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RESEARCH ARTICLE

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Patient and caregiver attitudes to cognitive and behavioral testing in Amyotrophic Lateral Sclerosis

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ABSTRACT

Background: Cognitive and behavioral changes affect up to 50% of people with Amyotrophic Lateral Sclerosis (ALS) and are associated with worse outcomes, yet remain under-recognized in clinical care. Understanding patient and caregiver perspectives is important for engagement with cognitive screening.

Methods: Semi-structured interviews were conducted with 10 patients with ALS and 9 caregivers, analyzed using reflexive thematic analysis. Participants were recruited via a multidisciplinary ALS clinic and the Motor Neurone Disease Association UK.

Results: Engagement with testing was shaped by emotional readiness, personal values, relational dynamics, practical barriers, and perceived value. Views ranged from seeing testing as an opportunity for preparedness and autonomy, to concerns it could undermine identity or add distress. Caregivers often valued testing to support planning but faced challenges balancing advocacy with respect for patient autonomy. Limited awareness of cognitive symptoms in ALS and unclear communication from clinicians reduced perceived relevance. Testing was most meaningful when tailored to personal priorities, introduced sensitively, and linked to actionable outcomes.

Conclusion: Cognitive screening in ALS requires a flexible, patient-centered approach that considers emotional readiness, relational contexts, and clear communication. Tailoring discussions and delivery to patient and caregiver needs may enhance acceptance and integration of cognitive assessment into holistic ALS care.

PLAIN LANGUAGE SUMMARY

What is this article about?

Up to half of people with Amyotrophic Lateral Sclerosis (ALS) have problems with thinking or behavior, and for some this can lead to dementia. Many are not routinely tested, and little is known about how patients and caregivers feel about such testing. This study explored their views, challenges, and how testing could be offered in ways that feel supportive and useful.

What were the results?

We interviewed 10 people with ALS and 9 caregivers. Views on testing varied widely. Some found it reassuring and helpful for planning, while others felt it was upsetting or a threat to independence. Lack of awareness sometimes led to symptoms being mistaken for aging or personality, which caused strain in families. Emotions and relationships mattered more than practical issues like travel in shaping how testing was experienced. Most were open to testing when it was explained clearly and offered sensitively.

What do the results mean?

Testing should be tailored to the individual, accounting for personal priorities, emotional readiness, family relationships, and what the results mean for daily life. Keeping these in mind may help professionals offer testing in a way that feels relevant and supportive for people with ALS and their families.

ARTICLE HISTORY

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KEYWORDS

Amyotrophic lateral sclerosis (ALS); cognitive impairment; cognitive screening; patient and caregiver attitudes; qualitative research; person-centered care

1. Introduction

ALS is a fatal neurodegenerative disease characterized by progressive motor disability [1]. Increasing recognition of cognitive and behavioral impairment has reframed ALS as a multisystem disorder that exists on the ALS-frontotemporal dementia (ALS-FTD) spectrum [2]. Up to 50% of patients experience cognitive or behavioral impairment and 15% develop frontotemporal dementia (FTD) [3–7]. Deficits typically involve verbal fluency, executive function, language, and social cognition [6,8,9], with apathy being the most prevalent behavioral symptom [10–12].

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Article highlights

- ALS is a progressive, incurable neurological disease; 50% of patients experience cognitive or behavioral impairment and 15% develop frontotemporal dementia.
- Patient and caregiver perspectives on cognitive and behavioral testing in ALS are underexplored; this study provides direct accounts from both groups.
- Patients and caregivers were generally open to testing when it was explained clearly and introduced at the right time; readiness to engage varied with coping style, disease progression, and relational context.
- While practical challenges such as travel and fatigue were acknowledged, engagement was strongly influenced by perceived relevance and emotional readiness.
- Limited awareness and unclear communication led to misattribution of symptoms, adding strain within families.
- Caregivers valued testing for planning but also described hidden burden and difficulty raising concerns without undermining autonomy or causing conflict.
- Testing carried meaning beyond its clinical purpose, with implications for autonomy, identity, control, and coping with ALS.
- Attitudes toward testing varied widely, highlighting the need for an individualized approach; this study offers a four-domain framework to guide practice: personal factors, relational dynamics, external factors, and perceived impact.

These changes are associated with worse prognosis [13–16], reduced quality of life [17], and increased caregiver burden [17–23], potentially affecting treatment adherence [24] and decision-making ability [25,26]. Yet, such changes may go unnoticed, masked by physical disability and reduced daily responsibilities.

Assessment of cognitive and behavioral change is recommended in clinical guidelines [27] as part of routine ALS care. However, implementation of screening tools such as the Edinburgh Cognitive and Behavioral ALS Screen (ECAS) [28] and ALS Cognitive Behavioral Screen (ALS-CBS) [29] remains inconsistent. Only 45% of UK [30] and 12.7% of international [31] ALS services surveyed routinely assess all patients, with reported barriers including limited resources, lack of trained staff, and clinician concerns about utility or causing distress [31–33].

Patient and caregiver attitudes are central to engagement with cognitive screening and influence uptake [34,35]. In ALS, however, these perspectives remain underexplored. Research has primarily focused on healthcare provider views, with patient attitudes often conveyed indirectly through healthcare provider reports [30–33,36]. Broader dementia research, however, suggests that patient and caregiver attitudes to screening can differ from clinician assumptions [37].

Understanding these perspectives is particularly important in ALS, where rapid progression may lead to prioritization of physical care, and the emotional impact of a recent ALS diagnosis may make conversations about cognition particularly difficult. Yet early assessment is important to support timely decision-making while patients can still participate meaningfully in discussions about their care [25].

This study explores patient and caregiver perspectives on cognitive and behavioral impairment and screening in ALS. Rather than quantifying attitudes or identifying predictors of engagement, it focuses on how cognitive and behavioral testing is understood and interpreted by patients with ALS and their caregivers, in order to inform patient-centered clinical discussions and care. Specifically, this study aims to:

(1) Examine how patients and caregivers perceive cognitive and behavioral testing in ALS.
(2) Identify key considerations described by patients and caregivers in how they engage with assessment.
(3) Explore how test outcomes could be made more meaningful for patients and caregivers.

2. Methods

2.1. Study design

A qualitative semi-structured interview study was conducted with patients with ALS (pALS) and their caregivers (cALS), using reflexive thematic analysis as outlined by Braun and Clarke [38]. Interviews were conducted by researchers with expertise in ALS and dementia care. The study adhered to Consolidated Criteria for Reporting Qualitative Research (COREQ) reporting guidelines [39] (see online Appendix 1). Ethical approval was obtained from the West of Scotland Research Ethics Committee (REC reference: 23/WS/0146). All participants provided written informed consent. Capacity to consent was assessed in line with the UK Mental Capacity Act 2005 [40].

2.2. Participants

Participants were recruited primarily from northern England via Sheffield Teaching Hospitals NHS Foundation Trust and the Motor Neurone Disease Association (MNDA) UK between March and November 2024. Eligible pALS had a confirmed ALS diagnosis and were able to communicate verbally or using assistive technology. Eligible cALS provided unpaid regular care to a pALS; this included family members, partners, or close friends. Most cALS lived with the person they cared for, and for some caregivers this role began prior to formal ALS diagnosis, reflecting support during a prolonged symptomatic or diagnostic period.

Purposive sampling aimed to capture a range of experiences across disease stage, cognitive and behavioral symptoms, and caregiving roles, resulting in a heterogeneous sample intended to support exploration of varied perspectives rather than comparison across clinical or demographic subgroups. Recruitment was via clinician referral and MNDA advertisements. All participants received a shopping voucher in recognition of their time.

2.3. Data collection

Semi-structured interviews were conducted in person by LI, AG, and YA, either in participants' homes or in private rooms at a hospital-based clinical research facility. Interviews lasted 45–90 minutes and were audio-recorded with consent. pALS and cALS were interviewed separately.

A semi-structured topic guide was used, developed with clinicians, researchers, and a patient and caregiver advisory group. The guide explored participants' understanding of cognitive and behavioral change in ALS, experiences of being offered or undergoing cognitive and behavioral testing, perceived benefits or concerns, and how testing and its outcomes were understood in relation to care and decision-making. Open-ended questions were used, with prompts applied flexibly. Example questions included: "What was your understanding of cognitive or behavioural testing when it was first discussed?," "How did cognition, or thinking ability, matter to you in the context of ALS and your care?," and "How did the results, or the possibility of results, affect how you thought about your care?" Interviews were professionally transcribed verbatim, and transcripts were cross-checked by the research team for accuracy. Field notes were used to record contextual impressions.

2.4. Data analysis

Data were analyzed using reflexive thematic analysis, following Braun and Clarke's six-phase approach [38]. Analysis was inductive, with codes and themes developed from the data rather than applied from preexisting frameworks.

Two researchers independently coded an initial subset of transcripts to support familiarization with the data and development of an initial coding structure. They then met to discuss interpretations and refine code definitions, with discussions focused on meaning, emphasis, and the boundaries of codes. The coding framework was refined iteratively as further transcripts were analyzed. Themes were reviewed in wider team discussions and compared across patient and caregiver interviews. Ongoing analysis guided recruitment decisions, applying the concept of information power [41], with recruitment concluded when additional interviews were no longer contributing substantively new insights relevant to the study aims. Themes were developed to capture shared patterns across participants' accounts and are illustrated using representative quotations.

2.5. Reflexivity

The research team brought expertise in ALS, dementia care, and qualitative research, and acknowledged that prior clinical experience could sensitize interpretation toward themes of loss, autonomy, and healthcare challenges. The team also shared a belief in the potential value of cognitive testing in MND care, which may have influenced framing of participant perspectives. The lead analyst (LI) maintained a reflexive journal to document potential biases during analysis. Triangulation across researchers and regular discussion supported critical examination and refinement of themes, promoting diverse perspectives and minimizing individual bias.

3. Results

3.1. Participants

Interviews were conducted with 19 participants: 10 pALS and 9 cALS. Participant quotations are labeled using identifiers (e.g., P01 = pALS; C01 = cALS), with matching numbers indicating patient-caregiver dyads. One participant with ALS (P10) did not have a corresponding caregiver. Identifying details have been removed from quotations to preserve anonymity. See Tables 1 and 2 for participant demographics.

Four overarching themes were identified, each with several subthemes (Table 3).

3.2. Theme 1: cognitive testing as a personal and emotional decision

3.2.1. Emotional readiness

Participants' emotional response to their ALS diagnosis shaped their sense of readiness to engage with cognitive testing. Initial shock gave way to a range of evolving emotions, which influenced how and when cognitive testing felt acceptable.

In the early aftermath of diagnosis, the idea of additional assessment and the possibility of cognitive decline often felt overwhelming. While participants did not necessarily reject testing, many described needing time and space to adjust before being able to meaningfully engage. This timeline varied according to individual coping styles.

> I had enough to get my head round … I have no problem discussing it now, it would have taken me a good year to really understand. (P06)

Some adopted a pragmatic or stoic approach, viewing testing as another challenge to overcome rather than actively pursued or resisted.

> It's always been: 'If there's a problem, deal with it, don't sweep it under the carpet.' It's that pragmatism. It's me dealing with it, not asking 'Do I really want to know?' (P04)

Some expressed more conflicted or distressing emotions. For one pALS, the idea of cognitive decline provoked anger and perceived worthlessness.

> I don't want to use the word 'upset' because it's not strong enough. Angry … Not being able to use my brain anymore, just a total decline into being a complete useless waste of time, for myself and everybody around me (P08)

Others responded with ambivalence, distancing themselves from the idea of cognitive involvement altogether by acting as though symptoms were not present.

> Probably myself wishes it wasn't there … if you treat it differently, you see it as a different thing. (C08)

Despite differing emotional responses, participants described approaching cognitive testing in ways that helped them preserve emotional stability after their ALS diagnosis, with readiness to engage reflecting individual coping styles.

3.2.2. Alignment with personal values

3.2.2.1. Autonomy. Alignment with personal values shaped how participants approached testing. Cognitive function was closely tied to autonomy and independence, described as central to decision-making, managing daily life, and retaining control despite physical decline.

Table 1. Patient participant characteristics ($n = 10$).

Participant ID	Age	Sex	Education (years)	ALSFRS-R Score	Time Since Diagnosis (months)	Cognitive Status (ECAS)	Behavioural Symptoms	Dysarthria
P01	49	F	14	24	4	Normal	Present	Present
P02	74	M	14	37	19	Normal	Present	Present
P03	63	F	12	29	38	Normal	Absent	Present
P04	69	M	18	13	40	Normal	Present	Present
P05	40	M	17	11	40	Normal	Absent	Present
P06	63	F	14	9	23	Impaired	Present	Present
P07	70	M	12	38	132	Impaired	Present	Present
P08	53	F	12	41	84	Impaired	Present	Absent
P09	67	F	14	43	2	Impaired	Present	Present
P10	43	F	17	36	21	Normal	Absent	Present

Cognitive Status based on ECAS total score using standard cut-offs (Impaired/Normal).
Behavioural Symptoms based on ECAS carer interview or reported concern (Present/Absent).
Abbreviation: ALSFRS-R = ALS Functional Rating Scale-Revised.

Table 2. Caregiver participant characteristics ($n = 9$).

Participant ID	Age	Sex	Relationship to Patient	Co-resident	Years Providing Care	Involved in Testing	Matched Patient ID
C01	50	M	Partner	Y	2	Y	P01
C02	72	F	Partner	Y	2	Y	P02
C03	65	M	Partner	Y	4	Y	P03
C04	69	F	Partner	Y	5	Y	P04
C05	38	F	Partner	Y	4	Y	P05
C06	62	M	Partner	Y	3	Y	P06
C07	71	F	Partner	Y	12	Y	P07
C08	54	M	Partner	Y	8	Y	P08
C09	30	M	Son	N	2	Y	P09

Involved in Testing refers to presence at cognitive and behavioural testing.
Matched Patient ID refers to the individual the caregiver supported.

Table 3. Overview of themes and subthemes.

Theme	Subtheme
1. Cognitive Testing as a Personal and Emotional Decision	1.1 Emotional readiness
	1.2 Alignment with personal values
2. The Patient-Caregiver Dynamic in Cognitive Testing	2.1 Differing priorities: present needs vs future planning
	2.2 The hidden emotional burden of caregivers
	2.3 Insight discrepancies
3. Communication and Practical Challenges	3.1 Information and understanding
	3.2 Practical barriers
4. Impact and Value of Testing	4.1 Clarity and validation
	4.2 Supporting planning
	4.3 Limits to perceived value
	4.4 Expectations and unmet needs

> Cognition is everything for me; to know I'm not cognitively impaired validates everything I do. If there was doubt, it would affect every part of my life. I wouldn't dare drive, take medication or go out alone. (P10)

Testing was viewed as a way to safeguard autonomy, supporting planning and continued involvement in decision-making. One participant described how he was able to revisit earlier decisions.

> I'd decided straight away I wasn't going to have a feeding tube. I didn't want to prolong the path to death. But over a couple of years I'm coming round to changing my mind. It's my decision and not somebody else's to make, and I can still make that decision because I still have an active mind. (P04)

Conversely, others feared that testing might undermine their independence, particularly if results could lead to assumptions about capacity or shift control away from them.

> Independence is everything, it slowly decreases with MND and takes a lot of time to get used to. I think if I had a cognitive problem too I wouldn't be able to handle it. (P05)

For many, simply having access to information about cognition, regardless of whether the implications were fully understood, was a way to maintain agency and self-determination.

> I think knowledge is empowerment and I think you should have access to that information, if you choose to explore it … I think it should be available. (C04)

Participants valued being offered testing as a choice, rather than an expectation, which allowed them to maintain a sense of ownership over the process.

> At first I think it would have been nice to sit with someone and they'd asked me what I did or did not want to discuss and when. (P06)

3.2.2.2. Identity. Participants described cognitive function as central to their sense of self, but also how they were perceived by others. Cognitive impairment risked a 'double burden' of being both misunderstood and further stigmatized.

> It's hard enough now. People already assume you have cognitive problems when you can't talk. So having actual cognitive problems would be one hundred times worse. It would be too much to be labelled again. (P10)

3.2.2.3. Life view. Participants' outlook on life shaped how they approached cognitive testing. Some adopted a proactive stance, finding purpose through action, using terms such as "fight it" and "everything is worth trying."

Others preferred to focus on the present, avoiding reminders of potential decline. For them, testing felt intrusive or unnecessary, disrupting their efforts to preserve normalcy.

> You can't expect them every day to be concentrating on what they're losing … to constantly think, well I've lost the use of this or I can't quite do this, it is wrong (C07)

Participants were also aware that some pALS would never experience cognitive decline and perceived focusing on this to be an unnecessary additional concern.

> It's something that might not come about so it could be something else to worry about that might not ever happen (C08)

3.3. Theme 2: the patient-caregiver dynamic in cognitive testing

3.3.1. Differing priorities: present needs vs future planning

Approaches to cognitive testing reflected the different roles patients and caregivers held in navigating ALS. Patients typically took a reactive approach, viewing testing as relevant only if cognitive symptoms became noticeable. Their focus was often on managing the present – coping with physical challenges, maintaining normalcy and avoiding burdening loved ones.

> I think as long as I know I'm fine I don't really need [testing], but if I thought I was going [to develop cognitive impairment] then you can see if you're being affected that way. (P03)

In contrast, caregivers often took a future-oriented approach, viewing cognitive testing as a practical tool to plan for care needs, legal arrangements, and potential changes in decision-making capacity.

> I know that my point of view is quite different to my partner's. I like to be prepared and know what's coming, including if it could affect cognition, even if it never does. I'd want lots of information so I know what we might be dealing with. (C05)

By planning ahead, caregivers felt they could offer more focused and effective care in the present.

> Just to know what you need to do in the future, and get everything in line, means you can then focus more on the caring side of things. (C09)

This misalignment in priorities made shared decision-making complex. While many decisions were made collaboratively, caregivers described the difficulty of raising concerns without overstepping boundaries or undermining autonomy.

> My partner makes all his own choices, we discuss things; if I have a concern I lay out my concerns but I do nothing without his consent. (C07)

3.3.2. The hidden emotional burden of caregivers

Caregivers often took on a protective role, absorbing emotional burden to shield the pALS from distress. They described a need to privately process information and prepare emotionally before broaching sensitive topics like cognitive testing and the possibility of dementia.

> I did a lot of research before talking to my partner … I needed to steel myself for what I was going to help him discover. (C04)

In some cases, this protective instinct reflected mutual preferences within the relationship.

> I would prefer information to go to my husband as I get upset at things, and if I'm given information I thought might upset him, I wouldn't tell him. (P10)

Caregivers spoke of the burden of carrying concerns alone, deciding how and when to raise them, not only with the pALS, but also with wider family.

> [I needed to support] our girls who were on that journey too. Everyone processes it differently. It can be hard to provide the support needed if you're reeling at the same time even though my partner and I were trying to walk the journey together. (C04)

Unlike physical symptoms, cognitive and behavioral changes were less visible and harder to explain. Caregivers described the strain of managing these changes, navigating others' misunderstandings, and advocating for support. This contributed to a sense of isolation around conversations about cognitive testing.

> People see her and think she's doing really well, but when you're living with her, the cognitive side is actually harder than the physical. We can help with walking, that's visible, but the mental side is harder to explain, and I find it the most difficult. I worry more about the behavioural side, especially when we're out. At home I can manage, but in public you don't want it to be a bad day. She often argues there's nothing wrong, and I don't think she sees it herself. Everyone expects the physical decline, but not the rest. I've tried explaining it's linked to the ALS, but family just think she's being awkward. (C08)

3.3.3. Insight discrepancies

Disagreements between pALS and their cALS about the presence of cognitive or behavioral changes created relational tension. Some pALS minimized or denied symptoms, which left cALS feeling further isolated and unable to validate concerns.

> I was so desperate just to get a diagnosis … I didn't know if it was thorough enough … I was just so desperate for other people to see what I'd seen on the bad days. (C09)

This led to some cALS worried about raising concerns in front of their partner to clinicians, worried about upsetting the pALS or being perceived as critical or controlling.

> Because my partner was sat here [with me in clinic] I felt like you couldn't really answer those questions truthfully because she'd get upset if I said something she didn't agree with. We go to hospital appointments together. If I was on my own, I'd report it; but if she was with me, I'd hope she'd bring it up. (C06)

3.4. Theme 3: communication and practical challenges

3.4.1. Information and understanding

Participants' understanding of cognitive and behavioral change in ALS influenced how they perceived the relevance of cognitive testing. For many, the offer of testing marked the first time they became aware that cognition or behavior could be affected. Those with prior exposure to ALS or dementia, through family or occupation, were more likely to incorporate this information. Others struggled to reconcile their existing understanding of ALS with preconceived ideas of dementia, viewing symptoms as unrelated or coincidental.

> I didn't think it was linked; I thought it was just a problem that I had as well as MND. (P08)

Communication about cognitive and behavioral change was inconsistent. Some participants reported receiving little or no information, while others felt too overwhelmed to process it, particularly around the time of diagnosis. In several cases, the purpose of cognitive testing was not well understood, with some confusing it with unrelated conditions or assuming it was for research.

> There's a lot of things we got told at the time, and because it's such a shock … I think you do turn off a little bit. (C08)

Some participants turned to self-sourcing information online or through charities, which could be helpful but also incomplete or confusing.

> We actually got very little information … we went and found it out ourselves. (C04)

Limited understanding led to misattribution of symptoms to other causes, including age, personality, or emotional reaction to illness. These strained relationships or led to missed opportunities for support.

> I feel really bad … some days I was just getting so frustrated with her I'd like shout at her, but it's because I didn't know that it was linked. (C09)

> I don't think you would think to raise it if you didn't know that there was a potential link. (C04)

3.4.2. Practical barriers

Travel to clinic-based assessments was a common difficulty, particularly for those with advanced disease. Long distances, reliance on others for transport, and physical discomfort made it challenging to attend in-person appointments.

> It's a two-hour journey … by the time I get here I'm already quite tired. (P01)

Fatigue raised concerns about test performance. Some participants felt they would have performed better at a different time of day, while others found testing burdensome, particularly when scheduled toward the end of a hospital visit.

> I was exhausted when I went in … I still did quite well, but someone else it might affect greatly the outcome. (P01)

Cognitive testing was typically one of several appointments during ALS clinic visits. While combining appointments into a single trip helped reduce travel demands, it often compounded fatigue.

> For us it's really helpful to turn up at the hospital, do a whole bunch of things together and then go home again. (C05)

Others described feeling anxious about how their performance, comparing the experience to sitting an exam.

> I'd be worried if I'd be all right at the end of it … I was hoping to get the full marks. (P08)

Remote testing was appealing for its convenience, comfort, and reduced stress. Being at home was seen to ease anxiety and promote openness. Others valued the reassurance of face-to-face interaction provided with in-person assessments.

> Going to hospital's quite stressful … at home you might be a bit more relaxed, bit more open. (C08)

3.5. Theme 4: impact and value of testing

3.5.1. Clarity and validation

For many, cognitive testing helped identify or make sense of changes, or validated concerns. Even when results showed no impairment, the process helped reassure and reduce uncertainty for both pALS and their families.

> It's a relief to have a bit of clarity … even just knowing that it's not something else going on. (C04)

For caregivers, testing could also provide an objective lens to support communication and reduce conflict, especially in the presence of differing insight.

> Sometimes you need more than just the opinion of the person or the caregiver … a more scientific way of saying, 'yeah, that tracks.' (C05)

3.5.2. Supporting planning

Cognitive testing supported practical, legal, or emotional preparation for the future. Even when no impairment was identified, the results helped clarify expectations and guide decisions.

> I need the information to prepare for what's coming … if that test gave us a bit of an inkling that there's something a little bit else going on, I would want to know. (C04)

Others described testing as a helpful reference point, allowing them to monitor potential changes and feel more prepared should concerns arise.

> It kind of confirmed where we were at … and we'll know what to look for if it changes. (C05)

3.5.3. Limits to perceived value

Not all participants viewed cognitive testing as useful. In the absence of noticeable symptoms, some felt it introduced unnecessary worry or focused attention on problems that might never develop.

> That might not ever happen. (C08).

Others questioned its relevance within the context of a progressive and terminal disease, especially when testing was not expected to change care or outcomes.

> It's not going to make a difference to the outcome of what's going to happen. (P04)

3.5.4. Expectations and unmet needs

Despite the potential value of testing, several participants were unclear about what it would lead to or felt disappointed by the absence of follow-up.

> Just a bit disappointed we didn't get like a follow-up … to see if things had deteriorated or improved. (C08)

Some expected more concrete outcomes, emotional support, or care planning, and were unsure how to act on the results.

> [The clinical psychologist] gave the doctor the information and we were just told 'the test was OK' and that was it … maybe a little more explanation would have helped. (C02)

Others expected testing to offer more clarity than it did or felt unsure whether results were meaningful in the absence of treatment options.

> If it's not going to change anything, what are we supposed to do with the information? (P04)

4. Discussion

Patient and caregiver attitudes toward cognitive and behavioral testing in ALS were highly variable but could be broadly understood across four themes: (1) cognitive testing as a personal and emotional decision; (2) patient-caregiver dynamics; (3) communication and practical challenges; and (4) the perceived impact and value of testing.

Across these themes, engagement with cognitive testing was embedded in the broader emotional and existential context of ALS. Testing carried implications for autonomy, identity, control, and future planning beyond its clinical purpose. Relational dynamics shaped how testing was approached, at times supporting shared understanding between patients and caregivers, and at other times generating tension. Practical considerations such as fatigue, travel, and test delivery influenced engagement, but were weighed against the perceived purpose and relevance of testing.

Openness to discussion and engagement with testing depended on context, including how and when cognitive assessment was introduced and how clearly its purpose was understood. Cognitive testing was more likely to feel relevant when participants could relate it to their personal priorities and to broader aspects of ALS care, such as reassurance, decision-making, or planning. Where testing could not be readily integrated into this context, it was more likely to be experienced as burdensome or of limited value.

4.1. Comparison with previous literature

While clinician perspectives on cognitive screening in ALS have been explored, direct insight from patients and caregivers remains limited [30–33,36]. Existing studies highlight its clinical value in identifying symptoms, informing decisions, and supporting communication [30–32]. Our findings affirm and extend this work. Many caregivers valued early identification to support planning and reduce burden, and patients often saw testing as a way to maintain autonomy and prepare for future decisions.

Prior research identified barriers to routine cognitive screening implementation, including limited time and staffing [31–33,36]. While participants in our study acknowledged practical challenges such as travel and fatigue, these were rarely decisive. Engagement was more influenced by perceived relevance and emotional readiness than by practical limitations alone.

Although concerns about patients being overwhelmed have been cited by clinicians [32], our findings suggest patient and caregiver perspectives are more nuanced. Readiness to engage was highly individual and dynamic, evolving with coping style, disease progression, and relational context. Caregivers were often more open to cognitive discussions earlier than patients. This aligns with broader dementia literature showing that patients frequently value diagnostic information for reasons such as future planning and prioritizing relationships, even in the absence of disease-modifying treatments, and that clinicians may underestimate this willingness to engage with cognitive screening [35,37,42,43]. It also aligns with ALS-specific work indicating that patients and caregivers want to be informed about cognitive risks [44].

Our findings highlight the risks associated with limited awareness of cognitive and behavioral changes in ALS. A lack of information and understanding among patients and caregivers contributed to symptom misattribution, delays in seeking help, and relational strain, underscoring the importance of clear, tailored, and timely communication about cognition and behavior within ALS care.

4.2. Implications for practice

This study highlights the variability in attitudes toward cognitive testing in ALS, demonstrating that a personalized approach is needed to support meaningful engagement. Rather than fixed barriers or facilitators to navigate, experiences showed how the same factor could be viewed positively or negatively depending on individual context. For example, testing could represent either an opportunity for control or a threat to independence. We propose four domains to guide a patient- and caregiver-centered approach: personal factors, relational dynamics, external factors, and perceived impact. Figure 1 summarizes key considerations across the testing pathway.

4.2.1. Personal factors

Clinicians should explore emotional readiness, values, and life outlook when introducing cognitive testing. Understanding priorities, such as maintaining independence or preparing for the future, can help align discussions. Open-ended questions and flexible timing can help ensure that testing feels relevant and appropriate, rather than imposed. Readiness may shift over time, so conversations should be revisited as the disease progresses.

4.2.2. Relational dynamics

Caregivers often have an active role in supporting decisions around cognitive testing but may struggle to voice concerns,

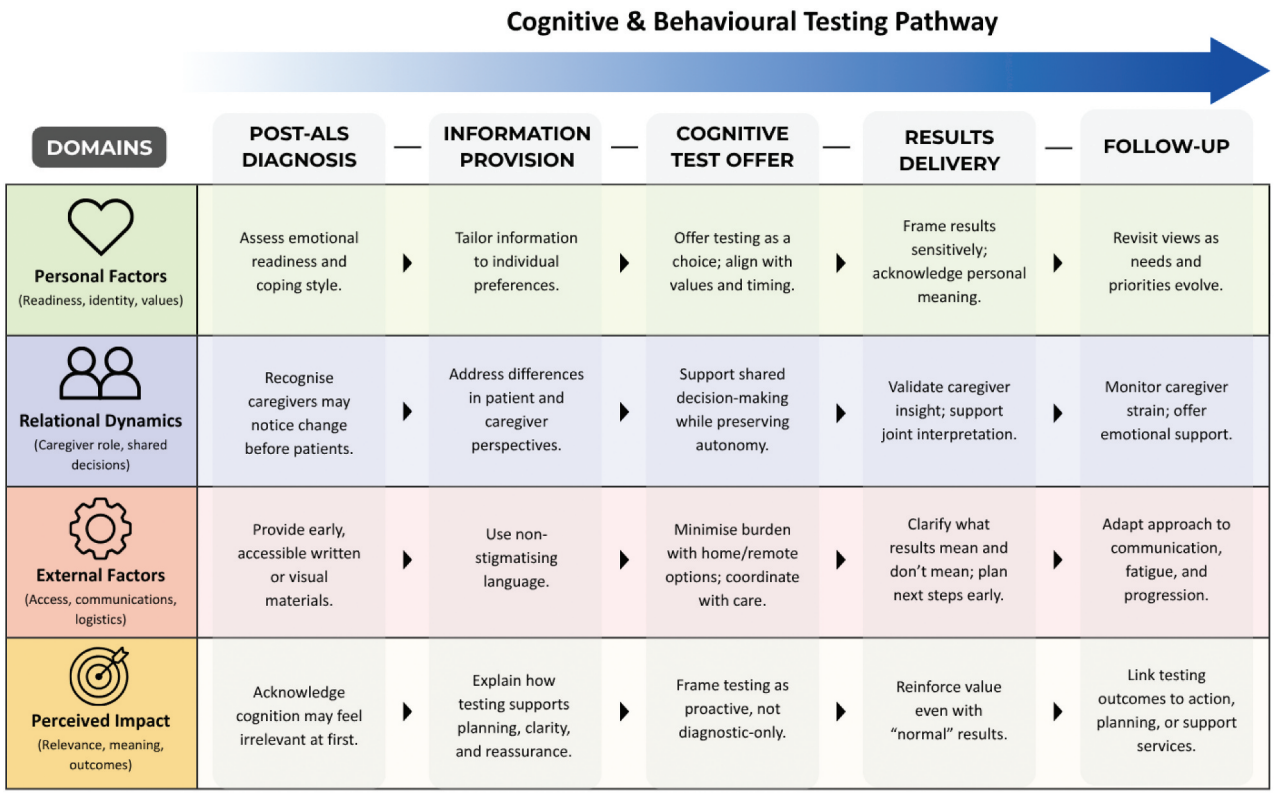

Figure 1. Key considerations for delivering person-centred cognitive and behavioural testing in ALS.

particularly when patient insight is limited or priorities differ. Clinicians can support open dialogue while respecting patient autonomy by offering caregivers opportunities to share observations privately, where appropriate. Caregivers may also need guidance and emotional support to manage the often hidden burden of cognitive and behavioral change.

4.2.3. External factors

How and when information is introduced about cognitive and behavioral change can significantly shape engagement. Clear, jargon-free explanations about the potential for cognitive symptoms, the purpose of testing, and what testing can and cannot achieve may help reduce confusion and anxiety. It may be helpful to provide information in stages and formats tailored to the patient and caregiver preferences, allowing time for processing and follow-up.

4.2.4. Perceived impact

Meaningful engagement with cognitive testing relies not only on the act of assessment, but on how results are framed and used. Clarifying how cognitive screening might support practical planning, reassure when there are no concerns, or identify additional support needs can help link testing to tangible outcomes. In a progressive and terminal disease like ALS, where autonomy is highly valued, framing cognitive testing as a tool for empowerment and preparation may make participation more acceptable. Follow-up communication about results and support options is equally important to maintain trust and utility.

5. Limitations

Participants were recruited from a specialist ALS care center and had all encountered cognitive and behavioral testing as part of their clinical care. The findings therefore describe how patients and caregivers understood and experienced cognitive and behavioral testing within this setting. While most caregivers were spouses and co-resident with the person with ALS, one caregiver was a nonresident adult child. This reflects the range of caregiving relationships encountered in ALS care and may shape perspectives on cognitive and behavioral testing. Interviews captured perspectives at a single point in time and experiences of testing may evolve as ALS progresses. Further work could extend these insights by exploring experiences in other care settings and over time, including how perspectives may differ across stages of disease.

6. Conclusion

This study highlights the complexity and variability of attitudes toward cognitive testing in ALS. Personal values, relational dynamics, external factors, and perceived impact all shaped how patients and caregivers engaged with assessment. Cognitive testing was not simply viewed as a clinical process, but as an experience carrying emotional, relational, and existential impact. Engagement was most meaningful when testing was aligned with individual priorities, introduced with sensitivity to emotional readiness, and clearly connected to practical outcomes. These findings underscore the need for a tailored, patient-centered approach to cognitive assessment

in ALS, supporting not only clinical goals but also the broader needs of patients and their families.

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Author contributions

LI led the study, including recruitment, data collection, analysis, and drafting of the original manuscript. AWG, DB, and CJM contributed to study design and data analysis, with AWG and YA assisting in data collection. LI, AWG, EM, DB, and CJM contributed to reviewing and editing the manuscript.

Disclosures

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

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