DOME
Project
Dementia in
Ethnic Minorities

Research Protocol

Developing a toolkit through interviews with memory clinic staff on working with South Asian service users

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DELTA Protocol

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1. Study Information

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1.2 Study Summary

Study Title	Developing a toolkit through interviews with memory clinic staff on working with South Asian service users
Study Design	Qualitative
Study Participants	Memory clinic and memory assessment service staff
Planned Size of Sample	25

1.3 Key Words

cognitive assessment, cognitive examination, cognitive impairment, cognitive test, BME, South Asian, diagnostic accuracy, ethnic minority, ethnic minorities, memory service, non-English, South Asian

2. INTRODUCTION

Background: British South Asians (BSAs) are susceptible for being diagnosed with dementia due to increasing ageing ethnic minorities and South Asians have a higher prevalence of diseases associated with dementia. BSAs referral to memory clinic services is low and they face barriers accessing memory clinics and the diagnostic process.

Aims: Develop a toolkit to improve BSA access to memory services and dementia diagnosis. This will have culturally adapted materials for BSAs translated into Urdu, a South Asian language and 4th most spoken in the UK. Materials include a cognitive test validated for Urdu speaking BSAs, staff training on cultural sensitivity and working with interpreters, and service user materials on dementia information and help-seeking. This is funded by the Medical Research Council.

Methods: Research will be with memory clinic staff across the UK, with a purposive focus on memory clinics in the North West. Two rounds of interviews with up to 25 memory clinic staff will investigate their experiences of working with BSA service users. The first round will discuss issues, gaps in staff training and working with interpreters. The second round will discuss addressing issues and ideas for improving BSA access.

3.BACKGROUND

The Office for National Statistics estimates that ethnic minorities make up approximately 14% of the UK population (1). These UK ethnic minorities are at a high risk for receiving a diagnosis of dementia (2, 3). They currently account for 25,000 current diagnoses (4) and this is expected to double by 2026 (5), and increase by seven fold in the next 40 years (6). This trend in dementia diagnosis has been attributed to an increasing ageing ethnic minority population as well as more of this older population now choosing to permanently reside in the UK (7, 8).

British South Asians, who are the UKs largest ethnic minority at 7% of the population, are at a particularly high risk (1). Estimated rates show that British South Asian elderly have the highest prevalence for dementia in the UK in those between the ages of 65 and 79, and second highest in those over the age of 80 (9). This is attributed to higher rates of dementia risk factors in South Asians (10, 11), such as diabetes, heart disease, hypertension and stroke (12). Factors such as significantly higher insulin resistance, calorie intake and rates of obesity contribute to this (11, 12).

Despite this, British South Asian referral rate to health services for dementia, including memory clinics, is low (11, 13, 14). British South Asians are more likely to avail services later into the progression of the disease, missing out on early intervention and medication, and less likely to engage in long term care (15, 16). This is attributed to several barriers in accessing diagnostic assessment, management and support for dementia.

British South Asian communities lack awareness around the causes and nature of dementia, which means they may not recognise early symptoms and only report to services when a point of high risk is reached (10, 14, 15, 17). There is also uncertainty on the process of accessing services (14, 15, 18). Symptoms of dementia may also be associated with other causes or mistaken for regular ageing (10, 11, 13-17, 19). Culture and stigma within British South Asian communities leads to an emphasis on family based care without outsider intervention (13, 20). Alongside a sense of responsibility and duty, this can also be motivated by fear of judgement and being shamed within their communities (11, 13, 14, 16, 17, 21). Spiritual beliefs may also attribute dementia to destiny or a punishment from God (10, 15, 18).

Language and cultural barriers also prevent British South Asians from accessing services to receive a proper diagnosis and treatment (13, 18). These barriers impact the diagnostic process, including the administration of cognitive tests, which when not matched for language and culture, result in higher rates of false positive and false negative scoring (failing to detect dementia or misdiagnosing with dementia respectively) (16).

British South Asians also face an inability to understand materials and resources on dementia information and help seeking as there is a lack of relevant literature available at memory clinics that is designed for or features South Asians (13, 15). British South Asians also find that their cultural and religious beliefs are not always met or respected, with qualitative research exploring reports of dissatisfaction, lack of cultural appropriateness and racial discrimination (13, 16, 21).

When this occurs, British South Asians become reluctant to use these services again and prevent others within their communities from accessing them (16). British South Asians are thus prevented from entering the memory clinic pathway and availing the full potential an early diagnosis, forming a care plan, and being signposted to further aid for relevant treatment, management and support.

We hypothesise that improving British South Asian recognition and acceptance of dementia and rate of referrals to memory clinics is only beneficial if the memory clinics themselves are accessible. Similarly, accounting for British South Asians in terms of the services for treatment, management, and support is only beneficial if British South Asians are able to access the memory clinics that will signpost them to these services.

Therefore, this research aims to improve British South Asian access to memory clinics, in accordance with the National Institute for Health and Care Excellence (NICE) Guidelines (22) propositions on dementia services and the NHS Accessible Information Standard (23). This will focus on the diagnostic assessment procedure, improving the relationship between memory clinic staff and service users, and providing understandable and accessible dementia information.

By taking the above barriers into consideration, we propose developing a toolkit that accounts for British South Asians in terms of educational and correspondence materials, and staff training. As the British South Asian population is a heterogeneous ethnic minority with several languages (13), we are translating all contents for service users into Urdu, a popular South Asian language which is also 4th most spoken in the UK (1).

4. AIMS

To develop a toolkit to improve Urdu speaking British South Asians' access to memory services and receiving an accurate and timely dementia diagnoses.

This toolkit will have materials that have been translated into Urdu and culturally adapted for British South Asians. Materials in such a toolkit will include a cultural sensitivity training programme for staff and materials for Urdu speaking service users.

5. METHODS

This research has been approved the University of Manchester Research Ethics Committee (Ref: 2020-10228-17254).

Design

A qualitative research study of the experiences of North West memory clinic staff in working with British Urdu speaking service users through the use of two rounds of audio recorded video interviews.

Inclusion and Exclusion Criteria

All participants will be:

- Currently working as staff for a memory clinic in the UK
- Over the age of 18 years
- Fluent in speaking and reading English
- Be able to give informed consent

Sample Size

In accordance with suggestions in literature for achieving thematic saturation, we will recruit up to 25 participants, or until no new data emerges.

Materials

Participant materials will include an information sheet, a consent form, and a demographics sheet. For the study, we will use a semi-structured interview schedule.

Site

Interviews will be conducted via Zoom at a date and time of the participant's choice.

Recruitment

Participants will be recruited through online convenience sampling via adverts posted on social media such as Facebook, Twitter, Instagram and LinkedIn. Potential participants will also be contacted through a mailing list that was formed through one of our research groups' events with memory clinic services' staff.

Participants will also be recruited through purposive sampling. Flyers and the participant information sheet will also be circulated to managers of memory clinics and memory assessment services across the North West, and they will be asked to circulate these among their staff.

Potential participants will be able to contact the research student via email or telephone if they are interested in participating. The research student will email the potential participant a copy of the information sheet and they will be given 24 hours to decide if they wish to participate.

If the potential participant agrees to participate they will be emailed a copy of the consent form and the demographics sheet to fill in and return. A date and time for the first interview will also be scheduled via email.

Procedure

The interview will be held via Zoom on the agreed date and time and will be audio recorded via Zoom. The participant will be informed that their audio will be recorded through the participant information sheet and they will also receive an alert on Zoom letting them know they are being recorded.

In the interview participants will be asked if they have any questions and these will be explained if needed. The schedule will be used to ask the participants about their experiences working with BSA service users including issues and barriers that exist, current protocol for addressing mentioned issues, current staff training on cultural sensitivity and the use of interpreters, experiences addressing issues and opinions regarding what should be provided to staff to counter them.

The interview will be up to 1 hour long, audio recorded and transcribed verbatim.

Analysis

Transcripts will undergo a reflexive thematic analysis to identify themes relating to barriers to access and issues memory clinic staff face in facilitating British South Asian services, and potential solutions. There will be a focus on data pertaining to cultural sensitivity and employing interpreters, but new themes may also be identified. Thematic analysis will be conducted using NVivo Software and charting within Excel.

Outcomes

Qualitative data from these interviews may inform the development of a training programme for memory clinic staff.

6. ETHICAL CONSIDERATION

1. University of Manchester Research Ethics Committee approval has been obtained.
2. Participants will be given informed and written consent. This will be after receiving both a verbal and written introduction to the research. They will also

be given opportunities during recruitment and before the study begins to ask questions.

3. Confidentiality will be maintained by assigning all participants a study code and this will be used in the place of names on all data collected. All transcribed data will be anonymised, removing identifiable information such as names or places.
4. Digital recordings of interviews will be stored initially on the University of Manchester's secure server (the research student's P-Drive) and deleted once they have been transcribed. There will be only digital copies of data which will be stored on the P-Drive for the duration of the study, and shared with the academic supervisor via Dropbox for Business. After the study is completed all data will be transferred to the university approved Research Data Storage (RDS) and stored for up to 5 years, after which it will be deleted.
5. Should a participant become distressed the participant will be asked if they would like to take a break, or if they would like to continue at a later date. A distress protocol has been developed that allows the research student to take additional steps in comforting the participant, asking if they would like to withdraw from the research, and offering the opportunity to speak to the Academic Supervisor (Dr. Waquas Waheed) via phone, as he is a consultant psychiatrist.
6. Should a participant become distressed the participant will be asked if they would like to take a break, or if they would like to continue at a later date. A distress protocol has been developed that allows the research student to take additional steps in comforting the participant, asking if they would like to withdraw from the research, and offering the opportunity to speak to the Academic Supervisor (Dr. Waquas Waheed) via phone, as he is a consultant psychiatrist.

7. DATA MONITORING AND QUALITY ASSURANCE

The academic supervisor and co-supervisor will be monitoring the project and will conduct meetings with the research student.

The study will be subject to the audit and monitoring regime of the University of Manchester.

8. PEER REVIEW

The research has been assessed by the research and supervisory team and by the funding body (Medical Research Council). The research has also been assessed by the University of Manchester Research Ethics Committee (UREC).

9. STATEMENT OF INDEMNITY

The University arranges insurance for research involving human subjects that provide cover for legal liabilities arising from its actions or those of its staff or it's supervised students (subject to policy terms and conditions).

10. PUBLICATION POLICY

Results of the research will be reported and disseminated through peer reviewed scientific journals, conference proceedings, publication on websites, other publications, a PhD thesis, public engagement information events and a toolkit for memory clinics to improve British South Asian access and diagnosis.

To ensure anonymity of participants when publishing research results, names will be substituted with study codes and contextual data and personal details will be avoided to prevent identification.

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