

Barriers and facilitators British ethnic minorities face when accessing neuropsychological services: a systematic review and qualitative analysis

Nadine Mirza, Anvita Vikram, Fatima Osmani, Natasha Kumar, Sabah Orakzai, Surina Sharma, Sheeba Ehsan

1. Why is it important?

- **14%** of the UK population identify as an **ethnic minority**¹- predicted to rise to 20% by 2051²
- British ethnic minorities are **highly susceptible** for developing and maintaining **neurological conditions** like dementia and stroke:
 - Due to an increasing ageing ethnic minority population³
 - Due to higher rates of risk factors like cardiovascular diseases, obesity, and diabetes⁴
 - Information and services on prevention and treatment is difficult to access for them⁵⁻⁶

Because of this...

African Caribbeans are twice as likely to suffer from stroke. South Asians show similar susceptibility⁷⁻⁸

British ethnic minorities have a higher prevalence of myalgic encephalitis⁹

British ethnic minorities are more at risk of developing epilepsy¹⁰

There are higher incidence rates of dementia in African Caribbeans and undetected rates in Asians¹¹

- Yet, British ethnic minorities are **underrepresented in services**⁶.
- No research has been done to explore British ethnic minorities experiences of neuropsychological services, and the barriers causing this underrepresentation.
- **How can we improve barriers and promote facilitators to access if we don't know what they are?**

2. What was the aim?

Identify the barriers and facilitators British ethnic minorities face when accessing neuropsychological services: a qualitative systematic review

MAIN FINDINGS



FIGHTING TO ACCESS SERVICES

It was a "battle" to access services in the first place and get support needed. Ethnic minority service users and carers had to "fight the system" and put in a huge amount of effort to be recognised as needing help, increasing existing burden. If they didn't speak up they lost out on support.



INFORMATION GAP

LACK OF TRANSLATIONS

- **Limited translations** on neurological conditions, assessments, and therapies.
- Struggle to research their condition via books or the internet due to language.



DIFFICULTY EXPRESSING ILLNESS

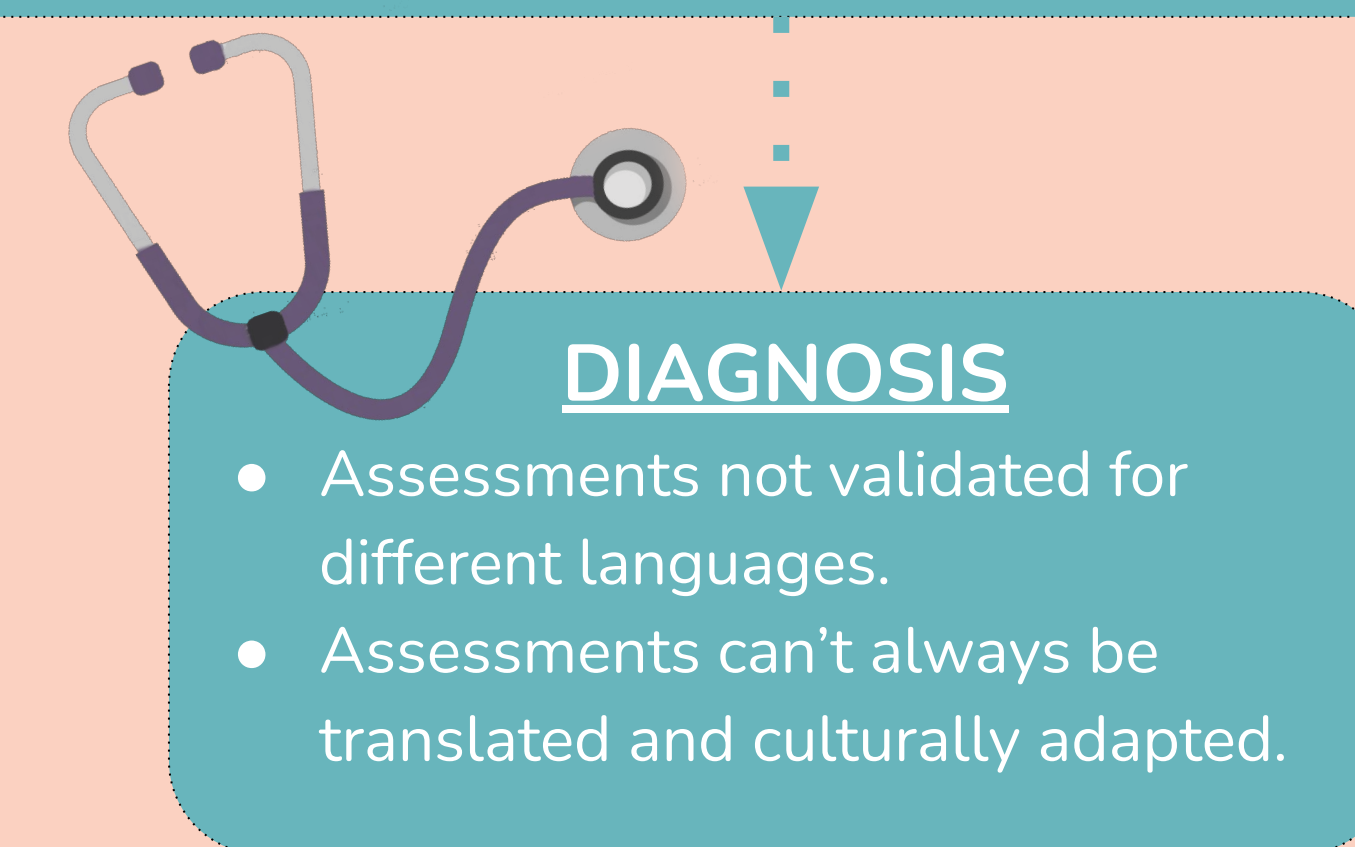
- Don't have words or cultural attitudes to understand condition.
- Follow **biomedical model** and prioritise physical symptoms.
- Think fatigue, loss of concentration and sleep problems can't be helped.
- Attribute symptoms to **natural ageing**.



COMMUNICATION ISSUES

SUBTLE COMMUNICATION

- Loss of informal conversation, which builds **therapeutic relationships**.
- Use non-verbal communication eg. gestures, eye contact, visuals.



DIAGNOSIS

- Assessments not validated for different languages.
- Assessments can't always be translated and culturally adapted.



TREATMENT

- Prefer traditional herbal medicine or spiritual healers.
- Traditional and neuropsychological practices can be complementary.
- Incorporate religion and spirituality.
- Family members may prevent self management steps.
- Service users may use "over caring" family stereotype as an excuse.



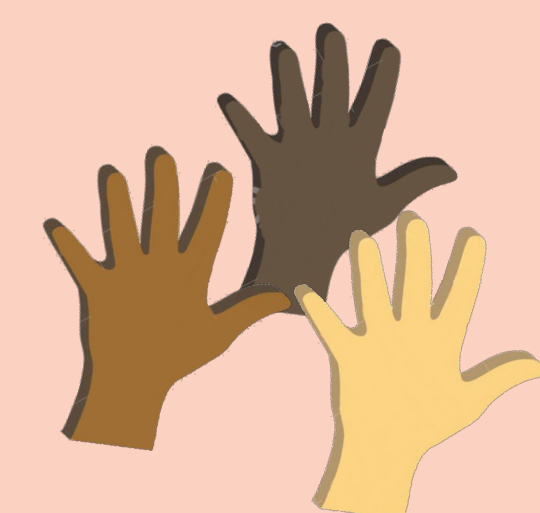
TOPIC APPROPRIATENESS

- Certain topics are only family affairs eg. finance and housework.
- Someone outside family can be an advantage over stigma in communities.

BELIEFS AND EXPERIENCES

ASSUMPTIONS ABOUT ETHNICITY

- Assumed preference for culture specific services over mainstream.
- Self management not always offered as it is assumed family will do everything.
- Staff should find out about **individual's beliefs**.



ABANDONMENT AND TRUST

- Carers felt like a low priority.
- Consultations were too short.
- Little time and support to adjust.
- Trusted medical professionals.



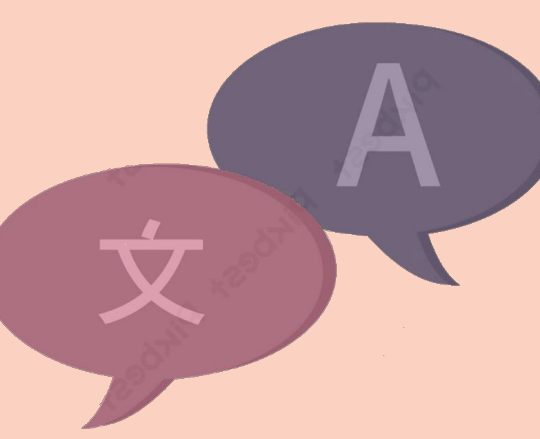
RACISM

- Battle to access can trigger feelings of inequality.
- Racism and stereotypes prevent diagnosis.



INTERPRETERS

- Family members have language limitations and bias.
- Service users feel embarrassed.
- Professional interpreters can inhibit rapport.
- Professional interpreters should be trained in process.



3. What did we find?

- Found **15 studies** providing barriers, facilitators, or both.
- Ten papers on **stroke**, 3 on **epilepsy**, 1 on **chronic fatigue syndrome** and 1 on **multiple sclerosis**.
- African Caribbean and South Asian individuals expressed views in 9 papers each.

4. How did we find it?

- Searched 6 databases for any **qualitative study on British ethnic minorities' views and experiences of neuropsychological services**.
- Studies were eligible if they included ethnic minority services users, their carers, and staff that worked with them, and described at least one barrier or facilitator.
- Data was extracted and synthesised to form **6 themes**.

5. What can we conclude?

- Themes highlighted gaps at different stages of the service pathway from **initial access to diagnosis to treatment**, with remaining themes prevalent across **entire pathway**.
- This is the first review to explore barriers and facilitators to accessing neuropsychological services in any context.
- Themes indicate what future research should focus on.

6. References

- Office for National Statistics, National Records of Scotland, Northern Ireland Statistics and Research Agency (2016).
- Lievesley, N. (2010). The future ageing of the ethnic minority population of England and Wales.
- Evandrou, M. (2000). Social inequalities in later life: the socio-economic position of older people from ethnic minority groups in Britain
- Chaturvedi, N. 2003. Ethnic differences in cardiovascular disease.
- Kenning et al. (2017). Barriers and facilitators in accessing dementia care by ethnic minority groups: a meta-synthesis of qualitative studies
- Dunning, G. & Teager, A. (2020). An evaluation of ethnicity in a neuropsychology outpatient department.
- Department of Health. (2007). Department of Health National Stroke Strategy.
- Ramadan et al. (2018). Incidence of first stroke and ethnic differences in stroke pattern in Bradford, UK: Bradford Stroke Study
- Bayliss et al. (2014). Diagnosis and management of chronic fatigue syndrome/myalgic encephalitis in black and minority ethnic people: a qualitative study
- Hamdy et al. (2007). Ethnic differences in the incidence of seizure disorders in children from Bradford, United Kingdom
- Pham et al. (2018). Trends in dementia diagnosis rates in UK ethnic groups: analysis of UK primary care data