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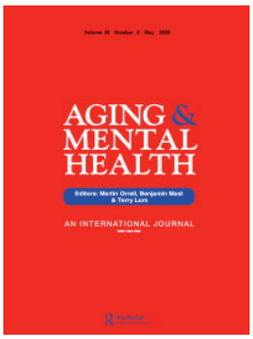

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Navigating diagnosis: UK informal caregivers' experiences of the dementia assessment journey

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ABSTRACT

Objectives: Despite UK policy initiatives to promote earlier dementia diagnosis, delays remain common and informal caregiver contributions are often overlooked. Informal caregivers are frequently the first to notice cognitive and behavioural changes, yet their experiences of the diagnostic process are poorly understood. This study explored informal caregivers' perspectives on navigating memory assessment services to identify contributions, barriers and unmet support needs.

Method: A narrative qualitative design was used. Eleven current or former caregivers of people with dementia were interviewed online or in-person. Anonymised transcripts were analysed using narrative analysis to identify shared patterns across diagnostic journeys.

Results: Informal caregivers described a five-stage journey: early symptoms, moving from suspicion to concern (primary care), specialist referral, receiving the diagnosis and life after diagnosis. Delays and obstacles occurred at every stage, including minimisation of concerns, inappropriate or delayed referrals, and long waiting times. Assessments were perceived as rigid and culturally limited, while interactions with services felt impersonal and post-diagnostic support was inconsistent.

Conclusion: Caregivers acted as informal co-diagnosticians but felt undervalued. Improving dementia diagnosis requires better integration of caregiver knowledge, culturally responsive assessments and proactive, tailored post-diagnostic support. Future work should co-design tools, awareness campaigns and remote multilingual pathways with stakeholders to enable earlier and more equitable diagnoses.

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Dementia; informal caregivers; diagnostic services; qualitative research; barriers to diagnosis

Introduction

Dementia is a leading cause of disability worldwide (WHO, 2021) and is projected to affect 150 million people by 2050 (Davies-Abbott et al., 2024). In the UK, one in six people over the age of 65 are affected, yet only around two-thirds receive a formal diagnosis, and up to 30% are diagnosed with an incorrect dementia subtype (Couch et al., 2024; Davies-Abbott et al., 2024). Diagnostic rates vary internationally, with approximately 50% in high-income countries compared to just 5–10% in low- and middle-income countries (Lian et al., 2017). These disparities are driven by symptom variability, stigma, and limited access to specialist assessment services, contributing to diagnostic delays of up to three years (Lian et al., 2017).

Timely and accurate diagnosis is essential for identifying reversible causes of cognitive impairment, and for enabling access to interventions and treatments that may delay progression (Ford et al., 2023; Speechly et al., 2008). Early diagnosis also allows individuals and families to access psychosocial and community support sooner, while providing more opportunity to make decisions about future care, finances and legal arrangements, improving quality of life, reducing uncertainty and delaying institutionalisation (Ford et al., 2023; Speechly et al., 2008). Early detection may also reduce overall prevalence; modelling studies suggest that delaying onset by two years could reduce cases by up to 20% (Wong-Lin et al., 2020).

The diagnostic pathway most often begins with family members or close proxies noticing changes and discussing concerns with informal networks before seeking professional advice (Wong-Lin et al., 2020). Despite public health efforts, barriers to help-seeking remain, including limited understanding of early symptoms, normalisation of cognitive changes as ageing, and stigma (Samsi & Manthorpe, 2014). On average, individuals wait 1.3 years before

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contacting a healthcare professional (Chrisp et al., 2012), and in some countries, such as Japan, over 40% present with moderate to severe impairment at their first consultation (Black et al., 2019).

Primary care is typically the first point of formal assessment, where general practitioners (GPs) assess symptoms and rule out treatable causes (Wong-Lin et al., 2020). Cognitive screening tools are commonly used at this stage; however, GPs frequently report low confidence in administering and interpreting these measures due to limited training and time constraints (Lassa et al., 2025; Wells & Smith, 2017). As a result, 21.2% of patients are advised to 'watch and wait', while 23.2% are referred without comprehensive assessment, contributing to inappropriate referrals and further delays (Roth et al., 2023). Patients are then referred to secondary care memory clinics for detailed assessment, diagnosis and care planning (Wong-Lin et al., 2020). Although memory clinics are cost-effective and associated with earlier diagnosis and delayed care-home admission (Wells & Smith, 2017), they face increasing demand, long waiting times, and inconsistent follow-up support.

Delays therefore occur at multiple stages, from symptom recognition to accessing specialist services. Evidence suggests this disproportionately affects minority and underserved groups. In the USA, Black and Hispanic adults have higher prevalence of Alzheimer's disease but are less likely than White adults to receive a timely diagnosis, reflecting structural inequalities, cultural factors, stigma, and reduced access to memory services (Hampel et al., 2022).

One approach to facilitating earlier detection is informant-based symptom recognition through informal caregivers. Family members and friends providing unpaid care are often the first to notice subtle cognitive and behavioural changes due to their close day-to-day involvement, making them a critical source of information for clinicians (Department of Health, 2009). Informal caregivers typically recognise symptoms around 1.9 years before first GP consultation and 3.1 years before formal diagnosis, underscoring their pivotal role in early detection (Speechly et al., 2008).

Qualitative research has explored caregivers' experiences of the diagnostic journey, with systematic reviews consistently identifying barriers such as denial, stigma, lack of knowledge, and limited support, alongside facilitators including prior awareness and encouragement from social networks (Parker et al., 2020). These experiences vary across sociocultural contexts. For example, African American caregivers have reported delaying help-seeking out of respect for older relatives and mistrust stemming from previous negative healthcare encounters (Cloutterbuck & Mahoney, 2003). Dutch caregivers have highlighted denial and GP misattribution of symptoms (Vliet et al., 2011), while Chinese caregivers have emphasised stigma and unclear diagnostic pathways as key contributors to delay (Lian et al., 2017). UK studies mirror these findings. Chrisp et al. (2012) found that help-seeking prior to GP contact was either facilitated by caregiver action or delayed by symptom normalisation and denial. Once help is sought, however, the process of obtaining a diagnosis can take 'several years', and post-diagnostic support is frequently described as inadequate, requiring caregivers to independently locate or fund services and information (Abley et al., 2013; Francis & Hanna, 2022). Although memory services and voluntary organisations can offer valuable support, access remains inconsistent (Abley et al., 2013).

In summary, informal caregivers play a central role in symptom recognition and navigation of the diagnostic pathway while experiencing significant emotional and practical challenges. However, much of the existing literature predates recent UK dementia policy initiatives aimed at improving early diagnosis, post-diagnostic support and public awareness, including the Prime Minister's Challenge on Dementia 2020 (Department of Health, 2015) and the 10-Year Dementia Plan (Department of Health and Social Care, 2023). Furthermore, existing literature has focused on isolated stages of the pathway or specific barriers to help-seeking, rather than examining the full trajectory and how informal caregivers navigate and shape the diagnostic process within UK memory services.

This study addresses these gaps by examining caregivers' experiences of memory assessment services and their role across the diagnostic journey. Using a qualitative narrative approach, it explores how caregivers understand, navigate and contribute to the diagnostic process, highlighting complexities of diagnosis and care.

Materials and methods

Ethical statement

Ethical approval was granted by the University of Sheffield (Ref: 058186; May 2024).

Participants

Participants were current or former informal caregivers of people formally diagnosed with mild cognitive impairment or dementia. Informal caregivers were defined as unpaid family members, partners or others providing support. Inclusion criteria required participants to be aged 18 years or over, able to speak and understand English sufficiently, and provide informed consent.

Recruitment

Informal caregivers were recruited between July 2024 and January 2025 through dementia-related forums, charity newsletters, community centres and Join Dementia Research. Interested individuals received an information sheet outlining the purpose of the study, participation, risks and benefits and their right to withdraw at any time. Those who agreed completed a written consent form and an optional demographic questionnaire prior to interview. Seventeen caregivers expressed interest, twelve met eligibility and consented, of whom eleven completed an interview. Non-participation was due to loss of contact, withdrawal before interview and not meeting eligibility criteria.

Recruitment continued until theoretical saturation was reached, defined as the point at which no new themes emerged. Sample size was therefore determined iteratively rather than pre-specified, consistent with qualitative research methodology (Hennink & Kaiser, 2022).

Data collection

Written informed consent was obtained in advance and verbally reconfirmed at the interview. Consent included permission for audio-recording, transcription, anonymised quotation and publication of findings. Participants were reminded of their right to pause, skip questions or withdraw.

In line with narrative methodology, interviews opened with an open prompt: 'Can you tell me about your journey with dementia and supporting the person you care for, and how that has brought you to where you are today?' This encouraged participants to shape their own narrative and emphasise important points.

Follow-up prompts were used flexibly, guided by participants' accounts, to explore key stages including early changes and help-seeking, assessment, caregiver involvement, diagnosis and post-diagnostic support. Interviews were audio-recorded, transcribed verbatim and anonymised.

Data analysis

Thematic narrative analysis (Riessman, 2008) was used to identify patterns across caregivers' accounts. The lead researcher familiarised herself with the data through repeated listening and review. Consistent with recommendations for good practice in thematic analysis, the first two transcripts were independently coded by LK and AWG to develop an initial coding framework, with differences in interpretation discussed and resolved collaboratively (Braun & Clarke, 2023). The remaining transcripts were then coded by LK using a reflexive and iterative approach, supported by a reflective diary and regular discussions with DB and AWG to consider alternative interpretations and maintain analytic rigour (Nowell et al., 2017).

The collective narrative was developed iteratively by comparing participants' accounts, identifying shared stages, turning points and meanings through team discussion, consistent with recommendations for transparency and trustworthiness in thematic analysis (Nowell et al., 2017).

Reflexivity

Narrative approaches recognise the influence of participant and researcher backgrounds (Clandinin & Caine, 2008). The research team comprised one Indian-British woman, two White-British women, one Chinese man and one White-British man, all with personal or professional exposure to dementia and view diagnosis as an enabling step towards care and planning. LK kept a reflective diary, documenting assumptions and emerging interpretations. Regular discussions with DB and AWG provided further reflexive scrutiny and supported alternative interpretations. Verbatim quotations were used to remain faithful to participant's accounts.

Results

Eleven informal caregivers (Table 1) participated in narrative interviews (ten online via Google Meet and one in-person) lasting 35-108 min. Analysis revealed that caregivers' narratives followed a five-stage diagnostic journey (Figure 1).

Early symptoms: denial, misattribution and cultural frames

Caregivers consistently described noticing cognitive and behavioural changes well before a formal diagnosis. As Carer 01 reflected, signs were evident *'at least a year before the diagnosis'*. Early symptoms were often recognised by caregivers but met with disagreement or minimised as normal ageing by relatives and wider familial networks, delaying acknowledgement that something was wrong.

Development of memory problems

Memory loss was the earliest and most prominent change. Carer 05 described her mother confusing familiar names: *'she'd get things mixed up or get names mixed up'.* At first these were dismissed, but as they became more frequent families began questioning whether *'there's anything more?'*

For some, memory changes took the form of temporal disorientation. Carer 07 recalled his grandmother asking him to *'bring in the sheep',* a task from her rural childhood, despite being in a modern living

Table 1. Caregivers' demographic information.

	Age	Gender	Ethnicity	Relationship to care partner	Diagnosis of care partner	Time since diagnosis (years)
Carer 01	72	Female	White British	Wife	Alzheimer's Disease	4 years
Carer 02	60	Female	White British	Daughter	Frontotemporal Dementia	5 years
Carer 03	53	Male	White British	Ex-spouse	Dementia	3 years
Carer 04	70	Male	White British	Brother	Frontotemporal Dementia	4 years
Carer 05	47	Female	White British	Daughter	Mother: Alzheimer's Disease	12 years
					Father: Alzheimer's Disease	2 years
Carer 06	61	Female	White British	Daughter	Mixed Dementia: Alzheimer's in FT region and Vascular	3 years
Carer 07	–	Male	African (Somali)	Grandson	Dementia	2 years
Carer 08	42	Female	African (Somali)	Daughter	Dementia	5 years
Carer 09	50	Female	White British	Daughter	Mother: Alzheimer's Disease	7 years
					Father: Lewy Body Dementia and Vascular Dementia	6 years
Carer 10	69	Female	White British	Daughter	Alzheimer's Disease	9 years
Carer 11	–	Female	African (Somali)	Granddaughter	Dementia	7 years

This table summarises demographic information for participating caregivers (N = 11). Where caregivers supported more than one person with dementia, details are reported separately. Missing data is indicated by '-', where information was not provided by participants. All diagnoses were caregiver-reported.

room. This temporal layering illustrated how dementia interacts with identity, culture and migration history, as deeply rooted memories resurfaced as cognition declined. Such examples reinforce that dementia is not culturally neutral, highlighting the importance of cultural competence in diagnostic practice, as behaviours that appear unusual in context may carry personal or historical significance.

Loss of recognition was described as particularly distressing. Carer 09 described how her father no longer recognised her mother as his wife. Witnessing this was painful and underscored the dual burden caregivers carried: managing practical care while grieving the erosion of relational bonds.

Development of behavioural and functional problems

Caregivers also reported early behavioural and functional changes. Following her father's death, Carer 02 noticed her mother seemed emotionally disengaged despite appearing sociable to others.

> *'From somebody who'd been married for sixty years, she didn't show emotion, she didn't participate in the funeral; she was completely disengaged'.* (Carer 02, daughter)

Functional decline also appeared in everyday tasks, such as bathing, dressing or responding appropriately to weather. Carer 04 recalled finding his brother sitting indoors *'with his gas fire on, with his coat on'* on the hottest day of the year. He reflected on his brother's living conditions and household hygiene, describing it as a *'putrid'* environment, reflecting the loss of executive function and insight associated with dementia.

> *'In the fridge and freezer there was a pile of vegetables, it was just putrefying, months of it, so the brown liquid was going down the fridge and all on the kitchen floor. The fridge was full of all sorts of decay. Eighty pints of milk unopened. Mouldy food and burnt pans and the house it stank'.* (Carer 04, brother)

Hallucinations were another early sign. Carer 09 recounted the challenge caring for both of her parents with dementia, who would often experience shared hallucinations and delusional episodes, ranging from lighthearted imagined outings such as *'Oh we're going to the cinema'* or *'We've been in a hot air balloon'* to frightening beliefs that *'murderers were upstairs trying to get them',* illustrating the unpredictability and emotional strain even before diagnosis.

Early conversations regarding seeking professional help

These early changes prompted consideration of seeking help, though motivations varied. While some were uncertain and wanted answers, others immediately suspected dementia, *'it became very quickly apparent to me that she'd got dementia'.* (Carer 10)

Denial was the most common barrier. Many relatives resisted acknowledging symptoms or attending appointments. Carer 02 recalled her mother being *'in complete denial',* before eventually accepting symptoms: *'She grabbed hold of me crying and saying "I know I need help"'*. In other cases, denial persisted, Carer 04 noted that his brother insisted he was *'fine'* until his death.

Families also normalised or misattributed symptoms. Carer 03 explained that relatives insisted her ex-partner had *'always been a bit quirky, a bit daffy',* delaying concern. Others linked symptoms to depression or bereavement.

> *'He obviously also had depression with losing me mum. I know that mood problems can cause memory problems'* (Carer 05, daughter)

Several caregivers highlighted how limited public understanding shaped these delays. Carer 08 described feeling more empathy for someone having a heart attack than someone with dementia, as cognitive decline is less understood, less visible and easier to minimise. Health literacy and societal narratives influence not only when families seek help but also how they interpret symptoms.

Figure 1. Narrative roadmap of the dementia diagnostic journey.
Five-stage caregiver narrative of the dementia diagnostic process: (1) early symptoms, (2) moving from suspicion to concern (primary care encounters), (3) specialist referral, (4) receiving the diagnosis and (5) life after diagnosis Note. Figure developed from findings of present study and created by LK using Canva (accessed September 2025).

Impact of culture and religion on help seeking

Culture and religion significantly influence help-seeking. In some communities, mental health difficulties carry stigma and there may be reluctance to pursue a diagnosis. As Carer 11 noted the Somali community, *'we're not the best at receiving mental health support, it's an insult'.* Religion was both a source of comfort and a barrier. Prayer offered strength, but reliance on religion could discourage medical evaluation. Carer 08 recalled responses such as *'oh he's just forgetful, we'll leave it to God, we'll pray over them',* framing memory loss as normal ageing rather than illness. Caregivers often described having to *'break barriers down'* to align cultural and spiritual beliefs with the need for clinical assessment.

These dynamics added another layer of emotional labour. Caregivers mediated between relatives, community expectations and healthcare services: protecting dignity while advocating for timely diagnosis and honouring cultural or spiritual beliefs while recognising emerging risk.

Moving from suspicion to concern: primary care encounters and professional dismissal

Caregivers described primary care as the first formal step in seeking clarity about emerging symptoms. Approaching a GP was motivated by the need to understand their relative's changes and initiate referral into the memory assessment pathway. Some relatives recognised their own difficulties and asked to *'talk to a GP about this',* whereas most caregivers faced more complex dynamics. When relatives denied symptoms or refused help, caregivers struggled to make progress, at the same time GPs were bound by confidentiality, often leaving caregivers feeling powerless. Overall, most caregivers were responsible for organising appointments, monitoring day-to-day changes and advocating for further assessment.

GP as initial source of support

Caregivers frequently accompanied their relatives to appointments, often leading communication. Despite no formal training, they documented symptoms, encouraged attendance and urged GPs to investigate. Carer 03 recounted asking the GP, *'If I can get him to come in, can you look at this issue?'* illustrating the emotional labour involved in persuading a resistant relative to attend and GP to consider.

However, even when caregivers provided detailed accounts, GPs were unable or unwilling to intervene without the relative's agreement, contributing to delays and uncertainty.

GP referral to secondary care

Experiences of referral varied widely. Few caregivers received prompt referrals, often where the relative had medical knowledge or existing professional relationships.

> *"I suspect she knew mum had been a GP and there was a bit of medical professional respect, co-professional respect".* (Carer 10, daughter)

More commonly, caregivers encountered delays and felt their accounts were dismissed. Some described years of repeatedly raising concerns without progression toward specialist assessment. Carer 03 described a decade-long struggle, during which the GP viewed her ex-husband as *'absolutely charming'* and assumed nothing was wrong.

> *"[GP] couldn't see anything wrong and this went on for ten years. At one point I'd gone back to the doctors and broken down in tears begging for help. I feel resentment towards the doctor because she was like 'if you think you're fine, you must be fine' instead of listening to me"* (Carer 03, ex-spouse).

Others described needing to *'persuade a rather reluctant GP'* to refer their relative, believing earlier action would have reduced distress and uncertainty.

GPs' understanding of dementia

Caregivers questioned GPs' confidence in recognising dementia, particularly when symptoms were misattributed to depression, or grief. Carer 01 recalled being told, 'I don't really know anything about dementia', which undermined trust and contributed to delay. When misattribution persisted, caregivers felt compelled to challenge clinical judgement. Carer 02's persistence prompted re-evaluation and eventual referral, underscoring the vital advocacy role caregivers play.

> *"I found it very patronising. There was no understanding that I knew her better than they did, that my words had to count for something. So I went back to the GP and said 'I can't accept another depression diagnosis".* (Carer 02, daughter)

Incorrect referrals were another source of delay. Carer 01's husband, who mentioned balance problems alongside memory issues, was sent to a tremor clinic, resulting in months of additional waiting before reaching the memory service.

Overall, caregivers' experiences in primary care reveal the emotional, logistical and advocacy burdens they carry in the diagnostic journey. Their insights were essential in initiating referrals, yet were not always recognised in decision making, contributing to delays in accessing support.

Specialist referral: waiting, assessment barriers and cultural mismatch

Caregivers described the referral to secondary care as lengthy, emotionally demanding and often logistically challenging. During this period, caregivers took on significant preparatory work: encouraging relatives to attend, managing travel and organising the visit. Many faced resistance, needing to persuade, reassure or even bribe their relatives to attend assessments. Carer 02 described her mother hiding the appointment letter and refusing to engage. Practical tasks such as supporting mobility, preparing the person to leave the house and coordinating transport added further strain.

Interactions with healthcare professionals

Experiences with secondary care staff were mixed. While some found clinicians knowledgeable and

patient, others felt the process was impersonal or rushed. Carer 01 recalled a consultant who appeared detached and *'not at all friendly, you could tell she was going to do twenty of those that day'*. Lack of reassurance was also common. Carer 02 described being told *'it would take years to get a diagnosis'*, which, after already waiting for referral, felt discouraging. These encounters contributed to perceptions that the pathway prioritised procedure over compassion.

Cognitive testing

Caregivers were concerned that pen-and-paper cognitive assessments captured only a small component of their relatives' abilities. Carer 10 described testing as overly formulaic:

> *"There was this model of what Alzheimer's is and looks like, it felt like a tick box; because mum knew who the Prime Minister was, she hadn't got dementia, but could she follow a recipe? No".* (Carer 10, daughter)

Some felt broader contextual information that did not align with scoring categories was overlooked. Accessibility was another issue, particularly for those not fluent in English. Carer 07 translated questions for his grandmother into her first language, but believed she would have performed better and clinicians would have obtained a more accurate symptom profile if assessed in a familiar language.

Informant testing

Informant questionnaires were seen as valuable opportunities to share observations that brief appointments miss. They believed their knowledge of day-to-day functioning was crucial to an accurate and timely diagnosis. Some reported that informant information, such as symptom timelines, significantly contributed to diagnosis.

> *"I'd given him a timeline when I first saw signs in 2009. Based on what I wrote, we received a rapid frontotemporal diagnosis"* (Carer 02, daughter).

Caregivers critiqued standardised questionnaires which often forced 'yes/no' answers, lacked nuance and focused primarily on memory, failing to capture behavioural or functional changes. Carer 06 felt the forms were *'sketchy'* and *'stereotyped'*, not reflective of her mother's distinctive presentation.

Many found it difficult to answer honestly when their relatives were present, fearing they would cause distress or undermine dignity, resulting in withholding clinically-relevant information. Others reported not being asked for input at all, subsequently feeling excluded despite being the primary witness to decline. As Carer 10 explained, this exclusion felt *'insulting'*, particularly when they believed their insights could have supported earlier diagnosis.

Non-traditional pathway to diagnosis

Some caregivers sought help through crisis-driven routes, such as accident and emergency (A&E). However, this approach also presented challenges. Patients' often denied symptoms when assessed by paramedias, leading to no follow-up; as in Carer 04's case, where no further action occurred for a year. When hospital admission did take place, caregivers were sometimes excluded from early assessments, leading to incorrect assumptions. Carer 03 described clinicians prematurely attributing her ex-partner's symptoms to alcohol use without consulting her or close friends.

> *"The consultant said to me, 'obviously this is from drinking'. I said 'I'm sorry, he didn't drink'. 'Well, you know, he was in a band'. I said, 'you've had me coming in, you've had his best friend coming, you didn't ask us if he was a drinker?' They'd leapt to all those conclusions without talking to any of his family".* (Carer 03, ex-spouse)

Overall, caregivers' accounts highlight the cumulative strain of long waits, emotional labour, inaccessible assessments and inconsistent communication. While specialist involvement was valued, many felt the system failed to integrate their knowledge or accommodate their relative's needs.

Receiving the diagnosis: relief, resentment and emotional weight

Caregivers described receiving the diagnosis as the end of a long and exhausting journey or *'continual fight'*. When diagnosis was finally confirmed, many felt an initial sense of relief, validating years of concerns and providing clarity about their relative's experiences. For some, this came after exceptionally long delays. Carer 08 estimated *'sixteen, seventeen years'* between first noticing her father's symptoms and receiving a diagnosis.

Relief was often mixed with sadness and helplessness, given the limited treatment options. As one caregiver reflected, *'Is it a blessing? We finally got answers but nothing for them to come back to how they were'*.

Diagnostic disclosure varied considerably. In most cases, clinicians informed the caregiver and the person together, but some caregivers were told separately and left to share the diagnosis. Carer 09 described receiving the news alone on two occasions, one for each parent, and then having to relay it to them, a diagnosis neither accepted. Caregivers felt this placed significant emotional strain on families and questioned whether disclosure should've been better delivered directly by healthcare professionals.

Secondary care delaying diagnosis

Many caregivers perceived the diagnostic process as unnecessarily prolonged, involving repeated appointments, slow progression through assessment stages and clinical hesitancy to confirm diagnosis. Some felt professionals appeared to delay diagnosis deliberately, as if early confirmation offered limited benefit. Carer 06 felt the attitude seemed to be *'let's put this off as long as possible'.*

These delays were especially frustrating when caregivers believed earlier diagnosis could have enabled treatment or supported better planning. Carer 05 described waiting months only to be told *'now it's Alzheimer's'* felt like a missed opportunity to slow progression.

Life after the diagnosis: support gaps, emotional strain and shifting roles

Caregivers described life following diagnosis as emotionally complex, marked by growing responsibility and changing relationships. Despite cognitive and behavioural decline, many spoke with pride and affection for their relatives. Carer 10 described her mother as *'one of the brightest people I've ever known',* while others emphasised separating the person from the illness, referring to a *'dementia version of them'.* Many valued when core aspects of their personality remained, Carer 05's mother *'stayed the lovely mum that she was',* even as her memory problems progressed. These emotional connections persisted even as role reversals emerged, which caregivers described as disorienting and tender.

> *"She introduced me to (doctor) as her mother, I had become her mother figure, it was really strange but really sweet, she was very dependent emotionally on me"* (Carer 10, daughter)

Information, support and signposting

Experiences of signposting after diagnosis varied. Some caregivers received prompt contact from services, which reduced the administrative burden. Others described support as fragmented or absent, often limited to a leaflet and being *'sent on our way'*, with no structured follow-up. Carer 11 likened this to *'shelter without a door or a roof',* reflecting the strain of navigating support alone after the years spent trying to reach diagnosis.

Accessibility was a particular challenge for families where English was not the primary language. Without translated materials or culturally attuned resources, caregivers felt excluded from understanding the diagnosis or available services. Beyond resources, support groups were only delivered in English, leaving caregivers without opportunities to connect with peers or learn practical strategies.

> *"My auntie didn't have the strongest English, so she would lack confidence going to these kinda places"* (Carer 07, grandson)

English-speaking caregivers often had to educate themselves through reading books and documentaries, then sharing this learning with relatives and neighbours.

> *"I did the research and helped my husband to understand how to help her. I got neighbours who sat and talked with her to keep some normality" (Carer 02, daughter).*

Delayed diagnosis also meant delayed access to formal support such as carer assessments or home adaptations.

> *"It's a major illness, it has a massive impact on the family, I don't feel you get the same level of support as you do with cancer."* (Carer 05, daughter)

Sacrifices and burden on caregivers

Caregivers described substantial sacrifices, including missed family events, reduced working hours and altered life plans. Carer 09 missed her daughter's twenty-first birthday due to a crisis involving her mother. Carer 03 remained legally married to her ex-partner for *'another five years'* to advocate as next-of-kin. Many reported long-term mental health effects, including stress, exhaustion and fears about developing dementia.

> *"Having both parents with Alzheimer's, I am really worried about my own health, and having gone through this stress. Running on adrenaline and autopilot, mental health is not great at the moment" (Carer 05, daughter)*

Coping strategies varied. Some employed a stoic approach, *'grinning and bearing it',* whereas families who shared responsibilities found practical strategies, using timetables or rotas helpful to distribute tasks. Others turned to religion as a source of strength.

> *"We put together a timetable for who's supporting her on what day to lighten the burden" (Carer 07, grandson)*

Seeking professional care

As needs increased, many caregivers sought professional support such as home carers or care homes. These decisions were difficult. Some families resisted external support, while other family members criticised caregivers for suggesting it. Carer 09 recalled a social care worker telling her *'You can't stick both your parents in a care home and expect someone else to look after them for you'* which intensified feelings of guilt.

Transitions into care homes were often distressing. Caregivers described the emotional pain of deceiving

relatives to facilitate admissions and witnessing their subsequent confusion or distress. Carer 10 remembered her mother knocking on the care home window as she left.

> *"It destroyed me. I lied to her but we got her into the care home and she used to stand at the window when I left her and knock on the window for me to come back"* (Carer 10, daughter)

These accounts illustrate the emotional weight carried by caregivers, who had to balance safety, wellbeing and love, often without sufficient external support.

Discussion

This study provides a detailed account of the dementia diagnostic journey from the perspective of informal caregivers in UK memory services. Unlike much existing literature, which focused on isolated stages or barriers, this study captured the full trajectory from initial symptom recognition to post-diagnostic support. Caregivers described a five-stage journey: early symptoms, moving from suspicion to concern (primary care encounters), specialist referral, receiving the diagnosis and life after diagnosis. Across all stages, the process was experienced as non-linear, with caregivers playing a central role in recognising change, initiating help-seeking and navigating services.

Caregivers often noticed cognitive and behavioural changes early but described their concerns were frequently dismissed by family members or community networks. Limited public awareness contributed to this, with symptoms commonly misinterpreted as normal ageing, reflecting broader evidence. Ali et al. (2023) found that 92.8% of respondents in Malaysia had low dementia awareness and 80% believed dementia was a normal part of ageing. Similar misconceptions were identified globally in the World Alzheimer Report (Alzheimer's Disease International, 2019). Caregivers therefore found themselves persuading others that something was wrong, reinforcing the need for public education campaigns to improve understanding of dementia and encourage earlier help-seeking.

Cultural and religious beliefs also contributed to delay. Chinese caregivers described stigma and shame associated with dementia (Sayegh & Knight, 2013), while other studies highlighted the concept of 'losing face', referring to reputation within the community (Lwi et al., 2023), leading families to conceal symptoms (Shatnawi et al., 2023). Caregivers also reported being encouraged to 'leave it to God' or rely on prayer. Fatalism refers to the concept that everything is God's will (Sayegh & Knight, 2013). While fatalism provided comfort, it also delayed medical help-seeking, highlighting the importance of culturally sensitive dementia education, including working with community and religious leaders to disseminate information and promote dementia-friendly initiatives (Shatnawi et al., 2023).

In primary care, caregivers were usually the main drivers of help-seeking, yet their concerns were often dismissed or attributed to depression, grief or ageing. Caregivers described needing to repeatedly return to the GP, document symptoms and advocate strongly for referral. These findings suggest that caregiver concerns may be overlooked when symptoms are atypical, subtle or overlap with other conditions, contributing to delayed referral and diagnosis. Previous literature has also linked this to GPs' limited knowledge and confidence in dementia assessment, particularly non-memory led presentations, with qualitative studies linking this to insufficient training (Crombie et al., 2024). Short consultation times and limited opportunities to build rapport may further increase the risk of misattribution (Bradford et al., 2009; Giebel et al., 2024). GP decision-making is also influenced by respect for patient autonomy and concern about the potential harm of diagnostic labelling (Visser et al., 2025). Training programmes show promise: Crombie et al. (2024) found GP knowledge and confidence improved following targeted education, supporting policy priorities within the WHO Global Action Plan on the Public Health Response to Dementia (2017), which emphasised improving awareness, strengthening dementia-specific professional training and promoting timely diagnosis and intervention, as well as the NHS England's Long Term Plan (2019), which highlights the importance of earlier diagnosis, better community-based dementia care and improved support for caregivers.

After referral, caregivers encountered further barriers, particularly long waiting times for memory services, ranging from 17.7 wk (Treloar, 2023) to 56 months (Mattke et al., 2024), with similar delays internationally (Mattke et al., 2024). Travel, cost and mobility difficulties also increase caregiver burden (Cotton et al., 2021; Shatnawi et al., 2023). While remote assessments may reduce some of these pressures, preferences vary, highlighting the need for flexible service models (Blane et al., 2021).

Caregivers questioned the relevance and fairness of standardised cognitive testing, particularly for people not fluent in English, had lower literacy levels or presented with behavioural rather than memory-led symptoms. This reflects wider literature, where many tools were standardised on highly educated, English-speaking White populations (Waheed et al., 2020), contributing to higher false-positive rates among ethnic minority groups (Janes, 2024). This suggests that improving diagnostic equity requires more than translated tests alone; assessments must also be culturally adapted (Cheng et al., 2019; Czerwinski-Alley et al., 2024; Habib & Stott, 2019). Digital tools may also offer solutions through remote, multilingual and adaptable formats (Muili et al., 2023) while reducing access barriers (Chen et al., 2023).

Caregivers in this study also felt that brief pen-and-paper tests did not adequately reflect behavioural, functional or day-to-day changes. Many placed greater value on informant input, symptom timelines and descriptions of everyday difficulties. These findings suggest that caregiver-reported information should be consistently collected alongside cognitive assessment, particularly where symptoms are subtle, atypical or culturally specific. Examples of this include the IQCODE or Cambridge Behavioural Inventory-Revised which can complement cognitive testing by capturing functional and behavioural changes that standard cognitive testing may miss (Sabbagh et al., 2012).

Post-diagnosis, caregivers reported limited information and support, echoing literature that caregivers' informational needs exceed service provision (Bressan et al., 2020). Many had to independently research dementia services, which was time-consuming and overwhelming. Support was also rejected when it was inaccessible, culturally irrelevant or poorly timed (Zwingmann et al., 2020). Therefore, tailored, accessible and co-developed resources are essential to guide caregivers following diagnosis.

Caregivers also described the emotional and practical burden of dementia care, including disrupted employment, social isolation and long-term stress (Brodaty & Donkin, 2009; Reid & O'Brien, 2021). Although psychological interventions such as psychoeducation, counselling and mindfulness-based approaches can reduce distress (Shoesmith et al., 2022), participants reported limited access, indicating the need for clearer signposting to mental health, bereavement and support services.

Overall, caregivers described a challenging, non-linear journey, characterised by 'back and forth' between primary and secondary care services and significant emotional labour. Despite lacking formal training, caregivers played a vital role in monitoring symptoms, advocating for assessment and providing essential informant information. However, their expertise was not always recognised within clinical encounters. These findings highlight the need for dementia pathways that value caregiver knowledge, reduce systemic delays and provide sustained emotional and informational support throughout the diagnostic process.

Clinical and service implications

Greater emphasis should be placed on recognising caregiver observations in both primary and secondary care. Caregivers were often the first to notice changes and held important information about decline that was not captured. More structured opportunities for caregiver input, including separate discussions where appropriate, may improve diagnostic accuracy and timeliness. The findings highlight the need for improved dementia training among healthcare professionals. GPs were often described as uncertain, reluctant to refer or inclined to attribute symptoms to depression, bereavement or ageing. Training should focus not only on recognising atypical and early symptoms of dementia, but also on understanding the value of caregiver knowledge.

Third, memory services should consider how assessments can be made more culturally and linguistically accessible. Participants described challenges associated with English-language assessments, low literacy and culturally unfamiliar questions. Greater use of interpreters, translated materials and culturally adapted assessment approaches may help improve equity. Finally, post-diagnostic support should be more proactive. Many caregivers described receiving minimal guidance after diagnosis and being left to identify services independently. Structured follow-up, clearer signposting, multilingual resources and culturally appropriate support may reduce burden and improve wellbeing.

Overall, the findings suggest that although UK dementia policy emphasises earlier diagnosis, reducing inequalities and improving post-diagnostic support, implementation remains inconsistent. Future policy should focus not only on increasing diagnosis rates, but also on improving the quality, accessibility and cultural responsiveness of the diagnostic journey (Table 2).

Table 2. Policy implications of findings.

Key findings	Policy implications
Limited public awareness of dementia and early symptoms; ethnic-minority communities described stigma and barriers to help-seeking	Reinforces the need for better public awareness campaigns and policy initiatives that engage community organisations, faith groups and culturally-specific services
Caregiver concerns often dismissed or misattributed in primary care	Improved GP training in dementia recognition, atypical presentations and caregiver concerns. Also reinforces policy ambitions around earlier diagnosis
Long waiting times and delays to memory services	Indicates a continuing gap between national commitments to earlier diagnosis and families' experiences of accessing care
Culturally and linguistically inaccessible assessments	Highlights the need for future dementia policy to place greater emphasis on equity, translated resources and culturally responsive care. Translated tests alone may not be sufficient, assessments should also be culturally adapted
Informant measures inconsistently collected	Suggests that policy and service guidance should place greater emphasis on incorporating caregiver knowledge of change alongside cognitive assessment
Fragmented or absent post-diagnostic support	Suggests that current policy commitments to personalised and ongoing support are not being experienced consistently by families. Greater access to proactive support, caregiver-specific interventions, including psychoeducation, counselling, peer support and culturally appropriate services, may also help reduce burden and improve wellbeing

Limitations

Retrospective accounts may be subject to recall bias, and some experiences were shaped by the COVID-19 pandemic. Although rigour was enhanced through independent coding of 20% of transcripts, reflexive diaries and regular team discussions, most transcripts were coded by a single researcher, which may have increased the risk of subjective interpretation. Although there was diversity in gender and ethnicity, representation across geography, sexual orientation and first language was limited. Future studies should use targeted community recruitment and offer interviews in preferred languages to improve inclusivity.

Future directions

Future research should examine how cultural and social factors shape help-seeking, communication and access to diagnosis. This would inform culturally responsive services, targeted clinician training and inclusive dementia pathways. Assessment tools should be co-designed with caregivers and developed in multilingual, culturally adapted formats to support more equitable diagnostic and post-diagnostic care.

Conclusion

This study reinforces the vital role caregivers play across the dementia diagnostic journey, from recognising symptoms to navigating life after diagnosis. Their accounts reveal persistent delays, inconsistent support and culturally misaligned assessment practices. Improvements are needed in public education, GP training, culturally adapted assessment tools and accessible post-diagnostic support. Co-design with caregivers is essential to create earlier, fairer and more compassionate dementia pathways.

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