

Understanding Dementia among the Bangladeshi community in England

Background: Despite a growing ageing South Asian immigrant population in England, little is known about the experiences of diagnosis and care for those living with dementia. Dementia in the South Asian ethnic groups has been characterized as ‘a hidden problem in a hidden population’ within a considerably marginalized group and for which the existing literature is limited.

Purpose: Worldwide, there have been a number of small, qualitative studies among South Asian people living with dementia. Consolidation through qualitative meta-synthesis can: (1) merge the experiences of a number of participants across studies to reveal fresh insights, (2) provide an enhanced understanding of the experience, (3) reduce replication by identifying gaps in current literature and (4) generate new research questions.

Methods: Following a systematic search of the literature, included qualitative studies were assessed by two independent reviewers for methodological quality. Data were extracted using the Qualitative Assessment and Review Instrument (QARI) developed by The Joanna Briggs Institute (JBI). Findings were synthesized using JBI approach of meta-synthesis by meta-aggregation.

Findings: Synthesis from thirteen papers were aggregated into six meta-synthesis themes as: (1) Poor awareness and understanding of dementia, (2) Permeated stigma and shame, (3) Burdens or blessings of family caring? (4) Healthcare decision making power within family, (5) Food as coping mechanisms, (6) Attitudes to current and future provision of dementia care services.

Conclusions: One research gap was identified using the population framework where despite increasing number of older people from the Bangladeshi community in England, little or no specific research has been carried out on their understanding and management of dementia. Yet, Bangladeshis have higher risk of developing type 2 diabetes and heart disease; both are important indicators of developing dementia in old age. In addition, in England they have lowest education rates, highest smoking rates, poorest socio-economic and worst health positions risk factors for underdiagnosis, poor access to healthcare services and support. The synthesis (1st part) findings will inform the research questions of the 2nd and 3rd parts of the study; focus groups interviews with adults of Bangladeshi origin people without dementia of all ages (18+ years, with no upper age limit) across all socio-economic backgrounds and semi- structure qualitative interviews with Bangladeshi older people living with dementia, their family carers/ significant others respectively.