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Understanding dementia among UK Bangladeshi: a synthesis of qualitative research on South Asian people with dementia

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Review question(s)

Through meta-aggregation clearly identify the gaps in the literature and produce new knowledge and understanding of the attitudes, perceptions, and beliefs of the Bangladeshi community about dementia and increase awareness and understanding of dementia among Bangladeshi communities in the UK.

What are the ranges of views (perceptions, beliefs, and experiences) about dementia of South Asian immigrants with dementia, their families and carers (formal and informal)?

What are the potential barriers to diagnosis or other factors associated with missed opportunities for dementia diagnosis and accessibility to services for South Asian immigrants?

What are the differences and similarities in the understanding of dementia between the South Asian immigrants' countries of origin and countries of settlement?

Are there any specific views about and experiences of dementia of UK Bangladeshi immigrants with dementia, their families and carers (formal and informal) which are different from other South Asian immigrants in the UK?

Searches

The search strategy aims to find both published and unpublished studies. Published literature will be searched electronically in the following databases: Web of Science, MEDLINE, CINAHL, SocINDEX, PsycINFO, British Library EThOS, Joanna Briggs Institute. The search for unpublished studies will include contacting experts in the field: Age UK, Alzheimer Europe, Alzheimer Scotland, Alzheimer's Research UK, Alzheimer's society, Alzheimer's Disease International, British Medical Association, Dementia Friends, MIND, Rethink Mental Illness, Time to Change. A three-step search strategy will be utilised in this review. An initial limited search of MEDLINE and CINAHL will be undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies. The search will not be limited by nationality or language, the search strategy aims to find published studies in English and non-English as well. Non-English articles will be translated into full text articles where possible. Studies published since 1950 will be considered for inclusion in this review.

Types of study to be included

This review will consider interpretive studies that draw on the experiences of South Asian people with dementia including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research. In the absence of research studies, other text such as opinion

papers and reports will be considered.

Condition or domain being studied

The number of patients with dementia in the UK is estimated to be 821,884, representing 1.3% of the UK population (Luengo-Fernandez, Leal, & Gary, 2010). However, there are no exact figures of the prevalence of dementia in ethnic minority groups in the UK. Estimates range from 11,000 (Year 2004) to 15,000 (Year 2009) people from black and minority ethnic groups with dementia (or 1.7% of all people with dementia in the UK (Dementia Advocacy Network, 2009; Department of Health, 2009). It is acknowledged that this figure is likely to be a considerable under-representation and set to rise because the large number of South Asian migrants who came to the UK between 1950 and 1970 for work are now ageing. Dementia in the South Asian ethnic groups has been characterized as a 'hidden population with a hidden problem' (Brownlie, 1991; Wilkinson, 2002). South Asian people with dementia are a considerably marginalized group for which the existing literature is limited (Wilkinson & Bowes, 2003). Among all the South Asian ethnic groups, the Bangladeshi population is one of the fastest growing minority groups and yet they have the lowest education rates and experience disproportionately high rates of unemployment, overcrowding; the poorest socio-economic and worst health positions than the overall population in the UK (Garbin, 2005; ONS, 2002). Despite the increasing number of older people from the Bangladeshi community, it appears that little or no specific research has been carried out on their understanding of dementia. However, there seems to be some evidence that research has been carried out on South Asian people as opposed to the Bangladeshi community alone. It is anticipated that the synthesis will provide a narrative of culturally sensitive issues in order to inform services about a growing immigrant population who are few or hard to reach. The main outcomes of this synthesis will be attitudes, beliefs and perceptions of patients, carers and health professionals on the barriers to facilities as well as perceptions of what is helpful (or not) and why.

Participants/ population

This review will consider studies that include:

(a) participants who are South Asian immigrants including Bangladeshi people aged 60 years or greater, with a self or carer reported diagnosis of dementia. Participants from all settings will be included (e.g. nursing homes, dementia clinics, community settings);

(b) formal and informal caregivers of South Asian and Bangladeshi people with dementia living in their own countries.

Exclusion: Non-South Asian participants with dementia (and their carers), South Asian participants less than 60 years old with dementia (and their carers) will be excluded from the study.

Intervention(s), exposure(s)

From within the above identified participants, this review will consider studies that investigate:

(a) What are the experiences of older people from South Asian communities, with dementia and their carers?

(b) What are the negative impacts or other factors associated with missed opportunities for dementia diagnosis in the South Asian communities?

(c) What are the barriers attached to the service support for South Asian people with dementia and their families/carers?

(d) What are the differences and similarities in the understanding of dementia between the South Asian immigrants' countries of origin and countries of settlement?

(e) Are there any specific views about and experiences of dementia of UK Bangladeshi immigrants with dementia, their families/carers (formal and informal) which are different from other South Asian immigrants in the UK?

(f) What are the key gaps in current knowledge relevant to these older persons from South Asian communities, which targeted future research could address?

Comparator(s)/ control

Not applicable.

Context

Communities and primary care based settings.

Outcome(s)

Primary outcomes

It is hoped that this review will identify themes embedded in the qualitative studies that describe experience of South Asian immigrants who have dementia and their carers, families in the United Kingdom.

Secondary outcomes

Secondary outcomes for caregivers will be included as caregiver's burden, dementia stress and health, physical health, economic impact and quality of life.

Data extraction, (selection and coding)

Two researchers will independently review all potentially relevant articles to determine whether an article fulfilled the inclusion criteria by using the JBI appraisal tool JBI-QARI (Joanna Briggs Institute - Qualitative Assessment and Review Instrument). Data extraction will use the EPPI-Reviewer 4: systematic review software and JBI-QARI software, to keep track of studies during the review. These tools will record the bibliographic details of each study considered by the review, where studies were found and how, reasons for their inclusion or exclusion, descriptive and evaluative codes and text about each included study, and the data used and produced during synthesis (Rees, Oliver, Woodman, & Thomas, 2011). Two reviewers (MH & AD) will independently assess the data against the inclusion criteria at abstract stage, discussion regarding differences will follow and agreement prior to data extraction. Where agreement cannot be reached a third reviewer may be involved (YH/KJ).

Risk of bias (quality) assessment

Qualitative papers selected for retrieval will be assessed by two independent reviewers (MH, AD) for methodological validity prior to inclusion in the review using standardised critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer (YH/KJ).

Strategy for data synthesis

Qualitative research findings will be pooled, where possible, using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their quality, and categorising these findings on the basis of similarity in meaning. These categories are then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesised findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form.

Analysis of subgroups or subsets

The synthesis of this meta-aggregation qualitative approach will explore the experiences of the following subgroups:

- a) Older Bangladeshi (>60) with dementia, and
- b) Formal and informal carers of Bangladeshi older people with dementia.

Dissemination plans

The completed synthesis of this qualitative research will form part of a PhD thesis and will be published in the JBI Library of Systematic Reviews.

Contact details for further information

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Conflicts of interest

None known

Other registration details

The Joanna Briggs Institute

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England

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Subject indexing assigned by CRD

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Great Britain; Humans

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Stage of review at time of this submission

Preliminary searches

Started

Yes

Completed

Yes

Piloting of the study selection process

Yes

No

Formal screening of search results against eligibility criteria

Yes

No

Data extraction

Yes

No

Risk of bias (quality) assessment

Yes

No

Data analysis

No

No

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