McQueen, Lewis, Cole, Scott ORCID logoORCID: https://orcid.org/0000-0001-8176-283X, Charura, Divine ORCID logoORCID: https://orcid.org/0000-0002-3509-9392 and Hodgson, Philip (2025) Navigating Dementia Services: An International Review of Informal Caregiver Perspectives. Dementia. (In Press)

## Background

It is estimated that dementia affects over 57 million people around the world (World Health Organisation (WHO) 2025), with one in two individuals either developing the condition or caring for someone who has it (Alzheimer's Research UK, 2023). The World Health Organization (2017) defines dementia as a syndrome caused by diseases that progressively damage nerve cells, impairing cognitive functions like memory, language, and perception. Alongside cognitive decline, individuals with dementia often experience changes in social behaviour and emotional regulation (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). It has been noted that every year, there are nearly 10 million new cases, currently making dementia the seventh leading cause of death and one of the major causes of disability and dependency among older people worldwide (WHO, 2025).

Dementia, however, should not be understood solely in biomedical terms, as the experience of living with the condition, and of caring for someone who does, is deeply shaped by social and cultural contexts. These lived experiences, including the emotional and relational dimensions, can be as significant as the biological manifestations of the disease (Davis, 2004; Novek & Wilkinson, 2019) and means that the intersection of medical and social narratives deeply influences the experiences of people living with dementia and their caregivers (Farhana et al., 2023).

This review focuses on informal dementia caregivers, an important and sizeable group often overlooked in dementia policy and practice. Informal care refers to unpaid assistance from family, friends, or neighbours and is recognised as an "important resource" in dementia care (Broese Van Groenou & De Boer, 2016; Department of Health, 2009). Despite their critical role, informal carers face challenges, including inadequate support and lack of clarity on care delivery in policy and services (Carers Trust, 2016; Alzheimer's Disease International, 2011). While some national guidelines stress the importance of supporting carers (e.g., NICE, 2018;

Rabins, P. V., 2007), there remains uncertainty about how to effectively implement such support, resulting in a large and growing group of active carers acting without adequate support.

Caregivers of people living with dementia experience unique emotional, physical, and social challenges, often worsened by societal stigma (Kim & Schulz, 2008). The caregiving role can lead to stress, exhaustion, and a reduced quality of life (Dickinson et al., 2017). Despite clinical guidelines, carers report unmet needs, struggling to access timely information, support, and services (Gorska et al., 2013; Lapridou et al., 2019; Sutcliffe et al., 2015). A study by Mansfield et al. (2023) examining Australian carers of people living with dementia unmet needs found that 76%-97% of carers reported unmet needs, highlighting gaps in support despite long-standing policies.

While caregiving is often associated with negative experiences, some carers report positive aspects, such as a sense of purpose and emotional rewards (Alves et al., 2019; Dickinson et al., 2017). However, these positives must be balanced with the emotional and physical burdens of caregiving (Yu, Cheng, & Wang, 2018). Strengths-based approaches to dementia care aim to highlight these positives but have been criticized for potentially overlooking the real difficulties carers face (Slasberg & Beresford, 2017).

As the number of people living with dementia rises, the demand for informal carers will increase (Carers Week Report, 2020). This underscores the need to design dementia services that prioritise the needs of carers and adopt a holistic approach, that integrates both biomedical and socio-cultural perspectives, in order to enhance the quality of care (Farhana et al., 2023). Services are unlikely to achieve improvements in care quality without including carer voices as previous research has shown that interventions lacking carers' input often fail to adequately address their needs (Holt Clemmensen et al., 2021; WHO, 2017). This review draws on a wide range of studies and synthesises research from diverse cultural and healthcare contexts and thus contributes to the evidence base for informing and improving dementia care policy and practice across international health systems. By critically analysing primary studies, this review aims to provide insights into improving clinical practice and supporting carers more effectively (Creswell, 2013).

## Method

This review sought to generate an understanding of the experiences of informal carers of people living with dementia, focusing on their interactions with dementia services, expectations, and suggestions for improvement. Findings from primary studies were analysed using thematic synthesis (Thomas & Harden, 2008), which allows qualitative data to be integrated across diverse contexts while remaining grounded in carers' lived experiences. This approach was chosen because it provides a clear, flexible, transparent, and systematic method for synthesising qualitative data, enabling the generation of novel insights that can expand professional knowledge and inform both policy and practice (Drisko, 2020; Giardulli et al., 2025; Noyes et al., 2024).

## Search

Study selection and searches were guided by the PICO framework, which is recommended to enhance comprehensiveness, with a structured search strategy applied across multiple databases using keywords, synonyms, and subject headings (Methley et al., 2014). Searches were conducted in November 2022 using MEDLINE, PsychInfo, and CINAHL, focusing on informal dementia carers' interactions with dementia services. Studies published in English were included, regardless of the country of origin, with no date restrictions. Hand searching using snowballing and citation searching were also used. The search was updated in October 2024. The details of inclusion and exclusion criteria, and search terms is shown in Table 1.

### Inclusion Criteria

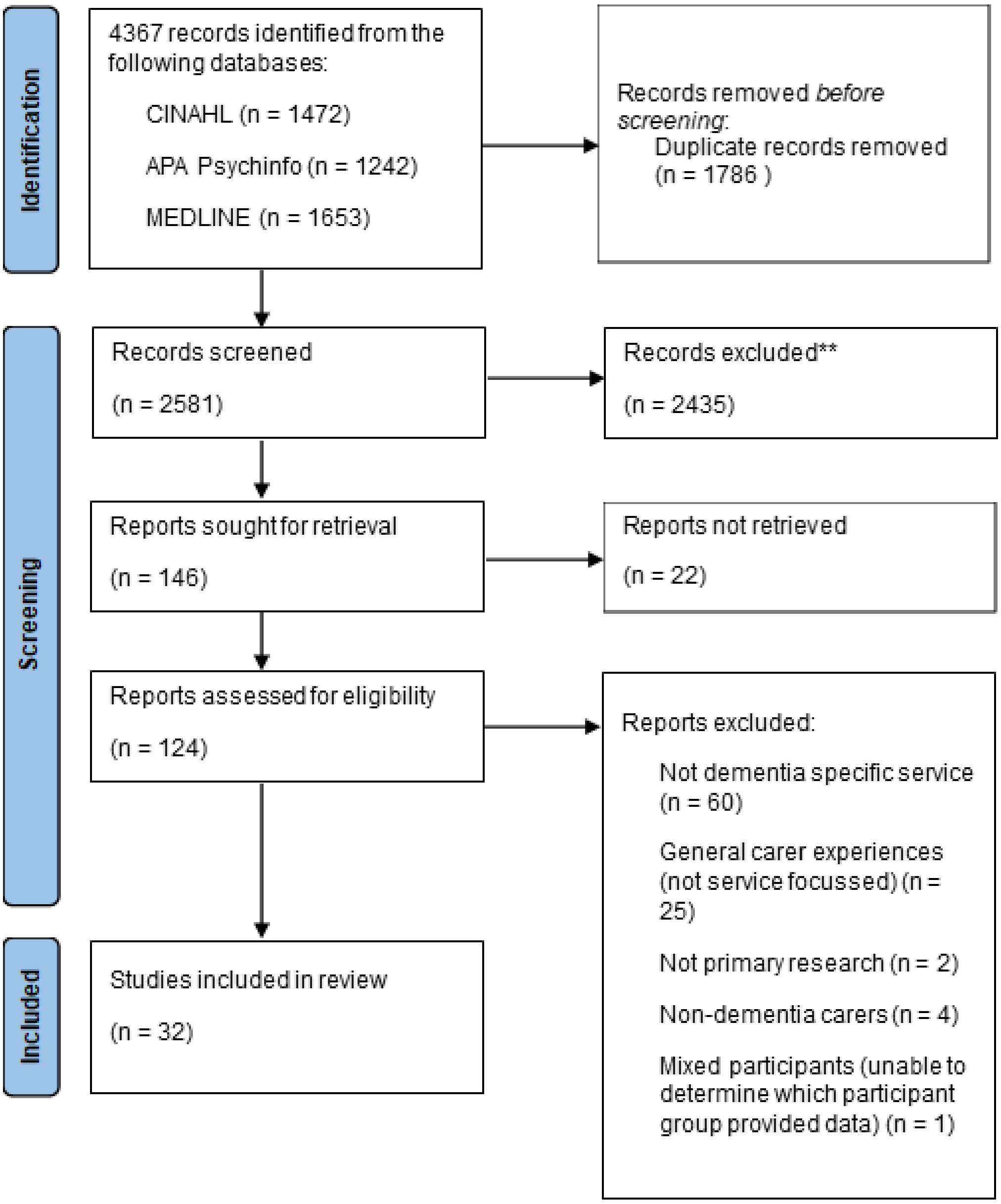
Studies were selected based on their focus on informal dementia carers' experiences with dementia health services. The Population, Intervention, Comparison, and Outcome (PICO) framework (Richardson et al., 1995) guided the inclusion criteria. Two independent reviewers applied these criteria using the Rayyan web app (Ouzzani et al. 2016). After removing duplicates, 2,581 articles were identified, which were screened by title and abstract. Inter-rater agreement during abstract screening was high, with reviewers agreeing on 2243 out of 2581 records (86.9%). Full articles were reviewed and re-assessed for relevance. Twenty-two articles could not be retrieved in full due to being unpublished or incomplete studies, and in some cases abstracts were available in English, but full texts were published in other languages for which translations were not accessible. Exclusion criteria included studies focusing solely on general caregiving experiences without specific reference to dementia health services. Non-health services, such as day programmes, respite, and support groups were excluded. This focus reflects a methodological decision, rather than an assessment of the importance of health or social care services. Diagnosis and coordination of dementia care are recognised as key areas for improving support for people living with dementia and their carers, and these are typically provided by healthcare services (World Health Organization 2017). Focusing on health services allowed the review to provide a coherent and focused synthesis of caregiver experiences, ensuring findings are directly relevant to health service delivery and improvement. The screening process is shown in Table 2 PRISMA flowchart (Page et al., 2021).

**Table 1** Study inclusion and exclusion criteria

| **Inclusion criteria** | **Exclusion criteria** |
|---|---|
| Participants | Participants |
| Participants were informal carers of someone with dementia | Care staff or formal care providers<br>Person with dementia |
| Intervention | Intervention |
| Dementia health services (e.g. memory clinic, community mental health team) | Non-health services (e.g. day programmes, respite, support groups)<br>Non-dementia focussed services |
| Comparison | Comparison |
| Qualitative studies (including interviews and focus groups) | Quantitative studies |
| Outcome | Outcome |
| Studies exploring informal carer experiences, perspectives, perceptions, expectations | Studies quantifying barriers, factors, behaviours |
| | |

| Search Terms |
|---|
| **Population:** carer OR caregive* - “in”: Abstract (AB) |
| **Intervention:** dementia service* OR memory service* OR dementia specialist OR dementia care – “in” Abstract (AB) |
| **Comparison:** Qualitative data collection and analysis |
| **Outcome:** experience* OR perspective* OR view* OR perception* OR attitude* OR expectation – “in” Abstract (AB) |

**Table 2** PRISMA flow diagram (Page et al., 2021)



## Critical Appraisal

Thirty-two studies met the inclusion criteria and were appraised using the Critical Appraisal Skills Programme (CASP) qualitative checklist (CASP, 2019), assessing study validity, results, and clinical applicability. A second reviewer independently appraised 37.5% of the included papers for methodological quality, and this was compared to the lead authors assessments to check for accuracy. There was complete agreement across the studies, yielding an observed agreement of 100%. Studies were rated as high quality (eight or more criteria met), medium quality (five to seven criteria met), or low quality (fewer than four criteria met), with low-quality studies excluded. Two studies were removed due to low methodological quality, leaving thirty studies for inclusion.

## Table 3 – Study Characteristics

| Authors | Date | Design | Country | Participants | Intervention/service | Dementia type | Carer relationship |
|---|---|---|---|---|---|---|---|
| **Abley et al** | 2013 | Interviews | UK (England) | 27 people living with dementia 26 Carers | Memory Clinics | Unspecified. "memory problems", during and post diagnostic process | Unspecified |
| **Assfaw et al** | 2024 | Interviews and diary study | USA | 10 carer | Multiple | Unspecified | 7 Child, Grandchild 1, In-law daughter 1, Spouse 1 |
| **Behrman et al** | 2017 | Interviews | UK (Wales) | 10 Carer 10 Professional | CMHT / Memory Clinic | Unspecified | 8 Spouse, 2 Child |
| **Benedetti et al** | 2013 | Interviews | Australia | 9 carer | Unspecified | Unspecified | 2 Spouse, 8 Child |
| **Bowes and Wilkinson 2003** | 2003 | Case studies | UK (Scotland) | 4 case studies 11 Professional | Unspecified | Unspecified | Unspecified |
| **Cotton et al** | 2021 | Interviews | USA | 10 carer | Unspecified | Unspecified | 7 Child, 2 Spouse, 1 Multiple caring role |
| **Davies-Abbott et al** | 2024 | Interviews | UK (Wales) | 9 carer 1 person living with dementia | Unspecified | Frontotemporal dementia 6, primary progressive aphasia 3, posterior cortical atrophy 1. person living with dementia – semantic dementia. | Unspecified |
| **Dodd et al** | 2014 | Interviews | UK (England) | Primary Care: Health care professional 10, patient 6, carer 7<br>Secondary Care: Health care professional 8, patient 7, carer 8 | Primary care dementia assessment clinic / secondary care memory services | Unspecified | Unspecified |
| **Dombestein et al** | 2022 | Focus group | Norway | 15 carer | General health services with particular mentions of dementia specialist nurses and memory clinics | Unspecified | Child |

|  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|
| **Fitzgerald et al** | 2018 | Focus group | Australia | 7 people living with dementia, 18 carer | Unspecified | Unspecified | Unspecified |
| **Giebel et al** | 2021 | interviews | UK | 42 carer, 8 people living with dementia | Social support services - includes memory service and tertiary support | Unspecified | Unspecified |
| **Giebel et al** | 2022 | Interviews | UK | 16 | Social support services - includes memory service | Alzheimer’s (8), Mixed (2), Vascular (2), YOD (3), Other (1) | Spouse 10, Adult child 10 |
| **Gilbert et al** | 2021 | Interviews | Australia | 104 | Multiple | Unspecified | Multiple |
| **Gorska et al** | 2013 | Interviews | UK (Scotland) | 31: 12 people living with dementia, 19 carer | Multiple | Alzheimer’s, Vascular, Mixed, Unspecified | Child and Spouse |
| **Innes, Abela + Scerri** | 2011 | Interviews | Malta | 17 carer | Memory Clinic | Unspecified | 4 Spouse, adult child 9, child-in-law 3 |
| **Juttla** | 2015 | Interviews | UK (England) | 12 carer | Multiple, includes CPN | Unspecified | 5 Spouse, 7 intergenerational carer |
| **Karlsson et al** | 2015 | Focus groups | Multiple: England, Estonia, Finland, France, Germany, The Netherlands, Spain, Sweden | 25 people living with dementia, 112 carer | Multiple | Unspecified | Spouse, child, grandchild, sibling, nephew, niece |
| **Ketchum et al** | 2023 | Semi-structured interviews | USA and Germany | 18 Carer | Multiple/unspecified | Unspecified | Child 14, Spouse 2, Grandchild 1, Carer for multiple people 1 |
| **Kitamura et al** | 2021 | Interviews | Japan | 5 carer | Home visit nursing (dementia specialist nurses) | Unspecified | Daughter 2, daughter in law 2, non family carer 1 |
| **Lillo-Crespo et al** | 2018 | Case study/interviews | Scotland, Slovenia, Portugal, Finland, Czech rep, Spain | 56 (21 people living with dementia, 23 family carer, 12 paid staff) | Multiple/unspecified | Unspecified | Spouse, Child, Child-in-law |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Pashby et al | 2009 | Semi-structured interview and focus group | Canada | 15 health care staff, 15 carer | Inpatient dementia assessment unit | Unspecified | Child, Spouse/partner |
| Risco et al | 2016 | Focus group | Spain | 25 professionals, 20 carer, 15 people living with dementia | General services/multiple | Unspecified | Unspecified |
| Robertson et al | 2022 | Interviews | New Zealand | 19 - 18 carer, 1 member of Alzheimer's organisation | Alzheimer’s association | Unspecified | 14 spouse - other participants unspecified |
| Robinson et al | 2009 | Focus groups | Australia | 15 carer | General services/multiple | Unspecified | Parent, friend, spouse |
| Samsi et al | 2013 | Interviews | UK | 27 people with cognitive impairment, 26 carers | Memory services | Unspecified | Spouse 15, daughter 3, extended family 2 |
| Sutcliffe et al | 2015 | Focus group | UK | 27 - 19 people living with dementia and 16 carer | General services/multiple | Unspecified | Unspecified |
| Turjamaa et al | 2020 | Thematic interview | Finland | 10 carer | Memory clinic | Unspecified | Spouse |
| Walker et al | 2017 | Semi-structured interviews | Australia | 16 - 9 people living with dementia, 7 carer | Multiple | Unspecified | Unspecified |
| White et al | 2024 | Semi-structured interviews | Australia | 25 carer | Multiple | Unspecified | 19 Child, Wife 6 |
| Willis et al | 2009 | Interviews | UK | 16 people living with dementia, 15 family carer | Croydon memory service | Alzheimer’s 6, mixed dementia 4, vascular 1, other 2, no dementia 3 | Spouse, child |
| Wolverson et al | 2023 | Semi-structured interviews | UK | 7 Carer | Mental health inpatient ward | Multiple | 4 wife, 1 husband, 1 son, 1 daughter-in-law |

## Data Synthesis

This review focused on synthesizing qualitative data regarding carers' experiences with dementia services. A qualitative interpretive approach was adopted to identify and interpret common themes, generating new insights. Our thematic synthesis involved three stages drawing upon Thomas & Harden (2008)'s framework:

1. **Stage One**: Coding text – line-by-line coding of findings sections to capture meaning.
2. **Stage Two**: Developing descriptive themes – grouping codes to form themes reflecting carers' experiences.
3. **Stage Three**: Generating analytical themes – synthesizing descriptive themes to derive broader insights.

NVivo software (Lumivero, 2023) was used for analysis, with stages one and two conducted in parallel. The findings from each study were combined into a list of descriptive themes, and Stage Three generated deeper insights through discussion and interpretation, and final conceptualization of the themes by the three members of the research team (LM, SC and DC).

## Table 4 – Overview of themes, the articles in which they were found, and examples from the articles

| Theme heading | Articles theme present in | Examples from the articles |
|---|---|---|
| The Impact of Navigating Complex and Confusing Service Delivery | Abley et al., (2013); Assfaw et al., (2024); Behrman et al., (2017); Benedetti et al., (2013); Cotton et al., (2021); Davies-Abbott et al., (2024); Dodd et al., (2014); Dombestein et al., (2022); Fitzgerald et al., (2019); Giebel et al., (2021); Giebel et al., (2022); Gilbert et al., (2022); Gorska et al., (2013); Innes et al., (2011); Karlsson et al., (2014); Ketchum et al., (2023); Risco et al., (2016); Robertson et al., (2022); Robinson et al., (2009); Samsi et al., (2013); Sutcliffe et al., (2015); Turjamaa et al., (2020); Walker et al., (2017); White et al., (2024); Wolverson et al., (2023) | *"Systemic safety failures were frequently identified, with almost unanimous dissatisfaction with the complexity of the care system." (Behrman et al. 2017).*<br>*"Caregivers found it time consuming and frustrating to access care, follow up with services several times, and navigate a fragmented and understaffed bureaucratic system." (Ketchum et al. 2023)*<br>*"Where support for dementia was provided, the respondents felt reassured that someone was available to support them if they needed it. However, contrasting reports suggested that others were offered little or no care support." (Giebel et al. 2022)* |
| Sub theme: *The Impact of Systemic Failure to Prioritize Communication* | Abley et al., (2013); Assfaw et al., (2024); Behrman et al., (2017); Benedetti et al., (2013); Cotton et al., (2021); Davies-Abbott et al., (2024); Dodd et al., (2014); Dombestein et al., (2022); Fitzgerald et al., (2019); Giebel et al., (2021); Gilbert et al., (2022); Gorska et al., (2013); Innes et al., (2011); Karlsson et al., (2015); Ketchum et al., (2023); Kitamura et al., (2021); Lillo-Crespo et al., (2018); Liu et al., (2021); Pashby et al., (2009); Risco et al., (2016); Robertson et al., (2022); Robinson et al., (2009); Samsi et al., (2013); Sutcliffe et al., (2015); Turjamaa et al., (2020); White et al., (2024); Willis et al., (2009) | *"I think it took that length of time to get there because of the fact that the services were not joined up. If each of them had been talking to one another, I think things would have moved a but quicker." (direct carer quote, Gorska et al. 2013)*<br>*"Communication seemed inconsistent, with the delivery of what were thought to be mixed messages (different things by different people), which, unsurprisingly, caused anger and distress." (Abley et al. 2013)*<br>*"Caregivers described specific situations that influenced service engagement such as staff lacking knowledge of dementia, professionalism, and poor communication skills." (Cotton et al. 2021)* |
| Sub Theme: *The Importance of a Relational approach* | Assfaw et al., (2024); Behrman et al., (2017); Benedetti et al., (2013); Cotton et al., (2021); Davies-Abbott et al., (2024); Dodd et al. (2014); Dombestein et al., (2022); Fitzgerald et al., (2019); Giebel et al., (2021); Gilbert et al., (2022); Gorska et al., (2013); Karlsson et al. (2015); Ketchum et al., (2023); Kitamura et al., | *"Caregivers often felt excluded from the diagnostic process and the sharing of the diagnosis [...] The sense of being uninvolved was also related to caregivers having to 'fight' and 'chase' clinicians for appointments and referrals." (Davies-Abbott et al., 2024)* |

| | | |
|---|---|---|
| | (2021); Liu et al., (2021); Pashby et al., (2009); Robertson et al., (2022); Samsi et al. (2013); Sutcliffe et al., (2015); Turjamaa et al. (2020); White et al. (2024); Willis et al., (2009) | *“They (carers) found it demotivating to have their knowledge or opinions disregarded, or when their consistent care for their parents seemed to have been taken for granted” (Dombestein et al. 2022)* |
| Services Causing Harm | Abley et al., 2013; Behrman et al., 2017; Davies-Abbott et al 2024; Dombestein et al., 2022; Fitzgerald et al., 2019; Giebel et al., 2021; Gilbert et al., 2022; Gorska et al., 2013; Karlsson et al., 2015; Ketchum et al., 2023; Kitamura et al., 2021; Lillo Crespo et al., 2018; Liu et al., 2021; Pashby et al., 2009; Risco et al., 2016; Robinson et al., 2009; Samsi et al., 2013; Turjamaa et al., 2020; White et al. 2024; and Willis et al., 2009 | *“Participant stories varied considerably around assessments conducted, indicating that standard guidelines for evidence-based best practice referral and assessment processes were not being followed. Some consumers and carers felt confused because they were referred to several different types of doctors. The lack of adherence to guidelines led to individuals being left feeling stressed and anxious.” (Fitzgerald et al., 2018)* |
| Thinking about and planning for an unclear future | Abley et al., 2013; Fitzgerald et al., 2019; Giebel et al., 2021; Gilbert et al., 2022; Ketchum et al., 2023; Kitamura et al., 2021; Robinson et al., 2009; Samsi et al., 2013; Sutcliffe et al. (2015); Turjamaa et al. (2020); White et al. (2024); Willis et al. (2009) | *“The caregivers were shocked by the diagnosis of dementia because they had never thought that the recipient would have dementia. The caregivers became very anxious about the future because they did not know how to care for people with dementia.” (Kitamura et al., 2021)*<br>*“Both people with memory problems and carers reported being shocked, wanting time to let it all ‘sink in’, and being dominated by feelings of concern for whether their ‘loved one’ could cope in the future.” (Samsi et al., 2013)* |
| The Centrality and Importance of Valuing Difference, Diversity and Culture | Assfaw et al., (2024); Benedetti et al., (2013); Cotton et al., (2021); Fitzgerald et al., (2019); Gilbert et al., (2022); Juttla (2015); Ketchum et al., 2023; Pashby et al., (2009) | *“I went looking and finding the information, but again, applying that information to our culture; that was not possible for us. So, you know if someone was able to understand our culture and give us the right advice; that would have been good” (Gilbert et al., 2022)*<br>*“Caregivers also expressed that if they sought outside support for dementia, they would want the people living with dementia to receive high quality and culturally respectful care. This was because of concern emanated from their experiences of discrimination observed in institutional settings.” (Assfaw et al., 2024).* |

## Findings

Among the 32 included studies, around 75% were conducted in Western, high-income countries, mainly the UK, Australia, and the USA. Most used qualitative interviews or focus groups to explore carers' experiences, with spouses, daughters, and sons as the primary caregivers, underscoring the central role of close family in informal dementia care.

The synthesis identified four main themes and two sub-themes reflecting carers' experiences with dementia services:

1. **The Impact of Navigating Complex and Confusing Service Delivery:** Carers struggled with fragmented systems, unclear pathways, and poor coordination.
    - *The Impact of Systemic Failure to Prioritize Communication:* Frequent communication challenges with professionals caused frustration and delays.
    - *Importance of a Relational Approach:* Carers stressed the need for respectful, collaborative relationships with healthcare providers.
2. **Services Causing Harm:** Dementia services sometimes worsened carers' emotional and psychological well-being due to poor delivery or harmful practices.
3. **Thinking About and Planning for an Unclear Future:** Carers faced anxiety over dementia's uncertain progression, often lacking guidance for future planning and feeling unprepared.
4. **The Centrality and Importance of Valuing Difference, Diversity, and Culture:** Cultural and linguistic barriers affected carers' access to appropriate care, highlighting the need for culturally competent, tailored services.

This synthesis offers a comprehensive understanding of the challenges carers face and underscores areas requiring improvement. Detailed analysis with carers' direct quotes follows to anchor the findings in lived experience

## The Impact of Navigating Complex and Confusing Service Delivery

Carers reported significant challenges navigating the fragmented and bureaucratic dementia care system, describing it as overwhelming and disjointed (Assfaw et al., 2024; Cotton et al., 2021; Giebel et al., 2021). A major frustration was the delay in obtaining a formal diagnosis, which often delayed access to essential care and created uncertainty about available services (Cotton et al., 2021). The gap between pre-diagnosis and post-diagnosis support created a sense of urgency for some, with carers lamenting that "*all the doors opened*" only after the diagnosis was received, a moment that was often "*too late*" for meaningful intervention

(Gorska et al., 2013). Once diagnosed, carers found the system to be “labyrinth-like” and struggled with bureaucratic hurdles, leaving them feeling unsupported (Samsi et al., 2013; Ketchum et al., 2023).

Carers expressed a strong desire for guidance, epitomised by the statement, “*I wish they could kind of lay out the path for you*” (Cotton et al., 2021). The lack of professional coordination left carers to navigate care on their own, which was emotionally draining (Ketchum et al., 2023) with one carer clearly citing their frustrations by stating “*It is such a stupid system.”* (Giebel et al., 2021). Carers described services as narrowly focused, and the lack of professional coordination often left them to piece together care themselves, resulting in a feeling of being “*in the system*” but still disconnected from the support they needed with one carer stating: “*services exist but it is hard work finding what is out there and unless you are fully in the system and in a memory service in the residential address it is almost impossible to access information as to what’s out there*” (Giebel et al., 2021).

Carers underscored the importance of well-defined care pathways and a single point of contact to streamline coordination, which could alleviate the confusion and frustration of navigating a fragmented system. One carer noted, “*I’d just like a joined-up service, it’s the main thing*.” (Gorska et al., 2013). The need for a clear point of contact to provide up-to-date, evidence-based information and support for carers was repeatedly highlighted, with suggestions for peer engagement and education to help them manage symptoms and plan for the future (Fitzgerald et al., 2019; Giebel et al., 2021; Risco et al., 2016). Some carers suggested that peer support and education could help manage symptoms and plan for the future (Fitzgerald et al., 2019).

Professional support, such as from navigators or specialists, was highly valued (Gilbert et al., 2022; Liu et al., 2021). Carers appreciated timely education on dementia, symptom management, and long-term planning (Ketchum et al., 2023). When support was appropriate and timely, carers felt reassured and less stressed (Innes et al., 2011; Juttla, 2015; Karlsson et al., 2015; Liu et al., 2021; Pashby et al., 2009; Robertson et al., 2022; Robinson et al., 2009; Sutcliffe et al., 2015; Turjamaa et al., 2020; Willis et al., 2009). One carer described the reassurance of responsive services: *“...they’ve [memory team] been there to support us... I could speak to them, they upped his medication... just knowing there was somebody there...”* (Giebel et al., 2022). Specialist dementia nurses offering home visits were especially valued for both practical and emotional support (Kitamura et al., 2021). However, many carers received minimal post-diagnostic support, sometimes limited to medication (Dodd et al., 2014; Dombestein et al., 2022). A lack of clarity around services, under-resourcing, and inadequate staff training added to carer strain (Innes et al., 2011; Giebel et al., 2021).

Even when support was offered, carers often did not know what questions to ask or which services could actually help, particularly right after receiving a diagnosis (Abley et al., 2013). Without clear guidance, many carers felt unequipped to handle the challenges that arose, with one carer lamenting: "*I didn't know how to deal with her irregular symptoms, and I've been annoyed at her because she didn't want professional help […] If I had gotten the right information and advice up front, maybe I wouldn't have been that frustrated [...] Maybe it would have been easier for the both of us*" (Dombestein et al., 2022).

Carers also shared frustrations with delayed interventions, with some describing missed opportunities for assistance due to the late arrival of support (Giebel et al., 2022), having insufficient information, without guidance (Innes et al., 2011; Ketchum et al., 2023) and disappointment over the lack of post-diagnosis support (Dodd et al., 2014).

In short, the complexity and delays in dementia services highlight significant gaps in the system's ability to meet carers' needs and provide effective support.

## The Impact of Systemic Failure to Prioritize Communication

Poor communication and fragmented dementia care were consistently cited as major barriers to timely, appropriate support. This issue spanned regions and systems, with carers reporting added strain due to disjointed services (Davies-Abbott et al., 2014; Giebel et al., 2021; Gilbert et al., 2022; Gorska et al., 2013). Many acted as intermediaries, relaying information between professionals, leading to delays and confusion (Giebel et al., 2021; Gilbert et al., 2022; Sutcliffe et al., 2015). One carer remarked, "...*services were not joined up. If each of them had been talking... things would have moved quicker*" (Gorska et al., 2013). These failures not only delayed care but also made the process feel unsafe (Behrman et al., 2017; Gorska et al., 2013).

Uncertainty about who to communicate with added to the confusion. Carers often felt disempowered by the lack of a clear point of contact, as one carer described: "*I wish someone would tell me something... I can't get anybody to listen to me*" (Robinson et al., 2009). This lack of clarity was compounded by inconsistent communication from professionals, leaving carers feeling unsupported and uncertain about how to proceed.

Although some carers appreciated clear and prompt communication, efficient communication was not the norm. Inconsistent communication, including missed follow-up calls, exacerbated carers' emotional distress (Abley et al., 2013; Pashby et al., 2009; Willis et al., 2009). Additionally, a lack of transparency regarding test results and outcomes added to carers' frustrations, with one carer noting, "*I can't understand when you go into a consultant, and* *you've got someone who's got memory problems and speech problems, and yet the partner, the wife, isn't allowed*" (Davies-Abbott et al., 2024).

In sum, systemic failures in communication and coordination significantly impacted the dementia care system, creating unnecessary burdens for carers and delaying access to appropriate care. A more integrated and communicative approach to care is essential to meet the needs of both carers and individuals living with dementia.

## The Importance of a Relational Approach

Effective dementia care depends on strong, collaborative relationships between professionals, people living with dementia, and informal carers. However, many carers face communication barriers and power imbalances that undermine these relationships. While some felt supported when mutual understanding was present, others reported feeling excluded and dismissed (Turjamaa et al., 2020). One carer stated, "*I want healthcare professionals to acknowledge my experience… what we say is fundamentally true*" (Dombestein et al., 2022). A failure to recognise carers as experts on the people living with dementia's personal needs, combined with patronising attitudes, led to frustration, isolation, and disengagement (Willis et al., 2009; Cotton et al., 2021; Fitzgerald et al., 2019; Gorska et al., 2013). Exclusion from care decisions and unclear responsibilities often escalated tensions, further damaging trust (Behrman et al., 2017; Karlsson et al., 2015). These power imbalances erode collaboration, a cornerstone of effective dementia care

Trust and mutual respect are critical for fostering collaborative relationships. Carers who had trust in their healthcare professionals felt more supported and confident in accessing services. One carer emphasized the importance of having a reliable contact: "*You've always got a chance of ringing them… they understand and that makes a big difference*" (Willis et al., 2009). The failure to foster mutual respect and understanding between professionals and carers is a critical flaw in dementia care. Without this foundation of trust, professionals and carers are unable to engage in meaningful, productive partnerships that would otherwise improve the care experience for the person living with dementia with one carer clearly stating "*mutual respect is fundamental*" (Behrman et al., 2017).

In summary, the failure to develop respectful, collaborative relationships between carers, professionals, and people living with dementia significantly hinders quality dementia care. Power imbalances and communication breakdowns prevent carers from fully contributing to care, leaving both carers and people living with dementia without the support they need. To improve dementia care, professionals must actively engage with carers, ensuring their voices are respected and their expertise is acknowledged.

## Services Causing Harm

Studies highlighted that carers often experience significant harm due to delayed diagnoses and inadequate services, leading to emotional distress and physical exhaustion. Prolonged diagnostic delays leave carers in uncertainty, as one shared: "*I just struggled… probably for about 3 years … I didn't have a diagnosis*" (Ketchum et al., 2023). Such delays heighten anxiety and complicate care management. One carer expressed exhaustion over waiting for support: "*I'm just so drained and so tired... and they say I've got to wait another six months... why do I have to wait?*" (Robinson et al., 2009). Many felt "*in limbo*" and that valuable time was being lost, feelings intensified by media emphasis on early diagnosis and intervention (Samsi et al., 2013; White et al., 2024)

Once diagnosed, the delivery of information is often insensitive and unclear, causing additional emotional strain (Abley et al 2013; Davies-Abbott et al. 2024; Samsi et al; 2013). Carers have described receiving diagnoses in impersonal ways, such as through letters, which left them feeling devastated and abandoned by the system (Abley et al., 2013; Samsi et al., 2013). After diagnosis, many carers report a lack of follow-up support, especially for those caring for individuals with vascular dementia, leaving them feeling lost and without clear guidance (Samsi et al., 2013).

Inconsistent application of evidence-based guidelines and unclear communication also lead to fragmented care. One carer described the experience of being shuffled between organizations, resulting in "*a horrible journey*" marked by exhaustion and confusion (Gilbert et al., 2022). Additionally, carers frequently report being dismissed or ignored by professionals, who fail to recognize their expertise in caring for their loved ones. As one carer recalled, a care coordinator told them, "*It didn't matter if I was there for my mother or not*" (Dombestein et al., 2022). This lack of respect contributes to significant emotional harm.

Overall, these studies reveal a deeply flawed dementia care system, where delays, poor communication, and a failure to follow guidelines precipitate and perpetuate emotional and psychological harm for carers. To improve care, it is essential to address these systemic issues and ensure that carers are treated with the dignity and respect they deserve while being supported in their caregiving roles.

## Thinking About and Planning for an Unclear Future

Dementia carers face immense challenges due to the unpredictable progression of the disease and the lack of adequate support for future planning. While carers manage complex caregiving demands, they often struggle emotionally, physically, and psychologically due to the uncertainty surrounding the future of both the person living with dementia and their caregiving role (Alves et al., 2019; Dickinson et al., 2017; Watson et al., 2019; Yu, Cheng & Wang, 2018). Despite the recognized need for effective support in future planning (NICE, 2018), carers are often left without sufficient guidance.

The emotional burden of receiving a dementia diagnosis is often overwhelming. The impact of receiving a diagnosis was described as "*terrifying*", with carers feeling fear and helplessness about the unknown future (Robinson et al., 2009). The sense of inevitable decline, shaped by the experiences of others, amplifies this distress, leaving carers with a future they "*didn't want to know about*" (Sutcliffe et al., 2015). This emotional turmoil is exacerbated by a lack of knowledge and resources to plan ahead, with one carer sharing, "*I was filled with anxiety, thinking about our future life and care for my mother*" (Kitamura et al., 2021).

Uncertainty in the caregiving journey heightens stress, with carers expressing a need for more comprehensive support (Abley et al., 2013; Fitzgerald et al., 2019; Gilbert et al., 2022; Ketchum et al., 2023; Kitamura, 2021; Robinson et al., 2009; Samsi, 2013; Sutcliffe et al., 2015; Turjamaa et al., 2020). A lack of timely, accessible information on future planning leaves carers feeling adrift and unable to regain control. Some attempt to prepare for future needs, but without guidance, these efforts are often reactive. One carer reflected: "*You want to make preparations... hoping you never need them, but knowing you probably will... it's a question of when do you get involved...*" (Sutcliffe et al., 2015).

A major barrier to future planning is the inaccessibility of clear, timely information. Carers often report detrimental effects from not receiving relevant guidance about dementia and available care options. While some found information reassuring and felt that it better enabled preparation stating that "*knowing everything was better than not knowing*" (Abley et al., 2013; Fitzgerald et al., 2019; Ketchum et al., 2023). Others were overwhelmed by the volume and complexity of information. One carer explained: "*if a person knows nothing and is just getting started, it is impossible to understand the whole process. I need hand-to-hand guidance on the future of the patient and caregiver. I have to understand the causes and changes that will take place… The caregiver must understand what the future will be. But this is confusing*" (Turjamaa et al., 2020).

In summary, dementia carers are left to navigate an uncertain future without the necessary emotional, informational, and practical support. The lack of cohesive, accessible resources leaves carers feeling overwhelmed and unsupported, intensifying their sense of helplessness and undermining their ability to effectively care for their loved ones. The call for "hand-to-hand guidance" reflects the need for a more nuanced, supportive approach to information delivery, one that is not only culturally and linguistically appropriate but also paced in a way that allows carers to absorb and act on it effectively.

## The Centrality and Importance of Valuing Difference, Diversity, and Culture

Carers from culturally and linguistically diverse (CALD) backgrounds face unique challenges in navigating dementia care due to cultural, linguistic, and systemic barriers that hinder access to information, services, and effective engagement with healthcare professionals (Gilbert et al., 2022). While all carers share common experiences, CALD carers have specific needs shaped by language, immigration history, income, and education, affecting service use (Cotton et al., 2021). Studies show they often prefer culturally aligned services, benefiting both themselves and the person living with dementia (Benedetti et al., 2013; Cotton et al., 2021; Gilbert et al., 2022; Ketchum et al., 2023; Pashby et al., 2009; Xiao et al., 2013)

One significant challenge is the cultural belief that caregiving should primarily be a family responsibility. For many CALD carers, this leads to a reluctance to seek professional help until the caregiving situation becomes a crisis (Benedetti et al., 2013). Even when these carers are aware of available services, language and cultural barriers prevent them from fully utilizing them. One carer shared, "*I went looking and finding the information, but again, applying that information to our culture; that was not possible for us*" (Gilbert et al., 2021). This highlights the gap in dementia services, where a lack of cultural and linguistic sensitivity prevents effective engagement with CALD carers.

A disconnect between cultural beliefs and professional care models further complicates support for CALD carers. Many believe care should remain within the family home, conflicting with professional recommendations for respite or institutional care. This mismatch often leads to frustration and strained relationships with providers. One carer shared, "*We tend to hang on until... there's really no other option*" (Benedetti et al., 2013), while another rejected institutional care outright: "*The response was 'nursing home,' and as soon as we heard that, it wasn't an option*" (Gilbert et al., 2022). These accounts highlight the tension between cultural expectations and formal care practices.

Language barriers further complicate caregiving, especially when carers must act as translators for the peerson living with dementia. This added role increases stress and makes navigating the care system more difficult. As one carer noted, "*You want elderly people to be independent... but the non-ethno-specific services make people dependent… [They] don't know how to navigate unless their English is fairly proficient*" (Xiao et al., 2013). Such reliance on carers marginalizes culturally and linguistically diverse (CALD) elders and adds to carers' burdens. These linguistic, cultural, and systemic challenges underscore the need for culturally competent, responsive services. The evidence challenges the assumption that a one-size-fits-all model is effective, showing how lack of cultural sensitivity perpetuates disengagement and deepens the vulnerability of CALD carers and families.

## DISCUSSION

This systematic review critically examined the experiences of informal dementia carers focusing on their interactions with dementia services, seeking to understand, inform and improve support for carers of people living with dementia. Across diverse cultural contexts and healthcare systems, carers consistently reported significant challenges navigating complex care systems. These included difficulties accessing health care services, delays in interventions, and the confusing nature of service pathways. The lack of effective support, coordination, and guidance from professionals exacerbated these challenges. Carers frequently highlighted poor communication and weak relationships with professionals as contributing factors to their dissatisfaction, reflecting a broader failure to recognize their expertise and needs. In contrast, positive relationships with professionals, coupled with well-coordinated services, were highly valued and resulted in improved trust and service utilization.

With rare exceptions, this review presents an unsettling picture of the current and enduring inadequacies in dementia services for informal carers, based on their first-hand experiences. This negative appraisal exists in contrast to clear policy mandates and guidelines aimed at improving support (e.g., NICE, 2018). The evidence reveals persistent gaps in service provision that directly impact carers' emotional and physical well-being, raising critical questions about the implementation and impact of current dementia care policies (Fitzgerald et al., 2019; Gilbert et al., 2022). Future dementia care models must prioritize carers' perspectives, ensuring that services not only recognize their vital role but also offer meaningful, practical support. Without such changes, dementia care will remain incomplete and, in many cases, harmful for both people living with dementia and their carers (Davies-Abbott et al., 2024; Samsi et al., 2013).

A prominent theme conceptualised from this review was the harmful impact of inadequate dementia services on carers, with participants describing significant emotional and psychological distress resulting directly from their interactions with the system. Experiences of anxiety, helplessness, and shock were frequently reported, underscoring the extent to which service failures can exacerbate the already challenging responsibilities of caregiving. While previous reviews, such as that conducted by Francis and Hanna (2020), have effectively highlighted systemic inadequacies in dementia care, they stop short of examining the direct consequences of these failings for carers. In contrast, the present review demonstrates that these deficiencies are not merely theoretical or procedural issues, they result in tangible and detrimental outcomes for carers' well-being. This review advances the field by evidencing the direct link between structural failings, such as poor accessibility, delayed responses, and fractured relationships with professionals, and the emotional harm experienced by carers. These outcomes suggest not only operational shortcomings but also a breach of fundamental ethical responsibilities as defined by professional bodies such as the British Psychological Society (2021) and the Nursing and Midwifery Council (2018), both of which emphasize the duty to prevent harm and ensure timely, person-centred care. The findings therefore call for an urgent and critical reassessment of how dementia services are structured, implemented, and evaluated, with particular attention to the lived experiences of carers and the ethical implications of service delivery failures.

Another key theme was carers' difficulty with future planning. The way one thinks about the future is important for mental health (MacLeod, 2025) and is therefore worthy of examination in the context of dementia carers' experiences. While some sought professional support for planning, many found it anxiety-provoking and avoided it. This contrasts with clinical policies, such as NICE (2018) and National Health and Medical Research Council (NHMRC, 2016), which mandate supporting carers and people living with dementia in future planning. Despite these intentions, carers' experiences reveal a gap between policy and practice. The persistent disconnect between policy aspirations and the lived experiences of carers reveals a critical shortfall in current implementation strategies. This disconnect highlights the need for more participatory, context-sensitive policy development that truly incorporates carers' lived experiences to improve relevance and impact.

The theme of diversity also emerged strongly in this review. Many carers expressed concerns about professionals not fully recognizing or addressing their culturally-specific needs, which further complicated the challenges of dementia care. Carers often preferred services that aligned with their own cultural identities, yet these preferences were not always acknowledged *or met* by service providers. This highlights the need for culturally-sensitive approaches within dementia services, as failure to incorporate cultural sensitivity can exacerbate carers' frustrations and hinder service engagement, as shown by some of the quotes from included articles.

A major implication for policy is the clear disparity between clinical guidelines, which advocate for future planning support, and the negative experiences of carers who find such planning overwhelming and distressing. Despite high-level policy frameworks that stress the importance of comprehensive care planning, this review highlights the failure to operationalize these principles effectively into practice. Clinical guidelines such as those from NICE stress the need to support carers in thinking about the future (NICE, 2018). However, carers' real-world experiences often reflect *a lack of* or even *harmful* support (Francis & Hanna, 2020). This mismatch between policy expectations and actual experiences reveals a fundamental flaw in how these policies are implemented and underscores the need for a more personalized, human-centred approach toone that considers the real-world emotional and psychological complexities carers face.

Finally, the interpersonal dynamics between carers and professionals, particularly issues of communication, trust, and cultural sensitivity, were pivotal in shaping carers' experiences. Positive interactions with professionals, characterized by mutual respect and understanding, were essential for fostering trust and improving service utilization. Conversely, negative interactions, often tied to inadequate professional support, increased carers' stress and led to disengagement from services. This suggests that improving interpersonal relationships should be a priority in both policy and practice, as these factors have a significant impact on the effectiveness and acceptability of dementia care services. This could involve harnessing new technologies, such as communication on personalised apps (perhaps adopting some Artificial Intelligence [AI] functions), or having a point of contact on video or audio call (although see below for words of caution of the adoption of AI-powered technologies in dementia care).

### Research and Practice Implications

Despite valuable insights gained from this review, several significant questions remain regarding the gap between policy recommendations and the lived experiences of dementia carers, particularly in the context of future planning. Previous research (Greenwood, Pound & Brearley, 2019; Greenwood et al., 2019; Mansell & Wilson, 2010; Pryce et al., 2017) has highlighted that, for some dementia carers, thinking about the future is challenging and often met with fear and negativity. Although clinical guidelines emphasize the importance of professional support for carers to plan for future challenges, this review reveals that, in practice, such support is frequently absent or inadequate.

This dissonance between policy and lived experience underscores the need to reevaluate how policies are developed and implemented. Ensuring that dementia care policy meets the needs of carers requires incorporating the perspectives of those with lived experience. Our modest aim is that this review will start important policy dialogues to this end. A crucial step in this process will be the implementation of complementary research approaches that assess both the satisfaction with dementia services and the effectiveness of their delivery. A comparative survey study, for example, could be used to assess the satisfaction levels of both carers and professionals, critically examining the alignment between policy goals and the actual experiences of carers and professionals delivering services. By collecting service-specific quantitative data, such a study could highlight discrepancies between service expectations and satisfaction, identifying areas where service delivery needs significant improvement.

Additionally, qualitative research, such as interviews with key stakeholders, including people living with dementia, carers, researchers, policymakers, and professionals, could provide in-depth insights into how dementia care policies are operationalized in practice. A focus on the specific challenges carers face, would be beneficial in exploring ways to improve dementia care. Attention should be given to improving communication, service coordination, and cultural sensitivity, and how these factors can be integrated into care models. The qualitative approach will uncover nuanced barriers that may not be captured through quantitative surveys, offering a deeper understanding of the lived experiences of those directly involved in dementia care.

In sum, future research and practice must address the gap between policy recommendations and the lived experiences of dementia carers. Further exploration of this issue, from the viewpoints of key stakeholders, including people living with dementia, their carers, researchers, policymakers, and professionals responsible for dementia service design and delivery, is needed to understand how research and policy translate into practice.

Moreover, future research on digital interventions in dementia care should focus on how these technologies align with the interpersonal and relational aspects of care emphasized by participants. AI-powered tools, for example, can translate complex speech into clearer language, potentially improving communication between people living with dementia, carers, and services (Su et al., 2022). However, it is vital that such innovations support person-centred care, social connection, and cultural diversity, as carers prefer technologies that complement—not replace—the human element of care (Brookman et al., 2023). Research should explore how digital tools enhance, rather than undermine, the crucial relationships at the heart of effective dementia care.

## Conclusion

This systematic review highlights persistent inadequacies in dementia services across different healthcare systems, particularly in the support provided to informal carers. Unlike meta-analysis methodology, this qualitative review draws on carers' own words to reveal lived experiences that expose major gaps in service delivery, especially in communication, coordination, and recognition of carers' expertise. These shortcomings contribute to carers' emotional and physical strain, reinforcing the need for a fundamental shift in how dementia services are structured and delivered.

Carers’ negative experiences often stem from poor communication, lack of professional collaboration, and inadequate support for future planning These issues are not merely inconveniences but can be actively harmful, increasing anxiety and distress among carers and, in some cases, exacerbating their (already substantial) emotional and psychological burdens.. The review also underscores the added challenges faced by carers from diverse cultural backgrounds, reinforcing the need for culturally sensitive, inclusive care models.

This review not only draws attention to shortcomings in dementia services but also raises critical questions about the translation of policy into practice. The ongoing dissonance between the goals of clinical guidelines and the real-world experiences of carers indicates the need for greater involvement of carers and people with dementia in policy and service design. The recent adoption of patient involvement groups and participatory research practices could facilitate carers’ contribution to health and care policy. Undoubtedly, a more personalized, human-centred approach, grounded in the lived experiences of those directly affected by dementia, is essential. Future research and policy must prioritize these perspectives to ensure dementia care is not only satisfactory but truly responsive to the diverse needs of carers and service users.

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