

Lived Experience of Dementia in Indian families living in NZ



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BACKGROUND

Dementia services in New Zealand (NZ) tend to be designed for English speaking people. There is little dementia-related data in the Indian Asian population.

AIM

The aim of our project was to describe the lived experience of dementia in Indian families living in NZ.

METHODS

- Participants: people living with dementia (PLWD) and their caregivers, identified through community organisations for senior citizens.
- Semi-structured Interviews (PLWD, caregiver or dyads), conducted in participant homes
- The topic guide included
 - ❑ understanding of dementia
 - ❑ experience of the C
 - ❑ impact on lifestyle
 - ❑ available support services,
 - ❑ any concerns or recommendations
- Interviews were conducted in Hindi, Fiji Hindi, or English, and transcribed verbatim.
- Thematic analysis¹ conducted to identify key themes, and sub-themes.

Table 1. Participant Demographic Characteristics

Parameters	PLWD (n=5)	Caregivers (n=10)
Age, median (range)	74 (65-77)	61 (41-81)
Female, n (%)	1 (20)	6 (60)
Marital status, n (%)		
Married	4 (80)	9 (90)
Widow	1 (20)	-
Divorced	-	1 (10)
Birthplace, n (%)		
India	2 (40)	7 (70)
Fiji	3 (60)	3 (30)
Years lived in NZ, median (range)	11 (10-25)	15 (3-25)
Preferred language, n (%)		
Hindi	2 (40)	5 (50)
Fiji Hindi	3 (60)	3 (30)
English	-	2 (20)

RESULTS

N=15 participants (age range 41-81 years) (Table 1) were interviewed. Five were with dyads and 5 with caregivers of those with moderate to severe dementia.

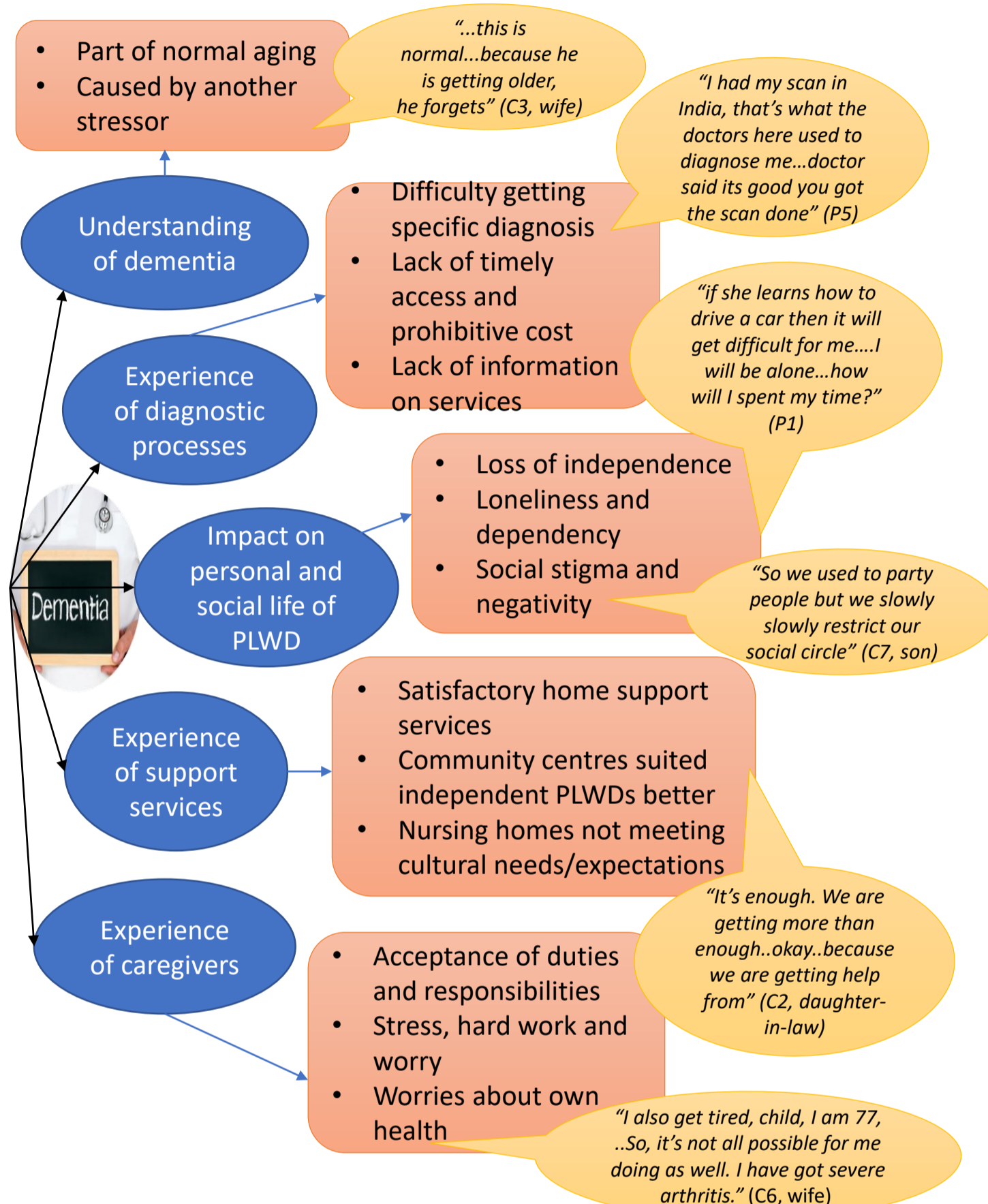


Figure 1. Summary of identified themes, and relevant quotes

CONCLUSIONS

This study is the first exploration of the lived experiences of dementia in the NZ Indian community. Dementia was commonly perceived as a normal part of aging. Challenges included a lack of understanding of diagnosis, and societal stigma, often leading to low utilisation of services (Figure 1). Unmet needs included getting a clear and timely diagnosis, culture specific services, carer support and training. Future healthcare planning for people with dementia and their families should include the development of culturally tailored services. More community awareness campaigns are also needed to improve the knowledge of and reduce the stigma associated with dementia.

REFERENCE

1. Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. The Sage handbook of qualitative research in psychology, 17-37.

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