What is expected of this function differs depending on several factors such as professional training (different skills or what is deemed as important to address) and where the care coordinator is working (e.g., within a team or an agency, between different agencies or authorities, or in an organisation representing civil society). In previous research, the care coordinator has frequently been described to be a case manager, with the main responsibility of coordinating health

and care services for people with dementia [7, 87]. Furthermore, the work conducted by case managers differs in implementation due to several factors, such as variations in legislative frameworks governing the process, funding policies, or cultural variations [10, 15, 17]. This warrants further research, both to understand what is expected of a professional care coordinator working with people with dementia and to explore how various structural factors influence their work and responsibilities.

Interprofessional collaboration is highlighted in our findings as being important for the collaboration and coordination of health and care services for people with dementia. Nonetheless, research on how to achieve constructive collaboration and how to organise this work is scarcely addressed. Previously, several studies on interprofessional collaboration and coordination of health and care services have primarily focused on barriers [1, 2, 12, 88, 89], but how to handle these barriers remains to be addressed [83]. Barriers were also a prominent feature in the articles included, such as lack of communication or understanding of various team members' competences. Further research is needed to study how these identified barriers could be reduced. One approach to overcome some of these structural barriers could be to study how professionals with specific knowledge about dementia could be utilised as a resource for other professionals. Additionally, exploring the use of structured assessments of care needs [90] in the context of collaborating and coordinating health and care services for people with dementia may prove valuable.

Our findings suggest that people with dementia and their significant others need support to navigate the health, social care, and welfare system, as it is often complex in its nature. Furthermore, what support is available and suitable for addressing the health and care needs of the person with dementia and their significant other might be unknown or difficult for them to understand. Dementia is a syndrome associated with, for example, cognitive declines and communication problems [6]. It might, therefore, be difficult for an older person with dementia to know what support or services to request in accordance with their needs [91]. Hence, it falls upon professionals to promote involvement in the decision-making process by providing relevant information in an accessible manner and visualising what support is available and how it could be implemented [92]. This has been briefly mentioned in our findings because little is known about how to organise the provision of such information. This is something that merits further research. However, a characteristic presented in our results is the assessment and planning of services that follow a predetermined structure to ensure that care needs are not missed or overlooked. This might be one way to achieve personalisation of care, as care needs are continuously monitored and assessed throughout the disease trajectory. Nonetheless, flexibility and responsiveness are important in relation to guidelines or predetermined structures to ensure personalisation of care and to prevent integrated care from being provided as a "tick box culture" [90].

Our findings also relate to various professionals with different disciplinary training who are relevant for

coordinating care and supporting collaboration between different care agencies. Different professionals have different perspectives and understandings of the characteristics of collaboration and coordination of health and care services for older people with dementia. Many of the included articles take a professional perspective. Therefore, there is a need for further studies that address the collaboration and coordination of services provided by various agencies from the perspective of the person concerned (i.e., the person with dementia). Our findings suggest that various professionals, depending on their affiliations, locations, or professional training, have different starting points in how they approach collaboration and coordination. Since different professionals represent different authorities or care agencies, there is a need for them to convene in various contexts to discuss how to proceed with a person with dementia. Furthermore, the term "location" also pertains to the physical location of the care coordinators' offices. For example, a care coordinator working from a local civil society organisation could reduce the barrier for people with dementia or their significant others to request or apply for formal support. Our findings suggest that civil society is an emerging stakeholder, facilitating participation for people with dementia in the decision-making process and empowering them as a group that seeks agency by being present in situations where health and care services are coordinated among professional stakeholders. This also underscores the importance of considering local communities to provide integrated care [4].

Personalisation of care, participation in decision making about future services, and empowerment were presented as characteristics in our findings. However, instead of being achieved, these processes were shown as something sought after when coordinating care for people with dementia. In dementia studies, a citizenship perspective has been developed and advocated for in research and practice to explore how empowerment can occur and support people with dementia in using their remaining capabilities to participate in decisions regarding future health and care services [91, 93, 94]. A citizenship perspective entails the empowerment of people with dementia, emphasising the individual's possibility to be independent, set their own goals, and have control over their own life [95]. Further research is needed to investigate how a citizenship perspective could be applied in the process of collaborating and coordinating health and care services for people with dementia, to align with an integrated care approach.

*6.1. Implications for Practice.* The findings suggest that the physical location of the care coordinator may reduce barriers for people with dementia when requesting or applying for support. Additionally, a care coordinator's professional background has implications for the health or care needs they address and how they prioritise various tasks in their daily work. This has implications for both policy and practice, as it might be essential to engage different care coordinators with diverse competencies to address both medical and social care needs, given that people with dementia often experience multiple and complex health and

care needs. The significance of establishing a relationship with the person with dementia and their significant others was emphasised in the findings. Communication is crucial for building this relationship. It is also relevant to explain and visualise the services available for the person with dementia to meet their health and care needs and to determine when these services are suitable to implement in their disease trajectory. Given the information asymmetry that exists between professionals and lay person, addressing this gap in knowledge about services is necessary. Furthermore, the findings suggest that specific knowledge and competencies about dementia are needed among both professionals and significant others to support and empower people with dementia in everyday life situations. Therefore, it is important to provide relevant educational efforts and skills training for professionals working in dementia care, as well as for significant others of people with dementia.

*6.2. Strengths and Limitations.* This scoping review has several strengths but also some limitations. A comprehensive literature search revealed many potential articles to include in the present scoping review. To reduce subjective bias in the article selection process, two researchers independently conducted the selection of articles, which was validated through consultation with the third researcher. Therefore, the approach to including studies for this scoping review was systematic. However, the concept used to inform the search, especially “collaboration” and “coordination,” is often ambiguous with various interpretations. In the process of including articles, an inclusive approach has been applied regarding the terms “collaboration” and “coordination” (see the published study protocol for a more detailed explanation of the concepts used [24]). Consequently, in the articles included, various understandings and perspectives related to these terms are presented. Some of these articles also offer more context and insight into these terms, which is why they are more extensively presented in our findings.

Furthermore, the focus of this scoping review was on empirical literature, and as a result, grey literature was excluded. Consequently, it is possible that not all studies that could have provided additional insights on the topic at hand were identified. Additionally, no reference search or citation search was conducted, despite being planned in the study protocol for this scoping review [24]. This should be taken into consideration, as relevant literature may have been missed.

The analytical process was a collaborative effort, undertaken by all three authors working closely together. This collaborative approach was chosen to prevent any skewed or biased result, which might occur if dependent on any of the researchers’ prior understandings, and to promote alternative interpretations of the included articles.

A critical appraisal of the evidence was performed based on the Research Pyramid [26] on the included articles’ abstracts. During the analytical process, several weaknesses in the abstracts were identified, including vague descriptions of methodology and lack of clarity regarding the number of participants, data collection methods, and analytical

processes. As a result, the critical appraisal may have been negatively influenced by shortcomings in the reporting of the design of the included studies in the abstracts.

Finally, the articles included in this scoping review were authored by researchers from various countries, each with its own legislative contexts influencing the practice of collaboration and coordination of health and care services for people with dementia. While this scoping review provides information about the authors’ affiliations, the analysis presented here has not considered the legislative context in which the different studies were conducted. In previous research, it has been noted that the legislative context is often absent or inadequately described, which makes it challenging to apply the results of a study to other settings [10, 17, 88, 96–98]. In future reviews, the analysis of articles could be included based on or analysed with regard to their legislative context.

## 7. Conclusion

In conclusion, in the qualitative part of this study, we were able to elaborate on the characteristics that have been presented in previously conducted research about collaboration and coordination of health and care services for older people with dementia. Engaging care coordinators with diverse competencies to address both medical and social care needs is essential, especially since people with dementia often experience multiple and complex health and care needs. It is also important to explain and visualise available services to the person with dementia and when these services are suitable for implementation. Specific knowledge about dementia among professionals and significant others is necessary to empower people with dementia in everyday life situations. Through the identification of characteristics described in previous research, we can now better understand how integrated care can be coordinated with the goal of creating the best possible conditions for the persons concerned, including their significant others, and for the professionals. Improved collaboration and coordination not only lead to better and integrated care for the patients but also contribute to more sustainable and robust health and care agencies, thereby strengthening the healthcare system.

## Appendix

### A. Search Strategy Used in PubMed

Alzheimer disease[MeSH Major Topic] OR (Alzheimer disease[MeSH Terms]) OR (Alzheimer\*[Title/Abstract]) OR (((Frontotemporal Lobar Degeneration[MeSH Major Topic]) OR (Frontotemporal Lobar Degeneration[MeSH Terms])) OR (Frontotemporal Lobar Degeneration[Title/Abstract])) OR (Frontotemporal dementia[MeSH Major Topic]) OR (Frontotemporal dementia[MeSH Terms])) OR (((Lewy Body Disease[MeSH Major Topic]) OR (Lewy Body Disease[MeSH Terms])) OR (Lewy Body\*[Title/Abstract]) OR (Lewy bodie\*[Title/Abstract])) OR (((Vascular dementia[MeSH Major Topic]) OR (Vascular dementia [MeSH Terms])) OR (((dementia[MeSH Major Topic]) OR

(Dementia[MeSH Terms])) OR (Dement\*[Title/Abstract])) OR (Senile\*[Title/Abstract])) AND (((((((((((health coord\*[Title/Abstract]) OR (care coord\*[Title/Abstract])) OR (care collab\*[Title/Abstract])) OR (health collab\*[Title/Abstract])) OR (health manage\*[Title/Abstract])) OR (care manage\*[Title/Abstract])) OR (Case Manage\*[Title/Abstract])) OR (Case Management[MeSH Major Topic])) OR (Case Management[MeSH Terms]) OR (integrated care\*[Title/Abstract])) OR (integrated health [Title/Abstract])) OR (comprehensive care [Title/Abstract])) OR (seamless care\*[Title/Abstract])) OR (transmural care[Title/Abstract]).

## Conflicts of Interest

The authors declare that they have no conflicts of interest.

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