

Lived Experience of Dementia in the New Zealand Indian Community: A Qualitative Study with Family Care Givers and People Living with Dementia

Abstract:

Currently, there are estimated to be 70,000 people living with dementia in Aotearoa, New Zealand (NZ). This figure is projected to more than double by 2040, but due to the more rapid growth of older age groups in non-European populations, prevalence will at least triple amongst the NZ Indian population. The impact of dementia in the NZ Indian community is currently unknown. The aim of this study was to explore the lived experiences of NZ Indians living with dementia and their caregivers. Ten caregivers (age range: 41–81) and five people living with mild dementia (age range: 65–77) were recruited from a hospital memory service and two not-for-profit community organisations in Auckland, Aotearoa, NZ. Semi-structured interviews were conducted by bilingual/bicultural researchers and transcribed for thematic analysis in the original languages.

Dementia was predominantly thought of as being part of normal ageing. Getting a timely diagnosis was reported as difficult, with long waiting times. Cultural practices and religion played a large part in how both the diagnosis and ongoing care were managed. Caregivers expressed concerns about societal stigma and about managing their own health issues, but the majority also expressed a sense of duty in caring for their loved ones. Services were generally well-received, but gaps were identified in the provision of culturally appropriate services. Future health services should prioritise a timely diagnosis, and dementia care services should consider specific cultural needs to maximise uptake and benefit for Indian families living with dementia.