

Caring across cultures: An exploration of the lived experiences of South Asian family carers of people living with dementia in Scotland

Introduction/background

Family carers are key in supporting the physical and psychological well-being of family members living with dementia, yet often, they are the 'invisible' individuals who remain in the background. While there are some studies highlighting the impact of family care amongst older adults and ethnic minority communities, there are knowledge gaps about the lived experiences and support needs of Black, Asian and Minority Ethnic (BAME) family caregivers in Scotland. There is particularly scant knowledge about the lived experience of South Asian family carers of people living with dementia in Scotland.

Study aim

This project explored the lived experiences of carers involved in caring for family members living with dementia in the South Asian community in Scotland. The project's main objectives were: to explore the motivations and experiences of becoming a family carer of a person living with dementia; identify the challenges and enablers faced by carers in their caring role; and explore what services and support carers felt would improve their caring experience and create a more positive environment of caring for those living with dementia.

Methods

The study recruited 12 South Asian family carers from seven local authority areas. The research team recruited through several community and religious organisations, as well as their own networks. The sampling method used was convenient. Semi-structured audio-recorded interviews were carried out in private community spaces convenient and accessible for the family member.

Findings

The findings revealed that there was a multitude of interconnected factors that influenced the person to take on the role of family carer for a person living with dementia among the South Asian community. These included religious, spiritual, cultural and moral considerations. Carers identified multiple challenges in their caring role which centred around the significant impact on their emotional well-being, the physical toll of caring and difficulty accessing culturally competent formal care. Carers felt that a number of coping strategies enabled them to continue in their role, these included a strong adherence to religious and spiritual beliefs, attachment to cultural values, as well as adopting and adapting the approaches to care. Carers felt that carer training and education, emotional support and better access to culturally sensitive support and service would help improve the caring experience and create a more positive environment for people living with dementia.

Conclusion

This small-scale study revealed how an interconnected blend of cultural, religious, and moral considerations impacted on the experiences and challenges of South Asian family carers of

people with dementia. The findings illustrated the need for culturally sensitive information support, training and education for them and formal carers.

Recommendations

- To make culturally sensitive family carer training and education available to support ethnic minority family carers understanding of dementia and learn some of the practical skills associated with caring for a person with dementia.
- Organisations providing emotional support and befriending services for minority ethnic family carers should ensure it is culturally sensitive.
- To make available culturally sensitive training and education for health and social care professionals and care services.
- Ethnic minority, religious and community organisations have a role to play in supporting ethnic minority family carers of people living with dementia.

If you would like more information about this study, please do not hesitate to contact the project lead:

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