

Patient Focus: Living with dementia in South Asian populations, issues and challenges for patients and caregivers



A **patient-led summary** exploring the evidence for awareness and understanding of dementia within the South Asian population, focusing on patient/caregiver issues and challenges.

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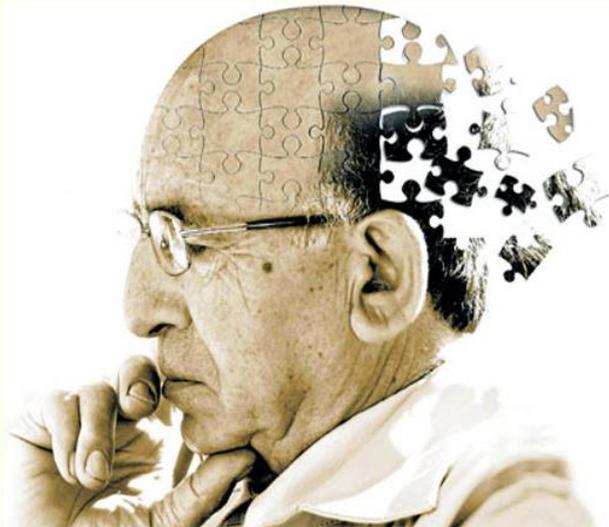


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Patient Focus points:

- **A better understanding of dementia, and the support available, is vital in South Asian communities**
- **Cultural perceptions can impact on the receipt of care for life-changing illnesses like dementia**
- **Further research is needed on how to support people living with dementia in South Asian populations**

Background to Patient Focus

Little was known about the awareness and understanding of dementia within the South Asian community including cultural challenges and perceptions. To explore this area further, a group of researchers conducted a *'qualitative synthesis'* (a review of research evidence that uses methods such as interviews) to understand the lived experiences of dementia within the community (Hossain et al. 2020). This patient-led summary explores the process and results of the review with a patient focus, identifying the impact for patients, caregivers and health services.

What methods were used to undertake the review?

Hossain and colleagues searched electronic databases for research evidence (studies) that reflected lived experiences and perceptions of dementia in the South Asian community. This included research conducted anywhere in the world, but translatable into English. Studies were chosen for inclusion in the review by two reviewers, with a third reviewer involved if there were any disagreements. Findings from the included studies were then grouped together and analysed by identifying similar or re-occurring themes.

What were the findings of the review?

The review found 2,515 papers that were relevant to the topic. Of these, 13 studies met the requirements for inclusion in the 'qualitative synthesis'. Most of the studies included were from the UK with participants from an Indian or Pakistani background. The primary means of collecting information for the study was through interviews with family caregivers, health care professionals and a small number of patients. Findings were combined into three themes: ***poor awareness and understanding of dementia, experience of family caregiving and attitudes towards dementia care provisions.***

Key points from each theme can be seen in the key results table:

Key results: identified themes and key points	
Themes	Key points
Poor awareness & understanding of dementia within the South Asian community	<ul style="list-style-type: none"> ▪ Early symptoms of dementia were perceived as normal ageing or related to other health problems such as diabetes. ▪ Cultural beliefs informed an understanding about dementia that ranged from '<i>a punishment from God</i>' to a '<i>deepening of one's relationship with God</i>'. ▪ Stigma and embarrassment were associated with dementia and not being able to provide care within the family home.
Experience of family care giving within the South Asian community	<ul style="list-style-type: none"> ▪ An 'obligation' to care for loved ones was felt with pressures on female family members to provide care. ▪ Challenges of family care can have a detrimental effect on mental wellbeing including upset or embarrassment from managing personal hygiene. ▪ Prayer and faith in God were used by caregivers as coping mechanisms with little support being requested from healthcare systems.
Attitudes towards dementia care provisions in the South Asian community	<ul style="list-style-type: none"> ▪ Families delayed seeking help and diagnosis from a GP due to a lack of knowledge around symptoms, fear and stigma. ▪ Help was often sought from family and friends in the first instance with diagnosis finally obtained following a different medical problem. ▪ There were concerns about culturally in-appropriate care homes including the provision of personal care needs by the opposite sex, or young staff. Searching for culturally appropriate care had negative connotations due to acceptance of traditional family caregiver roles rather than seeking help.

How well was the review conducted?

Researchers from the University of Central Lancashire (Poole et al. 2021) undertook a RaCES project (Rapid Conversion of Evidence Summaries) to explore how well the review was conducted using a '*critical appraisal tool*', a check-list of questions designed to appraise a review of evidence for its methods and presentation of findings. They found that all the criteria were met and despite some limitations (for example, some studies included other communities), the synthesis was found to be a satisfactory and accurate summary of the evidence.

What do the findings mean for patients and caregivers?

Poole and colleagues considered the findings of the review for patients and carers including what could be done to improve the issues surrounding awareness and understanding. They highlighted the following:

- A need for better education and understanding of dementia in the family and community. Information resources should be language appropriate and describe what dementia means given there is not an equivalent term in South Asian language. Working with leaders of the community may help to produce appropriate information.
- Improved understanding is required for both healthcare professionals and members of the community, including culturally specific issues and challenges surrounding dementia. Internet based support or training to improve understanding may be useful for caregivers and reduce some of the issues around seeking help from others outside of the family. More research is needed on these types of support within the south Asian population.
- Further research is also needed within other minority ethnic groups to explore their experiences of dementia in a challenging area for both patients and their families.

References:

Hossain M, Crossland J, Stores R, Dewey A, Hakak Y. Awareness and understanding of dementia in South Asians: a synthesis of qualitative evidence. *Dementia*. 2020;19(5):1441–1473.

Poole C, Harrison J, Hill J. Understanding dementia in South Asian populations: an exploration of knowledge and awareness. *British Journal of Neuroscience Nursing* 2021;17(4).

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