EAST-Dem study: Encouraging access for South Asians to dementia services

Dr. Naaheed Mukadam
NIHR Doctoral Research Training Fellow
University College London
Acknowledgements

• Co-authors: Gill Livingston, Claudia Cooper, Julia Hailstone, Amy Waugh

• NIHR funding: DRF-2012-05-141

• Contact: n.mukadam@ucl.ac.uk @Naaheed_Mukadam
“He wouldn’t sleep at night and then we’d put him in bed, he’d get up and then he’d be calling out for us to help him get back into bed. He’d wake up in the middle of the night and just strip his bed clothes …and say that someone’s trying to get in, someone’s trying to kill him through the window, things like that, hallucinations really. One day he got really aggressive. Normally he’d get angry, he’d shout and then he’d calm down, so I called the GP because I got really scared because he was doing things that he’d never done before like was getting quite violent, he was throwing things about, ”
Dementia: the challenges

- Currently costs the UK £17 billion per year\(^1\)
- Delayed presentation leads to poorer outcomes\(^2\)
- Later help-seeking in ethnic minorities\(^3\)

Black and minority ethnic population in UK

- 15% of the English population
- 39% of the London population.
- Largest minority group South Asian origin
  - 7% of the population in England and Wales
Systematic reviews

• Ethnicity and pathways to care in dementia
  – BME groups less likely to get a diagnosis
  – More likely to get help in crisis

• Interventions to improve detection of dementia or cognitive impairment
  – Some promise from GP education
  – Untargeted leaflets did not work
Method

- **Stage 1: Development**
  - Months 0-12

- **Stage 2: Piloting**
  - Months 13-24

- **Stage 3: Evaluation**
  - Months 25-60
Qualitative study

**Group**
- South Asians only
- Biggest study to date

**Aim 1**
- Explore barriers to help-seeking in more detail

**Aim 2**
- What would encourage earlier help-seeking?
Method

Recruit from community centres and snowballing

Focus groups or individual interviews

Aim for maximum variation sample

NVIVO analysis by two independent researchers

Modification of topic guide

Audio recorded and transcribed

Topic guide based on previous work

Topic guide based on previous work
Results of qualitative study

- 53 participants
- 60% female
- Mean age 57 (range 18–83 years).
- 74% Muslim, 60% of Bangladeshi origin
- 50% with secondary education
- 25% knew someone with dementia
Results

Themes

- Barriers to help-seeking
- Features of educational resource
- Ways to overcome barriers
- Threshold for help-seeking
# Overcoming barriers

<table>
<thead>
<tr>
<th>Barriers</th>
<th>How to overcome them</th>
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</thead>
<tbody>
<tr>
<td><strong>Individual-level</strong></td>
<td>• Memory problems are a physical illness</td>
</tr>
<tr>
<td><strong>Societal level</strong></td>
<td>• Reduce stigma</td>
</tr>
<tr>
<td></td>
<td>• Normalise help-seeking</td>
</tr>
<tr>
<td><strong>Healthcare-level</strong></td>
<td>• Information about help available</td>
</tr>
<tr>
<td></td>
<td>• Address language/literacy issues</td>
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</tbody>
</table>
## Information to include
- Physical cause
- When to seek help
- Benefits of help-seeking
- Help-seeking is part of family role

## Make it relevant
- Use personal story
- Video and written format
- Feature South Asian people

## Use trusted source
- Health service/GP
- Community centre
Piloting

• Draft intervention shown to memory service doctors, media professionals, other dementia researchers and to focus group in community centre
• Feedback to include Sylheti and include testimonial from person with dementia
• Video edited to make final intervention
The intervention
Feasibility cluster randomised controlled trial

Recruitment

Randomisation

Questionnaire post-randomisation and after 3 months

GP practices

My intervention

No additional information

Knowledge about dementia

Feasibility Acceptability Attrition

Attitudes to help-seeking
APEND questionnaire

- Developed from Theory of Planned Behaviour (Ajzen) using 51 South Asian participants
- TPB: Attitude towards behaviour, Subjective norms and Perceived behavioural control affect behavioural intention
- 19 items on Likert scale from 1-7

Julia Hailstone¹,*; Naaheed Mukadam²; Tamsin Owen¹; Claudia Cooper²; and Gill Livingston² (2016) The development of Attitudes of People from Ethnic Minorities to Help-Seeking for Dementia (APEND): a questionnaire to measure attitudes to help-seeking for dementia in people from South Asian backgrounds in the UK. International Journal of Geriatric Psychiatry
DKQ

- Dementia Knowledge Questionnaire
- Scored out of 19
- Tests knowledge about prevalence, aetiology, symptoms of dementia
- Used in South Asians before and found to have difference between groups

Progress so far

- 8 GP practices in and around London recruited
- Independent randomisation
- Modification to protocol – opt-in, vouchers
- One practice delayed mail-out due to admin
Progress so far

- 78 completed initial questionnaires – 41 intervention, 37 control
- Follow-up: 5 left
- 100% acceptable
- Plan to look at APEND questionnaire scores and DKQ
Summary and future plans

• First trial of educational intervention for South Asians
• Seems to be feasible and acceptable
• Possibility of full-scale RCT if seems promising
• Translate to other languages
• Consider other methods of dissemination
Thank you for listening

- Contact: n.mukadam@ucl.ac.uk
  @Naaheed_Mukadam