CROSS-CULTURAL DEMENTIA DIAGNOSIS

Dr Miranda Say
Clinical Psychologist
Tower Hamlets Memory Services
Overview

• Why is cross-cultural dementia diagnosis an important topic?
• Why are language and culture factors so key in dementia diagnosis?
• How do we best work to provide culturally-appropriate dementia assessment and diagnosis?
Why is cross-cultural dementia diagnosis an important topic?

- UK population is aging
- Dementia costs UK£23 billion a year – will increase in time
- People from BME groups form increasing % of older adults
  - People who migrated to UK in 50s, 60s and 70s now older adults
Increase in BME in UK 2001

- White: British, 87.32%
- White: Irish, 1.23%
- White: Other White, 2.64%
- White: Other White with Black Caribbean, 0.46%
- White: Other White with Black African, 0.15%
- White: Other White with Asian, 0.37%
- White: Other White with Other Ethnic Group, 0.3%
- Asian or Asian British: Indian, 2.01%
- Asian or Asian British: Pakistani, 1.39%
- Asian or Asian British: Bangladeshi, 0.55%
- Asian or Asian British: Other Asian, 0.47%
- Black or Black British: Black Caribbean, 1.09%
- Black or Black British: Black African, 0.95%
- Black or Black British: Other Black, 0.19%
- Chinese or Other Ethnic Group: Chinese, 0.45%
- Chinese or Other Ethnic Group: Other, 0.43%
Increase in BME in UK 2007

White British (84.3%)

15.7%
Increase in BME in UK 2016

White British, 78.57%

- White British, 78.57%
- White Irish, 0.88%
- White Other, 4.28%
- Mixed - White / Black Caribbean, 0.97%
- Mixed - White / Black African, 0.38%
- Mixed - White / Asian, 0.89%
- Mixed - Other, 0.79%
- Indian, 3.13%
- Pakistani, 2.29%
- Bangladeshi, 0.98%
- Other Asian, 0.84%
- Black Caribbean, 1.24%
- Black African, 2.14%
- Other Black, 0.25%
- Chinese, 1.16%
- Other, 1.21%
Increase in BME in UK 2026

White British, 74%

26%

- White British, 74.27%
- White Irish, 0.71%
- White Other, 4.92%
- Mixed - White / Black Caribbean, 1.27%
- Mixed - White / Black African, 0.51%
- Mixed - White / Asian, 1.19%
- Mixed - Other, 1.07%
- Indian, 3.81%
- Pakistani, 2.79%
- Bangladeshi, 1.24%
- Other Asian, 1.02%
- Black Caribbean, 1.33%
- Black African, 2.76%
- Other Black, 0.29%
- Chinese, 1.48%
- Other, 1.58%
Increase in BME in UK 2051

White British, 64%

36%
Why is this issue important?

- Culturally-appropriate diagnosis and care (NICE)
- Dementia profiles differ depending on BME group
  - Onset younger (early-onset dementia 2% national rate, 6% BME rate)
  - Getting diagnosis later in course of disease
  - Greater incidence of vascular dementia
- BME coming to services later at ‘crisis point’
  - Stigma
    - Dementia as ‘madness’ - no word for dementia in most South Asian languages (Azam, 2007)
    - Dementia may be seen as punishment, e.g. reincarnation - being punished for past life (Mackenzie, 2006)
  - Lack of awareness of dementia (Adamson, 2001)
    - Cognitive decline and withdrawal perceived as ‘normal ageing’ (Seabrooke & Milne, 2009)
  - Poor literacy, low level education, minimal English: less access to information and services
  - GPs’ assumptions
  - Insufficient signposting and information available
    - “A battle in which they were constantly fighting to receive information, advice and practical assistance” (Lawrence, 2008).
Model of BME coming to services later

- Assume nothing can be done to help
- Experience dementia as normal ageing
- Low awareness, understanding
- Bias/prejudice of clinician
- Difficulty accessing services
- Stigma
- Language, literacy, isolation
- Crisis point, ‘patient’ unwell, delayed treatment, carer stress
Why is this issue important?

• BME coming to services later at ‘crisis point’
  • Missing out on care, support and treatment (pharmacological and non-pharmacological)
  • Carers missing out on support
  • Person missing out on active involvement in decisions about their own future care (advanced decision making)
Role of language and culture factors in dementia assessment and diagnosis

• Impact how dementia is experienced, expressed, communicated (e.g. poor awareness of dementia, not understanding what is happening - fear)

• Impact how family manage and navigate challenges associated with dementia (e.g. dementia perceived as ‘madness’, fear of ‘contamination’, family excluded by local community)

• Important in diagnostic process of any disease but ESPECIALLY dementia as diagnostic process extra reliant on language:
  • Mood assessment
  • Mental state evaluation
  • Cognitive examination – optimal level of functioning (not only about their weaknesses)
What’s the answer?
Improving access to dementia diagnosis for BME

Multi-faceted approach

- Be mindful of role of culture and language in dementia assessment
- Understand local demographics and risk factors
- Educate community (target stigma, assumptions)
- Educate clinicians and GPs
- Improve the diagnostic tools

*Tower Hamlets as an example*
Improving cross-cultural dementia diagnosis: Be mindful of the role of culture and language in dementia assessment

- Dementia assessment heavily dependent on **linguistic factors**
- Other disease diagnosed solely on pathology results
- Importance of clinical interview to assess mood, subjective memory complaints, mental state
- *More than just a literal translation word for word…*
  - “Dil duk dha”
  - “My heart is hurting”
- *Chest pain? Referral to cardiology?*
  - “I am feeling mentally distressed”
Improving cross-cultural dementia diagnosis:
Be mindful of the role of culture and language in dementia assessment

• Different **cultures** express mood and memory problems in different ways

• Not just BME; also White British – e.g. East Enders: ‘war generation’ v ‘baby boomers’). More than just the words we use. Eg

  • “Stiff upper lip” – less likely to express feelings of sadness and despair?
  • Some cultures will somatise (e.g. my head hurts) to express sadness or memory problems.
  • Behaviour perceived as challenging in one culture and not another.
  • Abnormal experiences perceived as pathological in one culture and wisdom in another.
Improving cross-cultural dementia diagnosis:
Be mindful of the role of culture and language in dementia assessment

• Describing symptoms of dementia is even more tricky when someone is from a culture that has a poor understanding of dementia, so the terminology is not as well built into their language

  • Listen beyond the words the person is using

• Aware of being ethnocentric in our approach
  • Not every culture places same value on Western ideals and education
    • Eg not all interpret orientation in the same way…
Understanding local demographics and risk factors

Tower Hamlets

- Bengalis:
  - 40 ‘living’ languages in Bangladesh – subcultures
  - Immigrated at different ages, different decades, impact on identity

- Education and literacy – different testing approaches:
  - Indigenous East Enders education disrupted by war
  - Bengali women less education than men

- Occupation:
  - Roles – men have job, women working in home – how measure functional decline?
Educate community (address stigma and assumptions)

*Improving awareness of dementia and local services so people will seek help earlier.*

- High Muslim population – Mosque is a means of reaching the local Bengalis and communicating accurate information about dementia (meeting with Imams and going to dementia café)
- Leaflets about dementia in different local languages – available in GP surgeries
  - Working to increase chance of people in Bengali community to recognise memory problems in themselves or family members and present to GP
- Work closely with Alzheimer’s society who have Bengali, Somali and Chinese dementia advisors:
  - offer support post-diagnostically
  - work with local community giving accurate information
  - coffee club monthly for Bengali-speaking people with memory problems
  - Somali coffee club for women and men separately
  - talks on local radio
  - website with information in different languages
  - consultation for needs of local Somalis (commissioned by – identifying stigma and other boundaries to accessing services)
“I keep wondering if I’ve done something wrong to cause these problems in my mother. Is it because I divorced my husband and brought shame on the family? Is this our punishment?”

(Daughter of an BME service user in Tower Hamlets)
Educate community (address stigma and assumptions)

“Dementia is memory loss and problems with how you concentrate and speak sometimes. People with dementia can shout and get angry when they don’t feel understood. It’s a brain disease.”

(BME man who went to GP and requested referral to Memory Clinic, after having heard a talk about dementia at the East London Mosque).
Improving cross-cultural dementia diagnosis:
Educate clinicians and GPs

- GP liaison role
- Tower Hamlets Dementia Day/Trust-wide training seminars (e.g. good practice guidelines on working with interpreters)

**Good practice guidelines for clinicians when working with interpreters**

**TO OBSERVE**
- Be sure of client’s language, dialect and country of origin before booking interpreter; check if there are gender issues for the client.
- Brief interpreter before session (at least 15 minutes before first session)
- Explain your method of work and expected outcome to interpreter
- Let interpreter know if you will be using any specific terminology
- Introduce yourself and interpreter. Think how you will manage beginnings and endings.
- Set the ground rules including confidentiality and the fact that everything spoken in the room will be translated
- Arrange seating so that everyone can see each other
- Clarify that you, the clinician, have ultimate responsibility for the session. It is necessary that the interpreter feels able to trust you to hold that responsibility.
- Speak directly to the client.
- Be aware of cultural differences.
- Manage well-meaning family members who may try to interpret on top of or at the same time as the interpreter.
- Ask for clarification if there is a misunderstanding.
- Allow enough time for debriefing at the end.
- Work collaboratively together with the interpreter to form a counselling/therapy team.
- Speak in small chunks so that the interpreter can translate accurately.

**TO AVOID**
- Use of jargon
- Referring to the client in the third person to the interpreter
- Giving responsibility for the session to the interpreter
- Speaking in unmanageable chunks
- Leaving the interpreter in the room alone with the client.
- Having a private conversation with the interpreter in the client’s presence.
- Expecting the interpreter to be a general assistant or to look after the client.
- Interfering with the interpreting process if you have some knowledge of the language (undermining/confusing).
Improving cross-cultural dementia diagnosis: Educate clinicians and GPs

Good practice guidelines for working with interpreters – success of training

- 15 people in audience; 12 responses.

- **How well do you rate your practice of working with interpreter? (10 high)**
  - There was a significant difference in the scores for how they rated their practice before (M=5.9, SD=1.1) and after training (M=7.1, SD=1.6); t (11)=3.39, p < 0.01.

- **How confident do feel addressing issues presented when working with interpreters? (10 high)**
  - There was a significant difference in the scores for how confident they felt in addressing issues when working with interpreters before (M=6.1, SD=1.2) and after training (M=8.1, SD=1.1); t (11)=9.38, p < 0.001.

- Qualitative feedback indicates most valuable parts
  - briefing and debriefing interpreters and how to conduct this
  - clients’ needs and cultural consideration and boundaries

- Suggestions
  - how would a full session work
  - a refresher session after some time
  - training for interpreters (on working in MH and professionalism)
Improving cross-cultural dementia diagnosis: Educate clinicians and GPs

“I kept taking Mum back to the GP worried about her memory and her change in personality. She was getting so distressed, it almost ruined our family. The GP kept telling me that it was normal old age and kept sending us away. Then I saw a leaflet from the Alzheimer’s society. I’d never heard of dementia before then”

(Daughter of a BME woman who was diagnosed with dementia)
Improving cross-cultural dementia diagnosis: Educate clinicians and GPs

“The majority of our service users are BME. They don’t tend to get a lot of dementia – it’s more depression they get, which they express as body pain. We prescribe them an antidepressant for this”

(GP)
Improving cross-cultural dementia diagnosis: Use of appropriate diagnostic tools

- Importance of clinical interview and collateral history
  - Life story and context
    - e.g. I moved to the UK 30 years ago and raised my children by myself after my husband died
  - What was their optimal level of functioning? (may not be comparable to ‘western norms’)
    - e.g. Mum used to be able to cook a 5 course meal for 15 family members, and got us all to school on time, we all got educated and went to university, she negotiated living in a foreign country without dad, she did all the shopping
  - Clear picture of what has changed and when
    - e.g. for the past 6 months, she stays in bed longer, she doesn’t give her opinion in family matters, she put sugar instead of salt in the dinner and couldn’t taste the difference, she forgets her prayers
  - History of family relationships and expectations
    - e.g. Mum was always there for us and looked after us when Dad died. She’s in the UK now and my friends’ mothers are still really independent and are actively involved in family decisions. I don’t know why she isn’t.
    - e.g. she says: in my day, I looked after my mother when she was old. ‘It’s a sign of respect, looking after your parents. I expect to be treated the same way.
  - Any significant events that might have impacted this change?
    - e.g. DIL moves in and starts doing all the housework; son caught using drugs and went to jail; had a delirium or other physical health decline.

Self-report

Observation

Testing
Improving cross-cultural dementia diagnosis:

Use of appropriate diagnostic tools

Inappropriate screening tools (Khan, 2013)

- Western/Anglo-bias: western knowledge, Anglo-linguistic familiarity, education, literacy
- E.g. ACE-III
  - Who was the UK female PM?
  - Harry Barnes, very English address
  - Which picture has a nautical connection?
  - Repeat after me: “no ifs, ands or buts”
  - Read command: Close your eyes
  - List all the words starting with P in a minute
- Underestimate cognitive abilities of BME
  - MMSE false-pos rate (6% WBr, 42% Afro-Carribean)
- BAMSE (Kabir & Herlitz, 2000) – developed on people living in Bangladesh
- MOCA - considered relatively culturally-fair
  - Clock drawing
  - 1-A-2-B-3-C-4-D-5-E
  - Cube drawing
  - Animal naming (rhino)
  - Serial 7s backwards
  - Orientation date/month/year/day/place/city

* A screen versus differential diagnostic sensitivity (differential diagnosis)
  - Normative data
    - Effect of education (often <8 years; 9-12 years; >12 years)
    - Considering women and men together
Improving cross-cultural dementia diagnosis: Use of appropriate diagnostic tools

Need to identify ways to measure a person’s cognitive strengths and weaknesses

- Ensure person understands reasons for any cognitive testing and how the results will be useful to them
- Meaningful orientation and memory questions
  - What are your children/children’s names?
  - Where are we at present?
  - Has Eid day happened recently?
  - Have there been any big recent family events?
- Meaningful verbal memory test
  - e.g. a story that the person can relate to
  - List of words that are relevant to the person (e.g. RAVLT turkey, ranger. Instead eggs, market)
- Observation of person in their home
- Appropriate normative data
  - ?challenges
  - Interpreting with caution
  - Use of cognitive test as outcome for drug trials
Assume nothing can be done to help

Experience dementia as normal ageing

Low awareness, understanding

Bias/prejudice of clinician

Difficulty accessing services

Stigma

Language, literacy, isolation

Crisis point, ‘patient’ unwell, delayed treatment, carer stress
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- Work with Mosque
- Alz Soc Bangla, Somali outreach workers

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- Leaflets in different languages
- Dementia Café at Mosque
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Crisis point, ‘patient’ unwell, delayed treatment, carer stress

- Improved understanding of dementia
- Awareness of services available & how to access

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Education at Mosque on dementia

- Recognise early signs of dementia, not normal aging
- Improved understanding of dementia
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Crisis point, ‘patient’ unwell, delayed treatment, carer stress
Bias/prejudice of clinician

- Education about treatment and services available
  - Information in different mediums (radio, leaflets)

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- In-house training of CMHT staff
- Appropriate assessment
- GP liaison nurse
- Interpreter training

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- Awareness of services
  - Easy to access

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- Early diagnosis
- Treatment
- Care needs identified
- Services provided
- Carer support

- Alz Soc on local Bengali radio
  - Leaflets in different languages
  - Dementia Café at Mosque
Questions?