NIHR | Policy Research Unit
Policy Research Unit: Dementia and Neurodegeneration
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Policy Brief

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The assessment and diagnosis of neurodegenerative diseases in people from minority ethnic backgrounds

Overview

People from minority ethnic backgrounds can face additional barriers to timely and accurate assessment and diagnosis of neurodegenerative diseases. Understanding and addressing these barriers is important for equitable neurology care. We interviewed people about their experiences of the assessment and diagnostic process:

Six Neurologists (NHS)
Specialisms: dementia, movement disorders incl. Parkinson's disease (PD), motor neurone disease (MND), and Huntington's disease (HD)
4 White British neurologists
1 White Italian neurologist
1 South Asian neurologist

Three people with a neurodegenerative condition
2 South Asian participants with PD
1 Black participants with PD

Six family carers
4 South Asian carers (2 caring for a person living with dementia, 1 caring for a person living with MND, and 1 caring for a person living with HD)
2 Black carers (both caring for a person living with dementia)

Key Messages

- Good practice during assessment and diagnosis recognises the complexity of a person's identity and tailors communication and assessment to individual circumstances.
- Assessments must account for factors including migration history, English language proficiency, education, family dynamics, age, and socioeconomic status.
- Growing diversity among healthcare professionals and patients requires sensitivity to cultural beliefs, religious practices, and faith perspectives that may influence acceptance of diagnoses, treatment decisions, and care preferences.
- Capacity constraints across primary and secondary care, coupled with limited GP training in neurodegeneration, may contribute to avoidable delays in the diagnostic pathway.

Background

In the UK, approximately 50,000 people from minority ethnic backgrounds live with dementia,[1] 7,650 with PD,[2] 1,440 with HD[3] and 900 with MND).[4] Informing someone they have a neurodegenerative condition is an intimate and impactful moment carrying profound consequences for patients and their families. A timely, accurate, and sensitive diagnosis is critical. Little is known about how neurologists perceive and navigate culture and ethnicity when assessing and diagnosing people from minority ethnic backgrounds with suspected neurodegenerative conditions, or how patients and their families experience the diagnostic process.

Key Findings

Diagnostic pathway: The journey from the first GP contact to specialist neurology assessment and formal diagnosis is lengthy and complex, often marked by long waiting times, poorly coordinated care, and fragmented communication.

Communication challenges: Language differences are the most immediate communication barrier. In person interpreters can help build rapport and provide more accurate, efficient translation during examinations and assessments. They reduce the burden on family members and give patients privacy to discuss their diagnosis independently. Access to high quality, in person interpreting services, however, is inconsistent.

Cognitive test biases: Cognitive tests are tools used to check mental functions like memory, attention, language, and problem-solving. Family members and neurologists raised concerns about educational, cultural, and linguistic biases in some cognitive tests, which can affect assessment results and disadvantage certain groups.

Cultural and religious influences: Cultural and religious beliefs within families may affect the acceptance of a diagnosis, treatment choices, and care decisions. A deeper understanding of these perspectives can help neurologists and allied health professionals deliver more appropriate, acceptable care.

Implications for improving equitable and timely diagnosis

Translation services: High quality interpretation requires interpreters trained in assessing neurodegenerative conditions (e.g., familiar with examination procedures, common symptoms, and clinical terminology). For consultations where rapport and subtle nuance matter, in person interpretation tends to be most effective. It is important to record patients' language preferences and needs in primary care electronic records and ensure this information accompanies neurology referrals.

Cross cultural cognitive testing: Cultural and linguistic differences can affect the validity of some cognitive tests. Validated cross cultural tests that reduce linguistic, educational, and cultural bias offer useful alternatives when locally adapted tools are unavailable.

Workforce capacity: Regional variation in access to consultant neurologists can affect equity of access and consistency of care. Reviewing available workforce data can help identify geographical disparities and inform recruitment planning to address them.

Culturally aware workforce: Cultural beliefs, religious practices, and faith perspectives influence acceptance of diagnoses, care preferences, and treatment decisions. Reviewing existing cultural awareness training and tailoring training where appropriate to reflect the ethnic and cultural composition of local populations can improve communication and person centred care.

Conclusions

Coordinated action across services could help improve equity in the assessment and diagnosis for people from minority ethnic backgrounds:

- Primary care (GP) services are well placed to record patients' language preferences and communication needs in electronic records, and to ensure this information accompanies referrals to neurology.
- Clinicians and neurologists are responsible for selecting cognitive tests that align with the ethnic and linguistic profile of the populations they serve, and for incorporating validated cross-cultural tests where relevant.
- NHS Trusts, working with local neurology teams and commissioners, are best placed to use workforce data to plan services and address unequal access. They should work towards the Association of British Neurologists' recommended minimum of 1.6 WTE consultant neurologists per 100,000 people,[5] and support timely access to neurological diagnostics in line with the six-week standard.[6]
- Researchers carry responsibility for translating, culturally adapting, and validating cognitive tests, and for evaluating how adaptations affect test performance in diverse populations.
- Neurology services and their local NHS Trusts are positioned to coordinate interpreting service procurement and commissioning to reflect local population needs and quality standards.
- Local NHS Trusts can review existing cultural awareness training and consider adaptations or new programmes that strengthen health professionals' engagement with local ethnic communities.

Limitations

- The small sample size and limited strength of the evidence mean that recommendations have been made cautiously.
- Findings, particularly those relating to cognitive testing, are more relevant to dementia assessment and diagnosis than to the other conditions discussed.

- The available evidence did not allow us to assess the impact of geographical variation in service provision.
- Minority ethnic groups were discussed as a broad category, which may not reflect the substantial diversity between and within groups.
- Different neurodegenerative conditions are considered together, despite potentially having very different diagnostic pathways.

Age and migration factors	**Key considerations for equitable and culturally responsive neurology care**	Education and socioeconomic influences
Family dynamics		Interpreter access
Cultural awareness training		Cross-cultural cognitive tests

Where to find out more

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