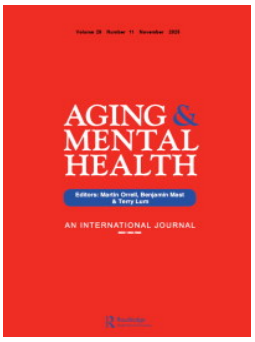

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What are the unmet needs in people affected by dementia? A scoping review of reviews

Wei Qi Koh[a], Martina Roes[b,c], Marjolein de Vugt[d], Duygu Sezgin[e], Manuel Gonçalves-Pereira[f], Nicole Müller[g], Ana Diaz[h], Dympna Casey[e], Chantal Ingram[i], Amy Kate Walden[i], Jochen René Thyrian[k], David Neal[l], Adelina Comas[m] and Louise Hopper[j]

[a]School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, Australia; [b]German Center for Neurodegenerative Diseases (DZNE), Witten, Germany; [c]Department of Nursing Science, Herdecke University, Witten, Germany; [d]School for Mental Health and Neuroscience, Alzheimer Center Limburg, Maastricht University, Maastricht, The Netherlands; [e]School of Nursing and Midwifery, College of Medicine, Nursing, and Health Sciences, University of Galway, Galway city, Ireland; [f]Comprehensive Health Research Centre (CHRC), NOVA Medical School, Faculdade de Ciências Médicas, NMS|FCM, Universidade Nova de Lisboa, Portugal; [g]Department of Speech & Hearing Sciences, University College Cork, Cork, Ireland; [h]Alzheimer Europe, Luxembourg City, Luxembourg; [i]School of Psychology, Dublin City University, Dublin, Ireland; [j]German Centre for Neurodegenerative Diseases (DZNE), Greifswald, Germany; [k]Institute for Community Medicine, University Medicine Greifswald (UMG), Greifswald, Germany; [l]Department of Medical Informatics, Amsterdam UMC, Amsterdam, The Netherlands; [m]Department of Health Policy, London School of Economics and Political Science, Care Policy and Evaluation Centre, UKLondon

ABSTRACT

Objectives: To examine through a social health lens the unmet needs of people affected by dementia, which includes people with dementia, their informal and formal (or professional) caregivers. ‘Unmet needs’ was conceptualised as inaccessible or a lack of appropriate interventions to address identified problems.

Method: A scoping review of reviews was conducted. Five electronic databases were searched, followed by a two-stage-screening process. Data were extracted into a standardised sheet comprising study characteristics and domains from the Camberwell Assessment of Needs for the Elderly (CANE), and narratively synthesised. Unmet needs of people with dementia were mapped onto a social health framework.

Results: Eighty-five reviews were included. The most frequently reported unmet needs of people with dementia were related to psychological distress, lack of daytime activities, and company, all of which contribute to poorer social health. Informal caregivers most frequently reported a lack of information about the disease trajectory, post-diagnostic care, and home-based practical support. Formal caregivers had related information needs; their psychological distress stemmed from a range of sources.

Conclusion: This review of reviews provides a high-level synthesis of the unmet needs of people affected by dementia. It underscores fundamental knowledge gaps and shortcomings in existing interventions and services particularly for formal and informal caregivers.

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Dementia; unmet needs; scoping review; inequity; social health

Introduction

Dementia is a multifaceted neurodegenerative disorder that influences cognitive functions, while also causing psychological, social, and somatic changes with long-lasting impact on individuals’ abilities and quality of life (World Health Organization, 2025). Worldwide, the number of people with dementia is estimated to increase from 57.4 million cases in 2019 to 152.8 million cases in 2050 (Nichols et al., 2022). The World Health Organization has called for dementia to be a public health priority (World Health Organization, 2012), and many countries have implemented measures to decrease disease burden. While pharmacological interventions are currently being developed, there is currently no curative treatment available for dementia, and people with dementia require varying extents of care and support throughout the course of the disease. Informal caregivers, such as relatives, family members and friends, play a critical role, providing physical, emotional, social and financial support, and monitoring and evaluating care strategies; informal carers provide care for over 60% of people with dementia (Brodaty & Donkin, 2009). While there are positive aspects of caregiving, informal caregivers are also often referred to as the ‘invisible’ patients, who can experience substantial subjective and objective burden (Laporte Uribe et al., 2017; Thyrian et al., 2015), such as mental and physical symptoms or disorders (Etters et al., 2008). Likewise, formal or professional caregivers such as nurses,

CONTACT Wei Qi Koh weiqi.koh@uq.edu.au

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therapists and support workers are at increased risk of professional burnout (Etters et al., 2008). The impact on those who provide care may be attributed to the complex nature of caregiving. Collectively, people living with dementia, their family members and care professionals will be referred to as 'people affected by dementia' in this paper.

The needs of people affected by dementia are complex, wide-ranging and diverse, best understood or structured within a biopsychosocial framework (Spector & Orrell, 2010). Although several studies have been conducted to evaluate the 'needs' of people affected by dementia (Miranda-Castillo et al., 2010; Black et al., 2013), there is no clear consensus of how 'needs' are conceptualised or standardised across studies, which impairs comparability across studies. A commonly agreed-upon definition is based on whether interventions are available and/or used to potentially help or alleviate a problem. In other words, needs may be met or unmet (Hoe & Orrell, 2021), based on whether effective evidence-based interventions are rendered, or not. The Camberwell Assessment of Need for the Elderly (CANE) (Reynolds et al., 2000) is a widely used and validated interview-based assessment based on this conceptualization. It evaluates 24 types of needs (met or unmet) among older people with mental health conditions (including dementia), such as accommodation, self-care, physical health, relationships and mobility (Reynolds et al., 2000). It also allows for the evaluation of informal caregivers' informational and psychological distress needs.

Unmet needs can affect the social wellbeing of people affected by dementia. The INTERDEM Social Health Taskforce, proposed a social health framework to focus on adaptation in disability, away from a traditional paradigm which focuses on health as avoiding disability (Dröes et al., 2017). The social health framework describes three key domains of social health in people with dementia, namely (i) having the capacity to fulfil one's potential and obligations, (ii) managing one's life with some degree of independence, and (iii) participation in social activities (Dröes et al., 2017). For instance, when people with dementia have unmet needs in self-care, and are not facilitated to manage day-to-day activities considering their cognitive difficulties, this can influence their ability to live independently (Jeon et al., 2021). These domains are further influenced by micro, meso and macro-level factors, including personal, disease-related, social, and environmental factors (Nichols et al., 2022). While this framework provides a structure to understand social health factors in people with dementia, there has been little research focused on understanding how, and what unmet needs affect each domain of social health. This knowledge deficit hinders the identification and development of interventions targeting unmet needs that impact on social health.

Aim

This scoping review of reviews aims to map the existing research evidence on the unmet needs of people affected by dementia, their informal caregivers and professional caregivers. Given that the purpose of this review is to provide a broad overview of this topic, a scoping review methodology is considered appropriate (Munn et al., 2018). The key research question is: 'What are the unmet needs of people affected by dementia, their informal caregivers and professional caregivers?'. Specifically for people living with dementia, this review also aimed to address the secondary question on how unmet needs align with the social health framework, identifying their connections to different social health domains and the factors that influence both unmet needs and social health. This project constitutes part of the work undertaken by the INTEREST (Innovations in diversity and equity in social health research in dementia) working group (https://goltc.org/projects/goltc-1734516556/) funded by the EU Joint Program—Neurodegenerative Disease Research (JPND), to investigate inequity and unmet needs in dementia with a special focus on social health and intersectionality.

Method

A scoping review of reviews was performed based on methodological guidance by the Joanna Briggs Institute and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018). The review protocol was registered a priori on the Open Science Framework (https://osf.io/9cebk) on 16 April 2024 and will be briefly described below.

Eligibility criteria and evidence sources

All types of reviews, such as systematic reviews, scoping reviews and integrative reviews were included if they were focused on the unmet needs of people affected by dementia, were published within the last 15 years (2009–2024) in peer-reviewed journals in English, German, Dutch, Spanish or Portuguese. No restrictions were placed on study contexts. Reviews were excluded if they focused on populations with other conditions such as Parkinson's disease or schizophrenia, or described, or analysed the needs of people affected by dementia but did not specifically focus on unmet needs.

Screening and selection

A comprehensive search strategy was developed in consultation with a research librarian, and a systematic search was conducted in March 2024 in five electronic databases: PubMed, Medline (*via* EBSCO), CINAHL (*via* EBSCO), Web of Science and Epistemonikos. The full search strategy can be found in Appendix 1. Study records were imported into Covidence and deduplicated. Each stage of a two-stage screening process was undertaken by at least two independent reviewers. First, the title and abstract of articles were screened (MR, DS, OP, WQK, JRT) and next, the full texts of potentially relevant full-text articles were reviewed (WQK, MR, DS, DC) for inclusion. Conflicts were resolved by discussions and/or by a third independent reviewer.

Data extraction and synthesis

Data was extracted onto a standardised data extraction sheet on Covidence, developed by the research team. Data extracted included study characteristics (e.g. author, year, study aims, review methodology, inclusion criteria) and unmet needs as characterised within the CANE framework; the category 'others' was also used to extract any data that did not fall within the CANE categories. Three reviewers (WQK, CI, AW) independently extracted data from the first three articles and discussed and established a consistent approach to data extraction. Thereafter, data from the remaining articles were extracted by individual reviewers. All reviewers consulted through two additional meetings during the data extraction process to discuss and agree the consistency of approaches to data extraction. Data was narratively synthesised based on guidance by Popay et al. (2006). Extracted data were listed, presented in a tabular form, and grouped into subcategories. Data were organised and presented categorically.

To further understand how the data aligns with the social health framework outlined by the INTERDEM Social Health Taskforce(Dröes et al., 2017), the unmet needs of people living with dementia were further mapped to the three key domains of the social health framework, and factors leading to unmet needs were mapped to one of the four influencing factors within the framework. This included personal factors, disease-related factors, social factors and environmental factors (Dröes et al., 2017). The mapping exercise enabled the visualisation of any potential interrelationships between unmet needs and influencing factors. This was led by WQK, and discussed at two meetings with MdV and MR.

Public involvement (PI)

Two existing working groups representing different European countries, as coordinated by Alzheimer Europe, were involved as Public Involvement (PI) contributors. The European Working Group of People with Dementia (EWGPWD) is composed of 14 people living with different types of dementia. The European Dementia Carers Working Group (EDCWG) comprises 15 informal carers of people with dementia. A face-to face session was organised with each group; the meeting with members of the EWGPWD took place in Brussels in March 2024, and the meeting with the EDCWG took place in June 2024 in Luxembourg. Ahead of each meeting, working group members received information that the meetings were focused on understanding unmet needs and social health in dementia. In the meeting with the EWGPWD, discussions focused on exploring members' perspectives and/or experiences of social health, and unmet needs. This was built upon during the subsequent meeting with the EDCWG, who were asked about their experiences and perceptions of unmet needs and social health. The Alzheimer Europe team moderated discussions, took notes and summarised discussion points.

Results

A PRISMA flow diagram of the systematic search and screening is presented in Figure 1. A total of 3,188 articles were retrieved from the database searches. Following deduplication, 2,025 articles remained for title and abstract screening. Following this, 252 potentially relevant articles were selected for full-text screening, and 85 reviews were included in this review.

Study characteristics

The characteristics of the included reviews are summarised in Appendix 2. Most were systematic reviews ($n=44$, 51.8%) and scoping reviews ($n=21$, 24.7%). The others were integrative reviews ($n=8$, 9.4%), literature reviews ($n=8$, 9.4%), narrative reviews ($n=3$, 3.5%) and an umbrella review ($n=1$, 1.2%). The number of studies included in each review ranged from 6 to 304 and were primarily from the United States, United Kingdom, Canada, Australia and countries of the European Union, although there were some articles from Asia (e.g. India, China) and the Middle East (e.g. Israel, Saudi Arabia). Most reviews evaluated the unmet needs of informal caregivers ($n=56$, 65.9%), followed by people with dementia ($n=30$, 35.3%) and formal caregivers ($n=20$, 23.5%). While most reviews indicated that they included any type of dementia, some focused specifically on YOD ($n=5$), frontotemporal dementia (FTD)/frontotemporal lobar degeneration (FTLD) ($n=4$), people with dementia and other comorbidities ($n=4$), people with dementia or mild cognitive impairment ($n=3$), and advanced dementia

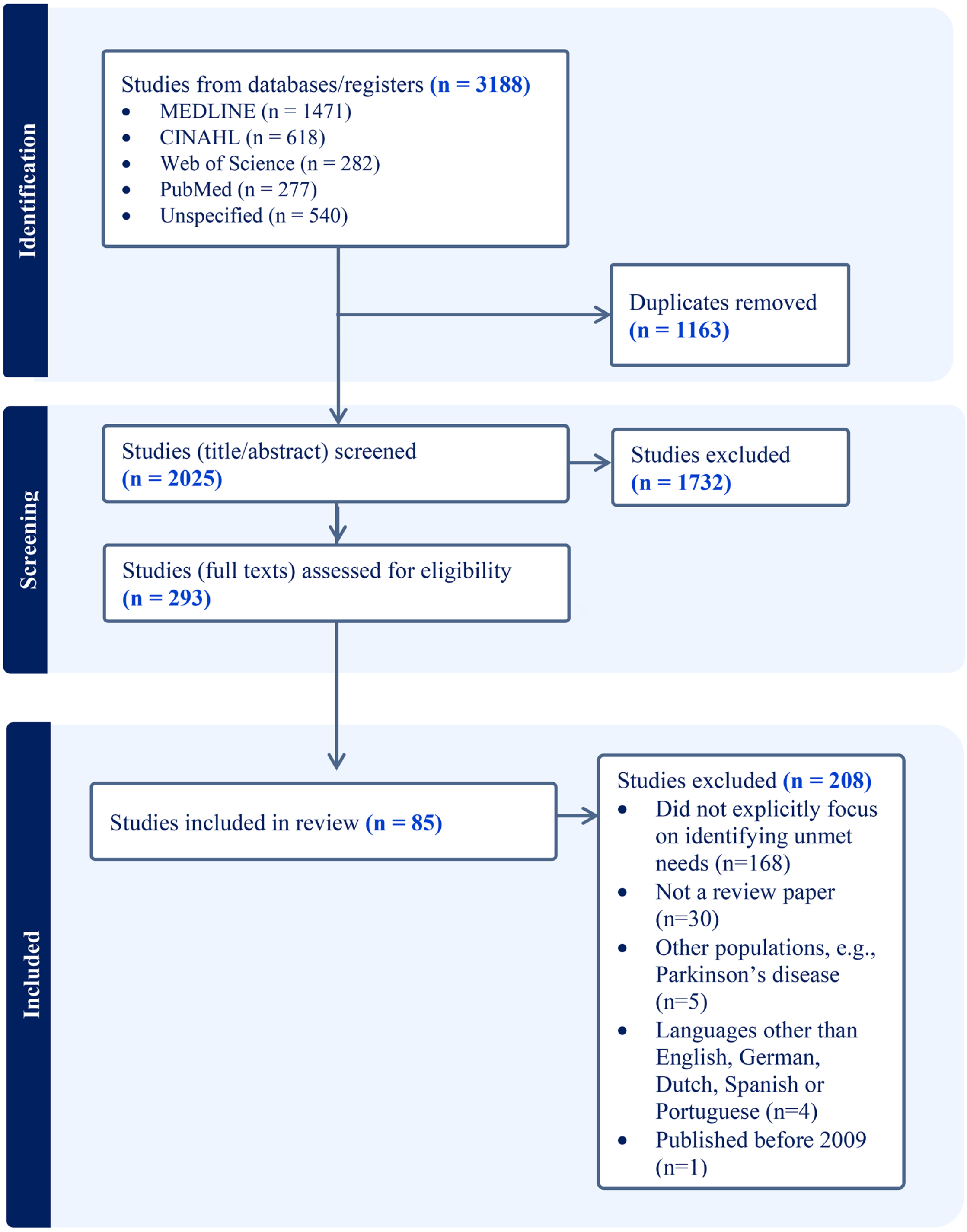


Figure 1. PRISMA flow diagram.

or end of life care ($n = 3$). Ten reviews *(n = 10)* focused on people from ethnic minorities, ethnically diverse backgrounds, and/or with migrant backgrounds.

Unmet needs of people living with dementia

Unmet needs in people living with dementia (Table 1) were identified across most of the CANE categories. The categories of unmet needs were ordered based on the frequency with which they were mentioned. The most frequently reported unmet needs were psychological distress ($n = 13$), accommodation ($n = 13$), daytime activities ($n = 11$), company ($n = 11$), accommodation ($n = 10$), and information *(n = 10)*. Psychological distress manifested mainly as frustration or uncertainty during the diagnostic process, where people with dementia expressed emotional turmoil when receiving a diagnosis, adjusting to the diagnosis, and managing challenges to the individuals' sense of self. In institutional settings such as hospitals and long-term care settings, psychological distress was reported when people with dementia felt ignored or dismissed by care staff, there was a lack of purposeful activities, and an absence of cultural sensitivity. Unmet needs for company were described as feelings of social isolation, a lack of

Table 1. Unmet needs in people living with dementia, based on the CANE framework.

Unmet needs	Description	References
Psychological distress ($n = 13$)	The diagnostic process resulted in frustration and uncertainty; receiving a diagnosis led to a sense of shock. People were overwhelmed with information provided during the process of diagnosis. Prospect of losses, challenges to self-esteem and changes to sense of self, led to depression symptoms. The absence of cultural sensitivity/congruity provoked distress.	Abdullah et al., 2023; Baptista et al., 2016; Beardon et al., 2018; Martin et al., 2019; Morrisby et al., 2018; Nunnemann et al., 2012; O'Malley et al., 2021; Petty et al., 2018; Prorok et al., 2013; Reilly & Houghton, 2019; Robinson et al., 2011; Røsvik & Rokstad, 2020; Sansoni et al., 2016
Daytime activities ($n = 11$)	People with FTD/FLTD had a significantly higher level of unmet needs in this domain. People with YOD had a lack of engagement in meaningful activities and of sense of purpose. There was lack of stimulation and activity engagement in institutional care.	Baptista et al., 2016; Bayly et al. 2020; Millenaar et al. 2016; Morrisby et al. 2018; Nunnemann et al. 2012; Reilly & Houghton, 2019; Røsvik & Rokstad, 2020; Sansoni et al., 2016; Sturge et al., 2024; Tan et al. 2024; Warren, 2022
Company ($n = 11$)	Limited social interactions or social isolation in people with dementia and people with YOD; particularly so if without shared language or in institutional care settings.	Abdullah et al., 2023; Baptista et al., 2016; Cabote et al., 2023; Gaviola et al., 2024; Jonsdottir & Gunnarsson, 2021; Martin et al., 2019; Millenaar et al., 2016; Morrisby et al., 2018; Petty et al., 2018; Robinson et al., 2011; Sansoni et al., 2016
Accommodation ($n = 10$)	Institutional care environments described as lacking privacy, impersonal, overcrowded, overstimulating, compromising freedom and sense of belonging, or making people feel disconnected from outside life. Risk of worsening mental, cognitive and/or physical conditions.	Barker et al., 2017; Beardon et al., 2018; Dresden et al. 2022; Fang et al., 2024; Hermann et al., 2015; Joy et al., 2023; Petty et al., 2018; Reilly & Houghton, 2019; Røsvik & Rokstad, 2020; Sturge et al., 2024)
Information ($n = 10$)	Unmet needs described, such as for information about diagnosis and disease trajectory, information about care contexts (e.g. hospitals, health and social systems), legal issues, end-of-life care and advance care planning.	Brijnath et al., 2023 Millenaar et al. 2016; Morrisby et al. 2018; Nunnemann et al., 2012; Reilly and Houghton 2019; Richardson et al., 2019; Sansoni et al., 2016
Self-care skills ($n = 7$)	Loss of function and self-care skills, particularly in institutional settings where there is a restrictive impact on independence and control. This can be further limited by staffing constraints and conflicting priorities.	Dresden et al., 2022; Fang et al., 2024; Morrisby et al., 2018; Robinson et al., 2011; Nunnemann et al., 2012; Reilly & Houghton, 2019; Robinson et al., 2011
Behaviour ($n = 6$)	People with dementia reported a mistrust of institutional care settings. Overstimulation may lead to anxiety and behaviour changes, e.g. calling out to staff, agitation or aggression. Particular risk with culturally or linguistically incongruent care, or when staff do not engage with people with dementia.	Cabote et al., 2023; Digby et al., 2017; Gaviola et al., 2024; Joy et al., 2023; Reilly & Houghton, 2019; Zhang et al., 2023
Eyesight, hearing, communication ($n = 6$)	Unmet needs relating to performing tasks that depend on senses and communication abilities. Lack of shared language with care providers (e.g. formal carers).	Barker et al., 2017 Baptista et al., 2016; Cabote et al., 2023; Gaviola et al., 2024; Morrisby et al., 2018; Sansoni et al., 2016
Drugs ($n = 4$)	People with dementia reported a mistrust of medications. Some people did not receive adequate medications, as pain could be misinterpreted as a neuropsychiatric symptom. Communities from non-majority ethnic backgrounds were less likely to be prescribed the right medication	Abdullah et al., 2023; Brijnath et al., 2023; Jonsdottir & Gunnarsson, 2021; Reilly & Houghton, 2019
Food ($n = 2$)	People with FTD/FLTD had significantly higher levels of unmet needs in this domain. The need for traditional food tended to be overlooked in long-term care for residents with CaLD backgrounds.	Cabote et al., 2023; Nunnemann et al., 2012
Continence ($n = 2$)	Unmet needs regarding urinary or faecal continence (no further description).	Abdullah et al., 2023; Nunnemann et al., 2012
Physical health ($n = 2$)	Unmet needs regarding physical health and general medical care. People with medical comorbidities are less likely to access services for medical treatment overall.	Bunn et al., 2014; Warren, 2022
Intimate relationships ($n = 2$)	Unmet needs concerning intimate relationships (no further description).	Millenaar et al., 2016; Sansoni et al., 2016
Money/budgeting ($n = 2$)	Financial issues due to loss of employment in people with YOD and FTD/FLTD (no further description).	Karnatz et al., 2021; Sansoni et al., 2016
Household skills ($n = 1$)	People with FTD/FLTD had significantly greater unmet needs in this domain.	Nunnemann et al., 2012
Caring for someone ($n = 1$)	Role loss, changes or diminishment in people with YOD (e.g. as provider, parent, spouse).	Sansoni et al., 2016
Memory ($n = 1$)	Unmet needs relating to memory (no further description).	Morrisby et al., 2018
Mobility/falls ($n = 1$)	Unmet mobility needs (no further description).	Baptista et al., 2016
Abuse or neglect ($n = 1$)	Risk of neglect associated with caregivers' limited understanding of dementia, difficulties addressing challenging behaviours and coping with burden of care.	Stenberg & Hjelm, 2023

**CaLD: culturally and linguistically diverse; FTD: frontotemporal dementia; FTLD: frontotemporal lobar degeneration; YOD: young onset dementia.*

social companionship, and having a loss of social roles.

Unmet needs regarding accommodation were primarily reported in reviews focussing on institutional care settings. Physical environments were described as unfamiliar, impersonal, lacking privacy, or causing sensory overstimulation with loud noises and crowded spaces. Some reviews found that such environments were said to restrict freedom, as people with dementia may not have direct access to some environments that were enclosed. Unmet needs regarding daytime activity in institutions stemmed from a lack of appropriate activities and personal space. These needs were particularly reported in reviews that focused on people with young onset dementia and FTD/FTLD, those living in rural settings, and in people with migrant backgrounds, where people affected by dementia expressed feelings of shame and avoided daytime activities to avoid negative judgements.

The PPI consultation with the ECWGD revealed that these findings were congruent with their lived experiences, and the PPI group further emphasised the need to consider cultural and language influences on unmet needs, particularly amidst an increasing migrant population.

Unmet needs of informal caregivers

In the studies reviewed, the informal caregivers of people with dementia included family members such as spouses, children, grandchildren or other relatives. Table 2 summarises their unmet needs. The most frequently reported unmet needs for information related to appropriate post-diagnostic care and services ($n = 23$). Paths to seeking assistance were

Table 2. Unmet needs in informal caregivers, based on the CANE framework.

	Unmet needs	References
Information	Post-diagnostic care options and services (e.g. navigating services, service flexibility and eligibility, cultural sensitivity) ($n = 23$)	Acton et al., 2023; Afram et al., 2015; Di Lorito et al., 2022; Jagoda et al., 2023; Johl et al., 2016; Kane et al., 2021; Khanassov & Vedel, 2016; Lee et al., 2019; Lindeza et al., 2020; McCabe et al., 2016; Mueller et al., 2022; Mwendwa et al., 2022; Nunnemann et al., 2012; Prorok et al., 2013; Queluz et al., 2020; Racine et al., 2022; Rees et al., 2021; Shea et al., 2017; Soong et al., 2019; Tang et al., 2011; Teng et al., 2020; Wiggins et al., 2023
	Disease trajectory and what to expect ($n = 22$)	Beardon et al., 2018; Brijnath et al., 2023; Bunn et al., 2014; Cross et al., 2018; Digby et al., 2017; Dresden et al.. 2022; Gaviola et al., 2024; Kane et al., 2021; Karnatz et al., 2021; Lee et al., 2019; Mwendwa et al., 2022; Petty et al., 2018; Rees et al., 2021; Richardson et al., 2019; Røsvik & Rokstad, 2020; Soong et al., 2019; Stenberg & Hjelm, 2023; Sturge et al. 2024; Tang et al., 2011; Warren, 2022; Xiao et al., 2023; Zhang et al., 2023
	Supporting various aspects of caregiving, e.g. medications, behaviour ($n = 15$)	Acton et al., 2023; Barker et al., 2017; Bunn et al., 2014; Innes et al., 2011; Jagoda et al., 2023; Khanassov & Vedel, 2016; Lee et al., 2019; Macdonald et al., 2020; Morrisby et al., 2018; Mueller et al., 2022; Poole & Patterson, 2022; Racine et al., 2022; Shiba et al., 2022; Stenberg & Hjelm, 2023; Zhang et al., 2023
	Clear and prompt diagnosis ($n = 12$)	Acton et al., 2023; Baptista et al., 2016; Francis & Hanna, 2022; Karnatz et al., 2021; Lindeza et al., 2020; Millenaar et al., 2016; Rees et al., 2021; Robinson et al., 2011; Sansoni et al., 2016; Soong et al., 2019; Tookey et al., 2021; Xiao et al., 2023
	Clear communication with formal care staff, e.g. being informed about care ($n = 12$)	Baptista et al., 2016; Francis & Hanna, 2022; Karnatz et al., 2021; Lindeza et al., 2020; Millenaar et al., 2016; Robinson et al., 2011; Rees et al., 2021; Sansoni et al., 2016; Soong et al., 2019; Tasseron-Dries et al., 2023; Tookey et al., 2021; Xiao et al., 2023
	Care transitions and making decisions about care placements ($n = 11$)	Afram et al., 2015; Barker et al., 2017; Beardon et al., 2018; Dresden et al., 2022; Hodges et al., 2021; Jones et al., 2019; Peacock, 2013; Richardson et al., 2019; Saragosa et al., 2022; Stockwell-Smith et al., 2018; Thompson & Roger, 2014)
	Information quality, quantity and accessibility, e.g. linguistic accessibility, information overload, literacy level ($n = 9$)	Beardon et al., 2018; Brijnath et al., 2023; Hermann et al., 2015; Johl et al., 2016; Lee et al., 2019; Petty et al., 2018; Warren, 2022; Wiggins et al., 2023; Lindeza et al., 2020
	Financial options ($n = 1$)	Afram et al., 2015
Psychological distress	Social isolation or alienation ($n = 18$)	Acton et al., 2023; Afram et al., 2015; Cross et al., 2018; Di Lorito et al., 2022; Jagoda et al., 2023; Johl et al., 2016; Kane et al., 2021; Lee et al., 2019; 2022; Lindeza et al., 2020; Macdonald et al., 2020; McCabe et al., 2016; Sansoni et al., 2016; Stenberg & Hjelm, 2023; Thompson & Roger, 2014; Wiggins et al., 2023; Xiao et al., 2023; Zhang et al., 2023
	Caregiving responsibilities are perceived as overwhelming, leading to poorer health outcomes in informal carers ($n = 18$)	Afram et al., 2015; Bressan et al., 2020; Campbell-Enns et al., 2023; Francis & Hanna, 2022; Jagoda et al., 2023; Kane et al., 2021; Karnatz et al., 2021; Lee et al., 2019; Millenaar et al., 2016; Mueller et al., 2022; Mwendwa et al., 2022; Poole & Patterson, 2022Peacock, 2013; Sansoni et al., 2016; Steenfeldt et al., 2021; Teng et al., 2020; Thompson & Roger, 2014; Zhao et al., 2020
	Adjusting to relationship changes led to overwhelming emotions, e.g. grief, and hopelessness ($n = 12$)	Black et al., 2013; Beardon et al., 2018; Dresden et al., 2022; Hodges et al., 2021; Joy et al., 2023; Karnatz et al., 2021; Lee et al., 2019; Macdonald et al., 2020; Miranda-Castillo et al., 2010; Mueller et al., 2022
	Difficulties balancing personal needs with caring role ($n = 9$)	Acton et al., 2023; Barker et al., 2017; Black et al., 2013; Cross et al., 2018; Duran-Kiraç et al., 2022; Joy et al., 2023; Lindeza et al., 2020; Tan et al., 2024
	Formal care services exclude them in care provision or are unsupportive; led to feelings of frustration, resentment ($n = 7$)	Beardon et al., 2018; Bunn et al., 2014; Cabote et al., 2023; Francis & Hanna, 2022; Graneheim et al., 2014; Saragosa et al., 2022; Stockwell-Smith et al., 2018
	Care transitions and decision-making leading to stress, guilt and loss ($n = 4$)	Afram et al., 2015; Beardon et al., 2018; Graneheim et al., 2014 Richardson et al., 2019
	Concerns about own future e.g. genetic risk of dementia, future planning ($n = 3$)	Rees et al., 2021; Lindeza et al., 2020; Poole & Patterson, 2022
	Concerns about not providing care adequately e.g. stress, anxiety, guilt ($n = 2$)	Lee et al., 2019; Teng et al., 2020
	End-of-life care and period after death led to depressive symptoms and grief ($n = 2$)	Barker et al., 2017; Peacock, 2013

described as complex, leading to delayed help-seeking. Informal caregivers also reported a lack of information about the course and prognosis of different types of dementia, such as not knowing what to expect (*n* = 22). In particular, informal caregivers of people with young onset dementia (YOD), frontotemporal dementia (FTD) or frontotemporal lobar degeneration (FLTD) described specific difficulties due to the lower prevalence or less known symptoms of the disease. Next, there was also a lack of information on how to face different aspects of caregiving (*n* = 15), ranging from medication to behavioural management. Other unmet needs included a lack of prompt and clear diagnosis (*n* = 12), lack of clear communication with formal caregivers about care plans (*n* = 11), information about care transitions, such as transitions from hospitalisation to home or to institutional care, and information necessary for informed decision-making (*n* = 11). In some studies (*n* = 9), caregivers reported that the quantity, quality or time of information provision was inappropriate. For example, information may not be linguistically accessible for non-English speakers (in anglophone health systems) or individuals with low literacy levels, or be difficult to understand overall. One study outlined a lack of information on financial options relating to care services and support.

Informal caregivers also reported unmet needs relating to psychological distress, such as grief, hopelessness, depression, anxiety and guilt. Some studies also reported that caregivers reported psychotic symptoms, substance dependence, self-harm or suicidal intent (Black et al., 2013; Dresden et al., 2022; Hoe & Orrell, 2021; Martin et al., 2019; Tan et al., 2024; Hermann et al., 2015; Richardson et al., 2019; Digby et al., 2017; Mwendwa et al., 2022; Lee et al., 2019; Lindeza et al., 2020; Khanassov & Vedel, 2016). These unmet psychological needs stemmed from various sources, as outlined in Table 2. The most frequently reported source of distress pertained to social isolation or alienation (*n* = 18), where informal caregivers expressed difficulties maintaining social relationships, and experienced shame, embarrassment and a sense of abandonment from their existing social networks or family members who may not be able to understand their experiences. Informal caregivers also expressed feeling overwhelmed or uncertain about some caregiving responsibilities (*n* = 18), given the protracted duration of care provision, the unpredictable nature of care, or having to provide care without seeking help from others. Some articles reported on the influence of culture or personal characteristics; for example caregivers from an Asian background were reported to perceive caregiving as a personal responsibility. Other sources of psychological distress included relationship changes (*n* = 12), where informal caregivers shared information about difficulties adjusting to the nature of their spousal relationship or parent-child relationship, including changes in their roles, responsibilities, and relationship dynamics such as emotional connections. Some caregivers reported distress stemming from difficulties balancing their personal needs with caregiving responsibilities (*n* = 9), feeling excluded by formal care providers in care delivery or in care decision making (*n* = 7), and feelings of loss during care transitions (*n* = 4). Distress also resulted from informal caregivers' concerns about their future (*n* = 3). In particular, the children of people with YOD reported difficulties planning for their future or had concerns about their genetic risk of dementia. Some caregivers were also concerned about not providing care adequately (*n* = 2), when witnessing the end-of-life care of their loved one with dementia.

Unmet needs of formal caregivers

While CANE was not intended for formal caregivers, it provided a starting point to consider their unmet needs. The unmet needs of formal caregivers are summarised in Table 3. The most frequently reported unmet need pertained to the lack of training or skills deemed necessary to provide care (*n* = 16). This ranged from basic care provisions needs, such as managing nutrition and hydration, assessing and managing pain, providing end-of-life care and managing associated emotional responses, managing behavioural and psychological symptoms of dementia (BPSD), advance care planning, and having cultural competency to be able to communicate with ethnic minorities. Another frequently mentioned unmet needs related to a lack of knowledge and information about dementia (*n* = 9), such as the disease progression and impact of the disease. Formal caregivers also expressed uncertainty about how to communicate with people with dementia (*n* = 5) particularly those with hearing or visual impairments, or with ethnic minority groups due to limited exposure and language limitations. These often led to difficulties connecting with individuals with dementia. When information was provided, informal caregivers expressed accessibility barriers (*n* = 3). These included cost-related barriers, a lack of nationally recognised accreditation, distance and travel-related barriers particularly in rural locales, and a lack of confidence and motivation to attend training. Other unmet informational needs included a lack of information about post-diagnostic care and services, particularly for ethnic minority groups (*n* = 2), and information on how to manage informal caregivers and people with dementia's care expectations (*n* = 2)

Formal caregivers expressed various unmet psychological needs, such as feelings of being overwhelmed, grief, and emotional strain. The causes of

Table 3. Unmet needs of formal caregivers, adapted from the CANE framework.

	Unmet needs	References
Information and/or training	Training or skills needed to provide care e.g. managing behavioural and psychological symptoms, pain assessment, providing end-of-life care, advance care plan, cultural competency ($n = 17$)	Bunn et al., 2014; Cleary & Doody, 2017; D'Astous et al., 2019; Dresden et al. 2022; Gaviola et al., 2024; Gwernan-Jones et al., 2020; Hermann et al., 2015; Jones et al., 2019; Jonsdottir & Gunnarsson, 2021; Joy et al., 2023; Kane et al., 2021; Morgan et al., 2011; Österholm et al., 2023;Røsvik & Rokstad, 2020; Richardson et al., 2019; Stockwell-Smith et al., 2018; Xiao et al., 2022
	Knowledge about dementia or information needed to understand dementia e.g. seeing memory loss as a symptom of ageing ($n = 9$)	Bunn et al., 2014; Cleary & Doody, 2017; Digby et al., 2017; Gwernan-Jones et al., 2020; Hermann et al., 2015; Jonsdottir & Gunnarsson, 2021; Jones et al., 2019; Røsvik & Rokstad, 2020; Zhao et al., 2020
	Communication with people with dementia and managing language barriers, including cross cultural communication ($n = 6$)	Duran-Kiraç et al., 2022; D'Astous et al., 2019; Hermann et al., 2015; Røsvik & Rokstad, 2020; Stenberg & Hjelm, 2023; Xiao et al., 2022, 2023
	Accessibility of information provided, e.g. catering to different educational levels, cost, distance, casual staff, technical abilities ($n = 3$)	Cabote et al., 2023; Cunningham et al., 2020; Morgan et al., 2011;
	Managing people with dementia and their informal caregivers' expectations (e.g. of cure) or for information and support ($n = 3$)	Robinson et al., 2011; Stenberg & Hjelm, 2023; Tasseron-Dries et al., 2023
	Post-diagnostic care and services, including specific resources for ethnic minorities ($n = 2$)	Duran-Kiraç et al., 2022; Shea et al., 2017
Psychological distress	Care provision led to feelings of being overwhelmed, frustrations and being unprepared ($n = 6$)	Cunningham et al., 2020; Digby et al., 2017; D'Astous et al., 2019; Joy et al., 2023; Morgan et al., 2011; Kane et al., 2023
	Conflicts between personal values and organisational priorities or other professionals' values; led to feelings of frustration, distress and feelings of inadequacy ($n = 4$)	Gwernan-Jones et al., 2020; Jonsdottir & Gunnarsson, 2021; Joy et al., 2023; Kane et al., 2023
	Burnout or job strain from limited workplace flexibility ($n = 3$)	Cunningham et al., 2020; Kane et al., 2023; Morgan et al., 2011;
	Grief, emotional strain and distress when witnessing deterioration in people with dementia in end-of-life care ($n = 2$)	Cunningham et al., 2020; Gwernan-Jones et al., 2020
	Social isolation, lack of peer support and extended periods of distress ($n = 2$)	Cunningham et al., 2020; Kane et al., 2023
	Fear for personal safety or of being harmed, especially when shouted at by the person with dementia ($n = 2$)	Digby et al., 2017; Joy et al., 2023

psychological distress are summarised in Table 3. The most frequently reported source of psychological distress resulted from direct care provision, which was described as being overwhelming and frustrating ($n = 6$). Formal caregivers also reported distress stemming from conflicts between their personal values and organisational priorities or other colleagues' values. For example, some informal caregivers reported that their managers prioritised the efficiency of care provision over quality care provision. Their concerns were reported as being unheard, and such conflicts led to feelings of powerlessness, frustration, inadequacy or distress ($n = 4$). Formal caregivers also expressed burnout or job strain, particularly given limited flexibility within their workplace ($n = 3$). Homecare workers in particular, expressed grief and emotional distress from providing end-of-life care with a lack of preparation for death ($n = 2$), and felt socially isolated due to a lack of social support as a result of shift work ($n = 2$). This often led to emotional strain, and risks of heightened grief, with extended grief increasing the risk of burnout. Finally, two studies ($n = 2$) highlighted that formal caregivers reported fear about their personal safety when providing care, particularly if the individual with dementia expressed agitated behaviours.

Summary of patient involvement (PI) consultation meetings

In the meeting with the EWGPWD, key unmet needs that emerged from discussions included a lack of clear and accessible information about post-diagnostic support services. Members with dementia discussed about difficulties understanding and navigating healthcare systems, which were seen as complex. They also discussed about the lack of appropriate support and care services that were tailored to the needs and preferences of people living with dementia. In particular, there is a lack of information and services for people with YOD or less common dementias, such as FLTD/FTD. Areas of daily life that they prioritised, such as driving, voting and remaining independent, were particularly lacking. Accordingly, members were unanimous that a sense of independence was crucial, and that people living with dementia should be able to 'master their *life like any other person*'. This should involve accepting and adapting to their new abilities and relationship changes. They also asserted that people with dementia should not be seen as not being able to contribute to society or to lead a meaningful life. Negative stereotypes towards dementia have been reported as negatively influencing wellbeing.

Informal caregivers from the EDCWG discussed a lack of dementia care and support services that attend to psychosocial and relational needs, and expressed that many existing services had an excessive focus on supporting basic or physical needs. They also expressed that that the general public lack awareness about dementia, and care professionals do not appear to have received sufficient training to work with people with dementia. Other unmet needs discussed included a lack of timely diagnosis, a lack of resources to support people with dementia and their caregivers, and acknowledgement or recognition about the role that informal caregivers play in supporting care. EDCWG members also shared that while dementia care guidelines and resources (e.g. national dementia plans) exist, they are often not implemented and did not change or improve the day-to-day lives of people with dementia and their informal caregivers.

Unmet needs of people with dementia visualised through the social health framework

Findings of the unmet needs of people living with dementia were triangulated with PI input, and were mapped onto the three domains and influencing factors of the social health framework (Dröes et al., 2017) as illustrated in Figure 2. Domain 1 relates to the abilities of people with dementia to fulfil their potential in society. This involves maintaining a sense of self-identity, being involved in communities, giving and receiving support, and participating in shared decision making. As seen in Figure 2, unmet needs that could inhibit the ability of people with dementia to fulfil their potential can be attributed to role loss and role changes as a result of the disease and its progression, a lack of engagement in routine activities and personal space, not being provided information about their disease trajectory, care pathways and care plans, and not being empowered to make decisions.

Domain 2 refers to individuals' ability to manage life with some degree of independence; this involves having autonomy, being able to problem-solve in daily life, and managing emotional and practical implications of the disease. A lack of timely and accurate diagnosis, and unmet needs relating to memory, mobility, continence, physical health, household activities, eyesight, hearing and communication can inhibit the ability of people with dementia to manage their own lives. Likewise, difficulties navigating pertinent care pathways, such as navigating legal issues and advance care planning limits their autonomy in disease management. In institutions such as hospitals or residential care, a lack of engagement with care staff and care routines, can also hinder the abilities and potential of people with dementia to manage their lives. As outlined in Table 1, people living with dementia experience a range of psychological distress precipitated by different issues, all of which can impair their ability to cope with the emotional consequences of dementia. Domain 3 relates to the potential of people with dementia to participate in social and meaningful activities, and to hold and maintain meaningful relationships. Unmet needs in this domain include a loss of social roles, limited social interactions and companionship, and social isolation. Particularly in institutional care contexts, this is also limited by restricted engagement in activities, limited communication with formal care staff particularly when there is a lack of shared language.

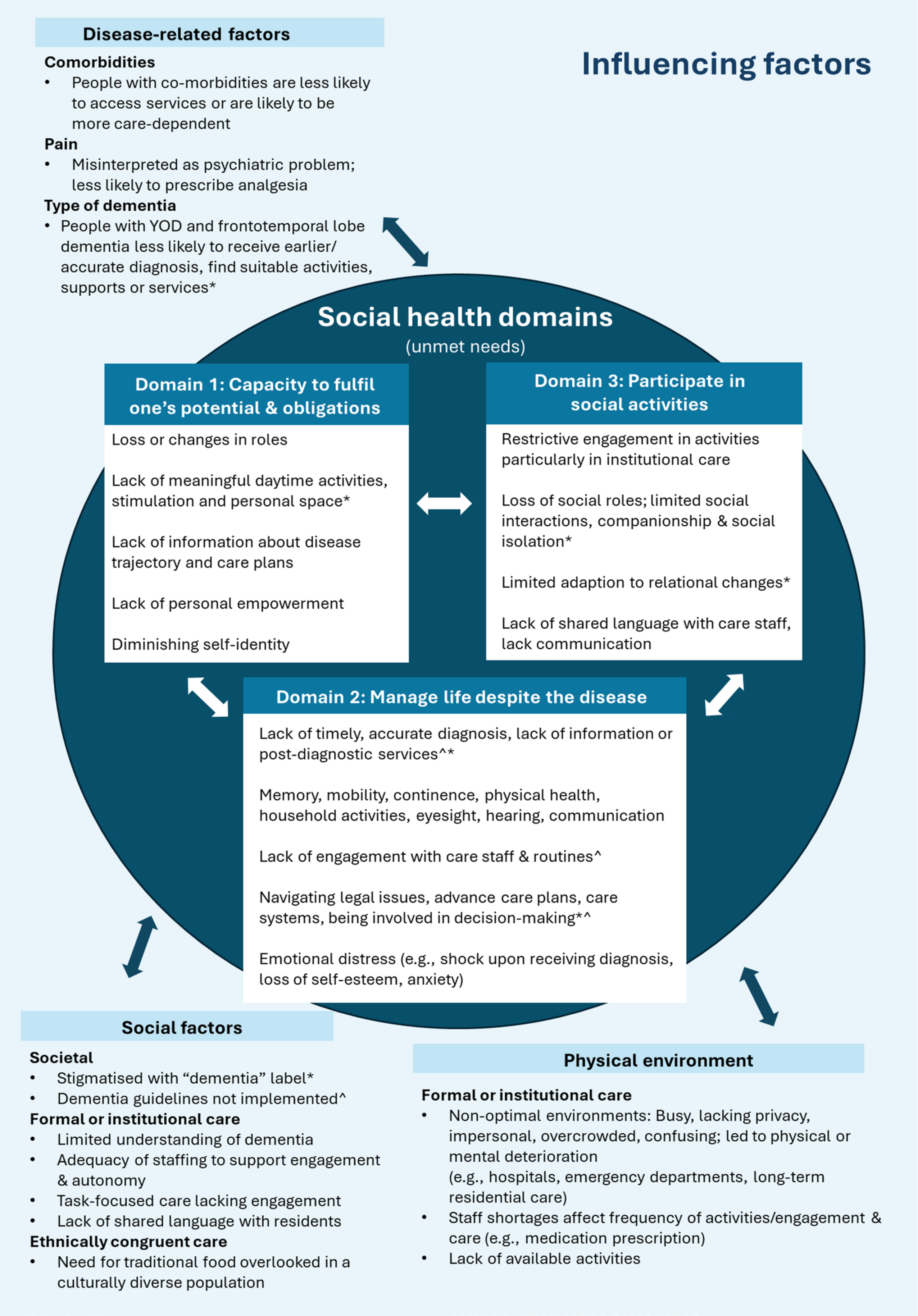
Influencing factors that correspond with unmet needs were mapped into disease related, social and physical environment related factors. Disease-related factors include the existence of comorbidities, such as intellectual disability, visual impairment or diabetes, and the type of dementia. People with comorbidities and less common forms of dementia, including YOD and FTD, are less likely to access appropriate services. Underdiagnosis or misdiagnosis of dementia has been reported to lead to a lack of appropriate treatment, which can influence the ability of people with dementia to carry out daily activities. Social factors include societal stigma, organisational or structural barriers such as, non-person-centred or culturally incongruent care approaches, a lack of shared language, and poor understanding of dementia. Influencing factors relating to the physical environment that were identified related primarily to institutional contexts, such as emergency departments, hospitals and residential care. Other influencing factors included non-optimal environments that were overstimulating or busy, impersonal, lacking privacy, staff shortages, and a lack of available activities.

Discussion

This scoping review of reviews synthesised key findings from 85 reviews to broadly examine the unmet needs of people affected by dementia, as captured in reviews published between 2010 and 2024. For people living with dementia, the unmet needs were mapped onto a social health framework to understand how they are influenced by, or influence social health.

Unmet needs in people with dementia

Mapping unmet needs of people with dementia from published reviews to the CANE framework revealed that the most frequently reported unmet



Disease-related factors

Comorbidities
- People with co-morbidities are less likely to access services or are likely to be more care-dependent

Pain
- Misinterpreted as psychiatric problem; less likely to prescribe analgesia

Type of dementia
- People with YOD and frontotemporal lobe dementia less likely to receive earlier/accurate diagnosis, find suitable activities, supports or services*

Influencing factors

Social health domains
(unmet needs)

Domain 1: Capacity to fulfil one's potential & obligations

Loss or changes in roles

Lack of meaningful daytime activities, stimulation and personal space*

Lack of information about disease trajectory and care plans

Lack of personal empowerment

Diminishing self-identity

Domain 3: Participate in social activities

Restrictive engagement in activities particularly in institutional care

Loss of social roles; limited social interactions, companionship & social isolation*

Limited adaption to relational changes*

Lack of shared language with care staff, lack communication

Domain 2: Manage life despite the disease

Lack of timely, accurate diagnosis, lack of information or post-diagnostic services^*

Memory, mobility, continence, physical health, household activities, eyesight, hearing, communication

Lack of engagement with care staff & routines^

Navigating legal issues, advance care plans, care systems, being involved in decision-making*^

Emotional distress (e.g., shock upon receiving diagnosis, loss of self-esteem, anxiety)

Social factors

Societal
- Stigmatised with "dementia" label*
- Dementia guidelines not implemented^

Formal or institutional care
- Limited understanding of dementia
- Adequacy of staffing to support engagement & autonomy
- Task-focused care lacking engagement
- Lack of shared language with residents

Ethnically congruent care
- Need for traditional food overlooked in a culturally diverse population

Physical environment

Formal or institutional care
- Non-optimal environments: Busy, lacking privacy, impersonal, overcrowded, confusing; led to physical or mental deterioration (e.g., hospitals, emergency departments, long-term residential care)
- Staff shortages affect frequency of activities/engagement & care (e.g., medication prescription)
- Lack of available activities

Figure 2. Unmet needs of people with dementia mapped onto the social health framework.
^ indicative of points resonating with EDCWG; *indicative of points resonating with EWGPWD

needs were psychological and emotional. A range of emotional reactions occurred during different stages of the dementia trajectory from initial diagnosis, receiving information, experiencing role loss and identity loss. Unmet needs for daytime activities, companionship and accommodation were also key areas of deficit. While these unmet needs have been reported by many people living with dementia, this review found that in particular these needs were not addressed by care services of people with dementia with YOD and FTD/FTLD. Unmet needs are influenced by context and this was particularly evident in people with dementia living in institutional care environments. In other words, unmet accommodation needs were not identified in people with dementia living at home, but related uniquely to institutional care environments. This was reflected in discussions with the EWGPWD and EDCWG, who further stressed upon challenges in seeking and accepting their diagnosis, as well as pivotal changes in their lives such as job loss or losing their existing social network. They also emphasised the importance of engaging in meaningful occupations such as citizenship and contributing to family life and society, taking on voluntary work or taking care of grandchildren. This was described as important in facilitating a sense of belonging within the society.

Additionally, food, physical health, money, household skills, mobility and falls (all related to managing one's daily life) only surfaced in few of the reviews included. This suggests that in recently published literature, research foci on how societies meet the needs of people with dementia in these domains are lacking. An alternative interpretation might be that these needs are routinely met, across different societies. However, the lack of prominence of at least some of these domains in the published research may have more to do with who has access to or is included in the research. Examples of groups that might have been excluded from research may include people living in poverty, people without access to sufficient and safe food, people in poor physical health and with poor mobility. These marginalised groups are less likely to be able to participate in research, especially in the context of dementia. The CANE domains of safety (deliberate and accidental self-harm) were not identified. Safety is a critical issue in relation to the domain of autonomy, as maintaining autonomy while ensuring safety often requires a delicate balance. While unmet safety needs were not raised by EWGPWD, it was raised by the informal caregivers EDCWG as key issues that they deliberated when facilitating autonomy while mitigating risks to people with dementia. Caregivers play a crucial role in facilitating autonomy for people with dementia, helping them maintain independence and engage in meaningful activities. However, safety concerns may sometimes constrain their ability to do so, as caregivers often feel responsible for preventing harm and managing risks. This tension can lead to overly protective approaches that may inadvertently limit autonomy. From a research point of review, findings from the literature and PI consults may indicate that the link between dementia and safety factors has not been investigated to the extent that results are synthesized into published reviews, or not perceived as a priority in terms of needs by researchers or people affected by dementia. Future research should further examine how safety concerns intersect with autonomy and identify strategies that support both, ensuring that the voices of both people with dementia and their caregivers are adequately represented in shaping priorities.

Unmet needs of informal carers

The most frequently reported unmet needs in informal caregivers pertained to the disease trajectory, various areas of post-diagnostic care (e.g. ways to navigate care at different stages of the disease), and ways of facilitating a range of caregiving roles. This echoes existing literature that the needs of people with dementia change with disease progression (Huang et al., 2024), as well as findings from the PI consultation. The wide range of subcategories identified under the 'information' category paints a picture of far-reaching, multi-dimensional uncertainty, ranging from lack of practical information (e.g. the healthcare options and services available) and its accessibility (e.g. digital/health literacy- or language-accessibility, information overload) to uncertainty about how to deal with and what to expect as dementia progresses. Next, the most frequently reported areas of psychological distress in informal caregivers stemmed from social isolation or alienation, caregiving demand, and adjustment to relationship changes across different stages of the disease. Interactions and experiences with care services and providers were also a source of distress, particularly when they felt that formal caregivers did not involve them in care provision. These findings provide key areas of focus for dementia care services and providers to support informal caregivers.

Unmet needs of formal carers (i.e. health and social care professionals)

Informal caregivers often look to formal caregivers and service providers to address these information needs. However, our findings suggest that formal caregivers may also lack the knowledge, skills or confidence to address informal caregivers' information needs, with their highest reported area of shortcoming being training or skills needed to provide care, knowledge about dementia, and communication. In contrast to professional caregivers who work in institutional care (e.g. hospitals, nursing homes) contexts, home care workers provide care at the homes of people with dementia. The difference in context appears to influence the sources of psychological distress in formal caregivers. For formal caregivers working in institutional contexts, distress stemmed primarily from care provision, such as when their organisations or colleagues' care philosophy did not align with their personal values. However, for home-care workers, psychological distress appeared to stem from supporting people with dementia in their own homes. They often provide care without receiving immediate support from their peers (Bergqvist et al., 2024), leading to a sense of not being supported, undervalued and isolated (Forward et al., 2024).

Unmet needs and social health

Mapping the unmet needs of people with dementia to the social health framework (Dröes et al., 2017) enabled further characterisation of how unmet needs influence different aspects of the social wellbeing of people with dementia; and how disease-related, social and environmental factors influence individuals' needs. For instance, people with YOD/FTD/FTLDs were often less well-served in terms of timely diagnosis, and provision of appropriate services, as evidenced by the findings of this review. This might also have been attributed to the complexity of diagnosing FTD/FLTDs (Vila-Castelar et al., 2022). Similarly, unmet needs may be particularly pronounced in individuals with other rarer forms of dementia, which are often underrepresented in the literature. The absence of explicit references to these conditions in existing reviews suggests that their specific needs may not yet be sufficiently understood or prioritized in research. As a result, people with these dementias may face additional barriers in accessing timely and appropriate support. There is significant scope for the investigation of intersections of care to consider how different factors can create unique health challenges for different individuals with dementia (Roes et al., 2022).

Furthermore, unlike for people with dementia, the conceptualisation of social health in caregivers of people with dementia is substantially less developed, making it difficult to apply the same framework. Existing models, such as the social determinants of health' (SDOH) framework, provide a broad understanding of factors influencing caregiver health but do not specifically address caregiving in the context of dementia. It includes five domains that influence health outcomes across the lifespan, namely economic stability, educational access and quality, healthcare access and quality, neighbourhood and built environments, and social and community support (National Academies of Sciences, Engineering, and Medicine Division, 2019). While the SDOH framework is not specific to dementia, Gaugler et al. (2023) proposed a model to understand the social factors influencing the health of informal caregivers of people with dementia and proposed mechanisms of impact that may influence health outcomes. These included financial strain, health literacy, health services, activity engagement and social isolation. While this model serves as a springboard to consider social health in informal caregivers and influencing factors, there is a need for a clearer conceptualisation of its definition, and for a more systematic approach to consider influencing factors, such as disease-related or personal factors (e.g. cultural background) to facilitate its applicability across contexts. For instance, our review found that informal caregivers of people with YOD and FLTD have unique relational needs; and needs change across the disease trajectory. Such factors should be considered in future iterations of the model.

Finally, the number of studies focused on the unmet needs of people with dementia and caregivers from countries such as China, India, Sub-Saharan Africa was small. As it stands, the literature on the unmet needs of people affected by dementia is still dominated by research framed within 'Western' cultures of research, conceptualizations of health and ill-health (including dementia) and research. However, dementia is a global phenomenon, and there is a dire need for more research partnerships between the global north and the global south in order to foster mutual understanding of how the unmet needs of people affected by dementia are best understood within their respective contexts and how they can best be met (Vila-Castelar et al., 2022).

Strengths and limitations

This scoping review of reviews is the first of its kind to synthesize unmet needs of people affected by dementia, and to map these unmet needs onto a comprehensive needs assessment tool and a social health framework. A review of reviews is, in essence, a 'double distillation' of the states of affairs investigated in the primary literature. The resulting broad trends are the product of multiple filters, including research (and funding) priorities, researchers' disciplinary backgrounds, or the primary studies' inclusion and exclusion criteria, among others. In addition, primary literature which have been published more recently may not have been included in existing reviews. It is therefore important to keep in mind that a review of reviews represents a trade-of

- it is a reliable and principled method of synthesizing a very large body of published research, but at the same time, the results are two levels removed from the lived experiences of (in this case) people affected by dementia, and the complexity of factors that influence the impact of dementia is to an extent simplified. In addition, PI consultations have revealed that our findings correspond with lived experiences by people living with dementia and their informal caregivers. An established methodological framework was used to guide the review process, and a comprehensive search strategy was established to include non-English language articles. However, while we undertook a comprehensive search of electronic databases, grey literature was not searched. Moreover, a quality assessment of included reviews was not undertaken, which may have resulted in lower quality reviews being included. Nevertheless, all included reviews reported the use of a systematic process in their evidence synthesis approach.

Conclusion

This review critically synthesises a considerable volume of research undertaken in the last 15 years to broadly identify the unmet needs in people affected by dementia, based on a pre-defined conceptual definition of 'need'. The highest reported area of deficit for people with dementia were in supporting psychological needs, having appropriate daytime activities and company. For informal caregivers, the most frequently reported unmet information needs related to post-diagnostic care options and services, knowledge about the disease trajectory, knowing what to expect, and how caregiving should be rendered. Psychological distress mostly stemmed from social isolation and the demands of caregiving. Among formal caregivers, unmet training and information needs related to inadequate knowledge about dementia and practical skills to provide care. Their sources of psychological distress were also identified as contextually based. These findings provide important directions for dementia care providers to address if the unmet needs of people affected by dementia are to be managed effectively. A clear conceptualisation of what constitutes social health in people with dementia enabled considerations of how unmet needs affect their social wellbeing. Given that the conceptualisation of social health in caregivers of people with dementia is substantially less developed, it is clear that this is an important area for further development. Finally, future research should further investigate the intersections of care to consider how different factors can influence unmet needs and create unique health challenges for individuals affected by dementia.

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Ethical approval and consent to participate

No ethical approval was necessary or sought given that this is a secondary study

Consent for publication

Not applicable

Authors' contributions

Designing and developing the review protocol - WQK, MR, DC, DS, MGP, RT, NM, AD, LH
Article screening - WQK, MR, DS, DC, RT, MGP
Data extraction - WQK, CI, AW
Data synthesis—WQK, MR, MdV, MGP, LH
Drafting the manuscript—WQK, MGP, NM, MGP, RT
Reading and approving final version of manuscript—All authors

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ORCID

Wei Qi Koh http://orcid.org/0000-0001-8196-1628
Martina Roes http://orcid.org/0000-0003-4531-8584
Marjolein de Vugt http://orcid.org/0000-0002-2113-4134
Dugyu Szegin http://orcid.org/0000-0001-8378-6835
Manuel Gonçalves-Pereira http://orcid.org/0000-0003-1419-1306
Nicole Müller http://orcid.org/0000-0002-4405-5340
Ana Diaz http://orcid.org/0000-0002-5533-0344
Dympna Casey http://orcid.org/0000-0001-5341-597X
Jochen René Thyrian http://orcid.org/0000-0001-6889-693X
David Neal http://orcid.org/0000-0001-7916-3299
Adelina Comas http://orcid.org/0000-0002-9860-9062
Louise Hopper http://orcid.org/0000-0002-9382-5241

Data availability statement

Data that were used in this review are publicly available. The data generated and analysed in this study has been made available through the appendices.

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Appendix 1: Search strategy

PubMed

#	Query	Results
1	'dementia'[MeSH Terms] OR 'dementia'[All Fields] OR 'dementias'[All Fields] OR 'dementia s'[All Fields]	280,409
2	'alzheimer disease'[MeSH Terms] OR ('alzheimer'[All Fields] AND 'disease'[All Fields]) OR 'alzheimer disease'[All Fields] OR ('alzheimers'[All Fields] AND 'disease'[All Fields]) OR 'alzheimers disease'[All Fields]	214,049
3	'lewy body disease'[All Fields] OR 'lewy body dementia'[All Fields]	6,212
5	'mild cognitive impairment'[All Fields]	26,377
6	'creutzfeldt jakob'[All Fields]'	9,047
7	'huntington's disease'[All Fields]	15,894
8	'posterior cortical atrophy'[All Fields]	599
9	#1 OR #2 OR #3 OR #5 OR #6 OR #7 OR #8	353,404
10	'unmet'[All Fields] AND ('health services needs and demand'[MeSH Terms] OR ('health'[All Fields] AND 'services'[All Fields] AND 'needs'[All Fields] AND 'demand'[All Fields]) OR 'health services needs and demand'[All Fields] OR 'needed'[All Fields] OR 'needs'[All Fields] OR 'needing'[All Fields])	21,865
11	'unmet care need'[All Fields]	11
14	'personal needs'[All Fields] OR 'personal need'[All Fields]	829
15	'care need'[All Fields] OR 'care needs'[All Fields]	19,528
16	#10 OR #11 OR #14 OR #15	39,904
17	#9 AND #16	1,519
18	#9 AND #16 Filter: from 2009 – 2024	1,293
21	#9 AND #16 Filter: Meta-Analysis, Review, Systematic Review, from 2009 – 2024	277

Medline via EBSCOhost

#	Query	Results
S1	(MH 'Dementia')	63,537
S2	(MH 'Frontotemporal Dementia')	4,762
S3	(MH 'Dementia, Vascular')	5,745
S4	(MH 'Dementia, Multi-Infarct')	1,090
S5	(MH 'AIDS Dementia Complex')	3,938
S6	(MH 'Alzheimer Disease')	123,920
S7	(MH 'Mixed Dementias')	10
S8	(MH 'Lewy Body Disease')	4,479
S9	'dementia'	179,998
S10	(MH 'Creutzfeldt-Jakob Syndrome')	6,878
S11	(MH 'Huntington Disease')	13,960
S12	'posterior cortical atrophy'	598
S13	(MH 'Cognitive Dysfunction')	39,191
S14	'mild cognitive impairment'	49,161
S15	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	302,359
S16	(MH 'Needs Assessment')	32,559
S17	(MH 'Health Services Needs and Demand')	55,298
S18	'unmet needs'	10,395
S19	'needs'	512,663
S20	S16 OR S17 OR S18 OR S19	512,663
S21	S15 AND S20	8,752
S22	S15 AND S20 Limiters: Publication date from 1/1/2009 – Current; Publication type: Meta-analysis, Review, Systematic review	6,784
S3	S15 AND S20 Limiters: Publication date from 1/1/2009 – Current; Publication type: Meta-analysis, Review, Systematic review	1,471

CINAHL via EBSCOhost

#	Query	Results
S1	(MH 'Dementia')	47,064
S2	(MH 'Frontotemporal Dementia')	952
S3	(MH 'Dementia, Vascular')	1,415
S4	(MH 'Dementia, Multi-Infarct')	308
S5	(MH 'AIDS Dementia Complex')	561
S6	(MH 'Alzheimer Disease')	0
S7	(MH 'Mixed Dementias')	60
S8	(MH 'Lewy Body Disease')	1,446
S9	'dementia'	78,353
S10	(MH 'Creutzfeldt-Jakob Syndrome')	1,414
S11	(MH 'Huntington Disease')	0
S12	'posterior cortical atrophy'	223
S13	(MH 'Cognitive Dysfunction')	0
S14	'mild cognitive impairment'	10,346
S15	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	85,156
S16	(MH 'Needs Assessment')	23,768
S17	(MH 'Health Services Needs and Demand')	29,695
S18	'unmet needs'	4,729
S19	'needs'	236,787
S20	S16 OR S17 OR S18 OR S19	236,787
S21	S15 AND S20	5,304
S22	S15 AND S20 Limiters: Publication date from 1/1/2009 – Current; Publication type: Meta-analysis, Review, Systematic review	4,204
S3	S15 AND S20 Limiters: Publication date from 1/1/2009 – Current; Publication type: Meta-analysis, Meta-Synthesis, Review, Systematic review	618

Epistemonikos

#	Query	Results
1	(title:((needs OR unmet needs) AND (dementia)) OR abstract:((needs OR unmet needs) AND (dementia))) Publication Type: Broad Synthesis	92
2	(title:((needs) AND (dementia)) OR abstract:((needs) AND (dementia))) Publication Type: Systematic review	448

Web of Science

#	Query	Results
1	ALL = (dementia)	246,198
2	ALL = (dementia) and Dementia (Should – Search within topic) and Frontotemporal Dementia (Should – Search within topic) and Vascular Dementia (Should – Search within topic) and Alzheimer S Disease (Should – Search within topic) and Dementia With Lewy Bodies (Should – Search within topic)	359,503
3	ALL = (unmet needs)	41,495
6	**ALL = (unmet needs)** and **Supportive Care Needs** (Should – Search within topic) and **Unmet Need** (Should – Search within topic)	42,415
7	**ALL=(unmet needs)** and **Supportive Care Needs** (Should – Search within topic) and **Unmet Need** (Should – Search within topic) and **Unmet Healthcare Needs** (Should – Search within topic) and **Needs Assessment** (Should – Search within topic)	53,480
8	**ALL = (unmet needs)** and **Supportive Care Needs** (Should – Search within topic) and Unmet Need (Should – Search within topic) and **Unmet Healthcare Needs** (Should – Search within topic) and **Needs Assessment** (Should – Search within topic) and **Needs** (Should – Search within topic)	1,035,523
9	#7 AND #2	1,327
10	#7 AND #2 and Review Article (Document Types)	311
11	#10 AND #2 and Review Article (Document Types) and 2009 - Current (Publication Years)	282

Appendix 2: Study characteristics

First author, year	Study aims / objectives	Type of review	Number of studies included	Care settings
Abdullah 2023	To review and summarise the literature on the health and social care needs of older people with dementia in low and middle-income Asian countries.	Scoping reviews	8	N/A
Acton 2023	To increase understanding of the challenges experienced in providing care to people with intellectual disability and dementia	Systematic review	12	N/A
Afram 2015	To provide insight into problems and needs of informal caregivers caring for people with dementia during care-transition from home-based care to institutional long-term care	Systematic review	13	Transition (Home to institutional care)
Baptista 2016	To examine factors related to the QoL of people with YOD and their caregivers	Systematic review	9	Community
Barker 2017	To explore the evidence on the decisional support needs of informal carers of people with end-stage dementia.	Scoping review	40	Range of settings
Bayly 2020	To Investigate education and support service needs, availability and use of services, barriers to service access and use, and solutions to these barriers for individuals with dementia and their caregivers living rurally.	Scoping review	68	Community (living at home)
Beardon 2018	To assimilate results of the studies and describe components of care that influence perceived quality.	Systematic review	20	Hospital settings (Acute)
Bressan 2020	To identify and synthetise the existing literature on the needs of family caregivers of people with dementia at home.	Systematic review	34	Community (living at home)
Brijnath 2023	To examine recent evidence on what constitutes culturally appropriate models of care in ethnically diverse populations.	Narrative review	N/A	N/A
Bunn 2014	To scope the extent, range and nature of research activity around dementia and comorbidity (in particular stroke, diabetes and visual impairment) in people with dementia	Scoping review	74	Community
Cabote 2023	To synthesise information about the needs of older people with dementia from culturally and linguistically diverse backgrounds living in residential aged care from the perspectives of the residents, families and care staff	Integrative review	15	Long term care facilities (residential aged care)
Campbell-Enns 2023	To summarize the experiences and needs of rural unpaid family caregivers of persons living with dementia	Systematic review (Qualitative)	36	Community
Cleary 2017	To present the findings from a narrative literature review of professional caregivers' experiences of caring for individuals with intellectual disability and dementia.	Narrative review	14	Range of settings
Cross 2018	To synthesise qualitative research investigating the experiences, perceptions of quality of life, and psychosocial impact of caregiving in adult caregivers of people with dementia	Systematic review	14	Community

(*Continued*)

Appendix 2: Continued.

First author, year	Study aims / objectives	Type of review	Number of studies included	Care settings
Cunningham 2020	To provide an overview of dementia and cancer training and education accessible to the homecare workforce.	Umbrella review	13	Community (living at home)
D'Astous 2019	To xplore the perspectives and experiences of homecare workers providing care for people with dementia living at home up to the end of life.	Systematic review	12	Community
Digby 2017	To identify and examine the existing research that has explored how people with dementia and the nurses caring for them view the experience of care in hospital.	Integrative review	24	Hospital settings (Acute)
DiLorito 2022	To explore the experiences and needs of LGBT caregivers of LGBT people living with dementia, identify current barriers to providing the type of support that address their needs, and what can be done to improve service preparedness to meet their needs	Scoping review	20	Community - any statutory (public sector), commercial (private sector) or voluntary organisation
Dresden 2022	To summarize research on optimal emergency department (ED) care practices for persons living with dementia (PLWDs) and develop research priorities.	Scoping review	49	Hospital settings (Acute - Emergency departments)
Duran-Kirac 2022	To provide an overview of the literature concerning access to health care for ethnic minority people with dementia and (in)formal caregivers.	Scoping review	24	Community (living at home)
Fang et al., 2024	To systematically identify, evaluate and synthesize qualitative evidence about the dignity-related nursing experiences of people with dementia in families and nursing homes, summarize the similarities and differences and analyse the causes and influencing factors.	Systematic review (Qualitative)	14	Community (living at home) + Long term care facilities
Francis 2022	To understand the experiences of informal carers' of individuals with dementia in the UK when engaging with services for support in their caring role.	Systematic review (Qualitative)	11	Community
Gaviola 2023	To map and synthesise available literature on approaches to care provision for people with dementia from culturally and linguistically diverse backgrounds living in nursing homes. The secondary aim was to identify gaps in the literature which could be the basis for future research or change to clinical practice.	Scoping review	25	Long term care facilities (residential aged care)
Graneheim 2014	To synthesise literature describing family caregivers and experiences of relinquishing the care of a person with dementia to a nursing home	Meta-ethnography	10	Transition (Home to long-term care)
Gwernan-Jones 2020	To systematically review and synthesise qualitative data from studies exploring the experiences of hospital staff who care for people living with dementia	Systematic review (Qualitative)	24	Hospital settings
Hermann 2015	To outline the specific needs of dementia patients, describe how geriatricians, neurologists and psychiatrists may contribute to better patient care in interaction with nurses, occupational therapists, physiotherapists, speech therapists, psychologists and social workers	Literature review (non-systematic)	N/A	Hospital settings
Hodges 2021	To review the existing literature on the support needs of carers acting as proxy healthcare decision-makers for people with dementia	Systematic review (Qualitative)	15	N/A
Innes 2011	To critically evaluate the available evidence from published scientific literature on informal/family dementia care in rural and remote settings to assess the current state of knowledge, identify support implications and make recommendations for future research.	Systematic review	26	N/A
Jagoda 2023	To review and synthesise the evidence on informal carers information needs in managing behavioural and psychological symptoms of dementia (BPSD) of their care recipients and related mobile health (mHealth) applications to inform the design of an mHealth application.	Integrative review	34	Community (living at home)
Johl 2016	To provide a critical appraisal of empirical research into the attitudes, experiences, and needs of these individuals providing care for a person with dementia within BME communities in the UK.	Systematic review	8	Community
Jones 2019	To review studies that explores decisions associated with the EoLC of people with dementia specifically to understand 1) who is involved in the decision-making process? 2. How are decisions made concerning EoLC and what is the outcome in facilitating a good death? 3. In what way do systemic factors impact upon EoLC?	Scoping review	25	Range of settings (making decision on EoLC)
Jonsdottir 2021	To identify and explore nurses' knowledge and attitudes towards pain assessment in older people with dementia and how it may affect pain management in this patient group	Literature review	10	Range of settings
Joy 2023	To explore the experiences and perceptions of healthcare staff in managing responsive behaviour of residents with dementia in older persons in residential care services.	Systematic review (Qualitative)	9	Long term care facilities

(*Continued*)

Appendix 2: Continued.

First author, year	Study aims / objectives	Type of review	Number of studies included	Care settings
Kane 2021	To examine the empirical studies published on caring for persons with dementia in Arab countries of the MENA (Middle East and North Africa) region	Scoping review	20	Community (living at home) + Long term care facilities
Kane 2023	To explore the training and psychosocial needs of homecare workers caring for people living with dementia	Literature review	7	Community (living at home)
Karnatz 2021	To provide an overview on existing literature about factors contributing to caregivers distress and on interventions that have the potential to decrease the burden of the caregivers of people with FTLD.	Scoping review	69	Range of settings
Khanassov 2016	To identify the needs of the patient-caregiver dyad and the effects of case management, to answer the question 'does the collaboration of family physicians with case managers respond to the needs of patients with dementia and their caregivers living in the community?'	Systematic review (mixed method review)	54	Community
Lee 2019	To identify experiences, needs, interventions and outcomes for caregivers of persons with Alzheimer disease or related dementia as they transition into this new role following diagnosis.	Scoping review	29	Community
Lee 2019	To examine prevalence, types, challenges and the impact of medical/nursing tasks (MNT) on caregivers of older adults with dementia	Integrative review	13	Community
Lee 2022	To identify experiences, unmet needs, and health-related quality of life (HRQoL) of family caregivers transitioning their care recipients with dementia into long-term care (LTC).	Scoping review	19	Transition (Home to long-term care)
Lindeza 2020	To understand the holistic experience of caring for a person with dementia, including not only the positive and negative aspects of caregiving through caregivers'Äô perspectives, but also the expressed factors that affect those experiences.	Systematic review (Qualitative)	81	Range of settings
Macdonald 2020	To synthesize evidence on the experiences and perceptions of spousal/partner caregivers of community-dwelling adults with dementia.	Systematic review (Qualitative)	19	Community
Martin 2019	To understand what is known from the existing literature about culture and language in relation to caregiving of residents with dementia in care homes, and the implications therein for the residents' wellbeing, specifically 1. culture and well-being in caregiving, 2. language and well-being in caregiving, 3. Welsh language and culture, in the context of healthcare provision and caregiving and implications on well-being	Scoping review	50	Long term care facilities (residential aged care)
McCabe 2016	To understand the perceived needs of immediate family caregivers of community-dwelling older adults with dementia	Systematic review	12	Community
Millenaar 2016	To systematically investigate: (i) care needs of both people with YOD and their informal caregivers; (ii) experiences with access to service and care; and (iii) experiences with the use of these service	Systematic review	27	Community
Morgan 2011	To evaluate the available evidence from the published scientific literature on dementia care and service provision in rural and remote settings from the perspective of formal/paid caregiving	Systematic review	46	Range of settings
Morrisby 2018	To summarize and disseminate the current international research evidence on the met and unmet needs of people with dementia and their carers, to inform researchers and policy-makers	Scoping review	27	N/A
Mueller 2022	To identify the needs of family and unpaid caregivers of older adults living with dementia across various care settings in the U.S.	Systematic review	31	Range of settings
Mwendwa 2022	The aim of this review was to address the following question: What are the experiences with caring for older people living with dementia in sub-Saharan Africa?	Systemic review	19	Community
Nunnemann 2012	To systematically review studies analyzing (World Health Organization, 2025) burden, problems, and needs of caregivers of FTLD patients, and (Nichols et al., 2022) the feasibility and efficacy of caregiver interventions in FTLD	Systematic review	19	N/A
O'Malley 2021	to collate the existing research base regarding the self-reported experience of receiving a diagnosis of YOD and to summarise the themes and patterns that emerged	Scoping review	8	Community
Österholm 2023	To map how different health and care agencies collaborate and coordinate services for older people with dementia	Scoping review	59	N/A
Peacock, 2013	To present what is known and highlight the gaps in the literature relevant to the experiences of family caregivers of persons with dementia at the end of life.	Integrative review	10	N/A

(*Continued*)

Appendix 2: Continued.

First author, year	Study aims / objectives	Type of review	Number of studies included	Care settings
Petty 2018	To present all available descriptions of emotional distress and explanations for emotional distress experienced by individuals with dementia, articulated personally and by others	Systematic review	121	Range of settings
Poole 2022	To critically evaluate empirical evidence regarding the needs and experiences of children who have a parent with young onset dementia (YOD)	Systematic review (QES)	16	Community
Prorok 2013	To examine aspects of the health care experience of people with dementia and their caregivers to better understand ways to improve care for this population	Systematic review (Qualitative)	46	Primary care
Queluz 2020	To identify and describe the literature surrounding the needs of caregivers of PWD and the solutions identified to meet these needs.	Scoping review	31	N/A
Racine 2022	To explore Indigenous caregivers' needs when caring for someone living with dementia and cognitive impairment symptoms in Indigenous communities.	Integrative review	51	Community
Rees 2019	To dentify the psychological and social impacts of YOD in the family, for asymptomatic relatives.	Systematic review	19	N/A
Reilly 2019	To explore the experiences and perceptions of patients living with dementia on the care they receive in acute settings	Systematic review	7	Hospital settings (Acute)
Richardson 2019	To understand the experiences and outcomes of care for people living with dementia who undergo this transition from the perspectives of key stakeholders; people living with dementia, their families and health care professionals	Systematic review	9	Transition (Hospital to a care home/ similar care facility)
Robinson 2011	To synthesise empirical evidence on patient and carer experiences in the transition to dementia	Systematic review	62	Community
Røsvik 2020	To describe the research on interventions to meet the needs of people with dementia in acute hospital settings regarding physical environment, organization of care, and staff knowledge of dementia and competence in person-centred care.	Integrative Review	15	Hospital settings (Acute)
Sansoni 2016	To examine the literature relating to the epidemiological aspects of YOD, the issues faced by people with YOD and their families, their needs and care requirements, and current programs and service initiatives	Literature review	304	Community
Saragosa 2021	To systematically search and present a synthesis of the qualitative health care transition literature involving people with dementia or cognitive impairment, and/or caregivers or relatives of persons living with dementia	Systematic review	18	Transition (Home, hospital, hospice, long-term care settings)
Shea 2017	To understand key stakeholders' experiences of respite services for people with dementia, with a view to informing respite service development	Systematic review	23	Community (dementia respite care)
Shiba 2022	To explore the experiences of families of people living with FTD	Systematic review	6	Community (living at home)
Soong 2019	To provide an overview of the information needs and information seeking behaviour of people with dementia and their non-professional caregivers.	Scoping review	20	Community
Steenfeldt 2021	To identify and describe the needs of family caregivers living with a person with dementia at home	Literature review	34	Community (living at home)
Stenberg 2023	To describe migrant family caregivers' experiences and perceptions of caring for a family member with dementia.	Systematic review	26	Community
Stockwell-Smith 2018	To identify barriers and facilitators to engagement of people with dementia and family carers in planning for discharge from hospital.	Literature review	11	Hospital settings (Acute & subacute)
Sturge 2024	To summarize the literature on what is known about measures used to modulate the life-space mobility of residents with dementia living in a residential care environment, with a focus on exploring the moral considerations and risks, sex and gender aspects	Scoping review	30	Long term care facilities (residential aged care)
Tan 2023	To investigate FTD and psychological and social impacts on caregivers and family members	Systematic review	36	N/A
Tang 2011	To examine the use and impacts of respite for older clients, with a particular focus on Australian research and on dementia respite.	Narrative review	N/A	Community (respite care)
Tasseron-Dries 2023	This study aimed to determine best practices for involving family caregivers in interventions aimed at preventing and reducing responsive behaviour stemming from unmet needs, including pain.	Scoping review	20	Long term care facilities (nursing homes)
Teng 2020	To describe experiences and perspectives of people with dementia and their family caregivers in making decisions about institutional care placement.	Systematic review (Qualitative)	42	Community (decision about institutional care placement)
Thompson 2014	To describe the domains of dementia family caregiver needs and their impact on the delivery of palliative care services	Literature review (non-systematic)	N/A	N/A

(*Continued*)

Appendix 2: Continued.

First author, year	Study aims / objectives	Type of review	Number of studies included	Care settings
Tookey 2021	To describe the subjective experience of being an informal carer of a person with FTD and to identify the specific needs, coping strategies and helpful support resources of this carer population	Systematic review	12	Community
Waligora et al. 2019	To understand the self-care needs and behaviors of ADRD ICGs and to discuss future research implications	Systematic Review	29	N/A
Warren 2022	To provide evidence to reframe the approach with which caregivers view the manifestations of behavioral and psychological symptoms of dementia (BPSD) to ensure quality of care for persons with dementia	Literature review	14	N/A
Wiggins 2023	To identify the psychological and social impacts of YOD in the family, for asymptomatic relatives.	Systematic review	19	Community
Xiao 2022	To explore social conditions affecting ethnic minority residents' ability to exercise their autonomy in communication and care while in nursing homes.	Systematic review	19	Long term care facilities (nursing homes)
Xiao 2023	To synthesise findings from rigorous qualitative studies on the experiences of family caregivers of people with dementia from a Muslim migrant background in high-income countries.	Systematic review	17	Community
Zhang 2023	To gain deep insights into Chinese diaspora caregivers' experiences and factors contributing to their experiences in the care of family members living with dementia in high-income countries	Systematic review	16	Community (living at home)
Zhao 2020	To establish an understanding of healthcare professionals' dementia knowledge and attitudes towards dementia care, and family carers' perceptions of dementia care in China.	Integrative review	38	Range of settings