

Motivations for being informal carers of people living with dementia: 2018 – 2024

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Introduction

Informal caregivers provide essential, unpaid, continuous care that enhances the quality of life for people with dementia and reduces demand on formal care services. This caregiving role, a complex dyadic process, impacts caregivers significantly, highlighting the need to reduce burden and support well-being^{1, 2}. Motivations for caregiving—such as reciprocity, love, duty, marital commitment, and responsibility—shape caregivers' experiences, as identified in Greenwood and Smith's systematic review³. Research also shows that ethnic and cultural differences in perceptions and social values affect caregiver motivations and experiences motivations^{4, 5}.

Objectives

1. Identify and describe the motivations of informal caregivers for individuals with dementia.
2. Examine similarities and differences in caregiving motivations across demographics, ethnicities, and cultures.

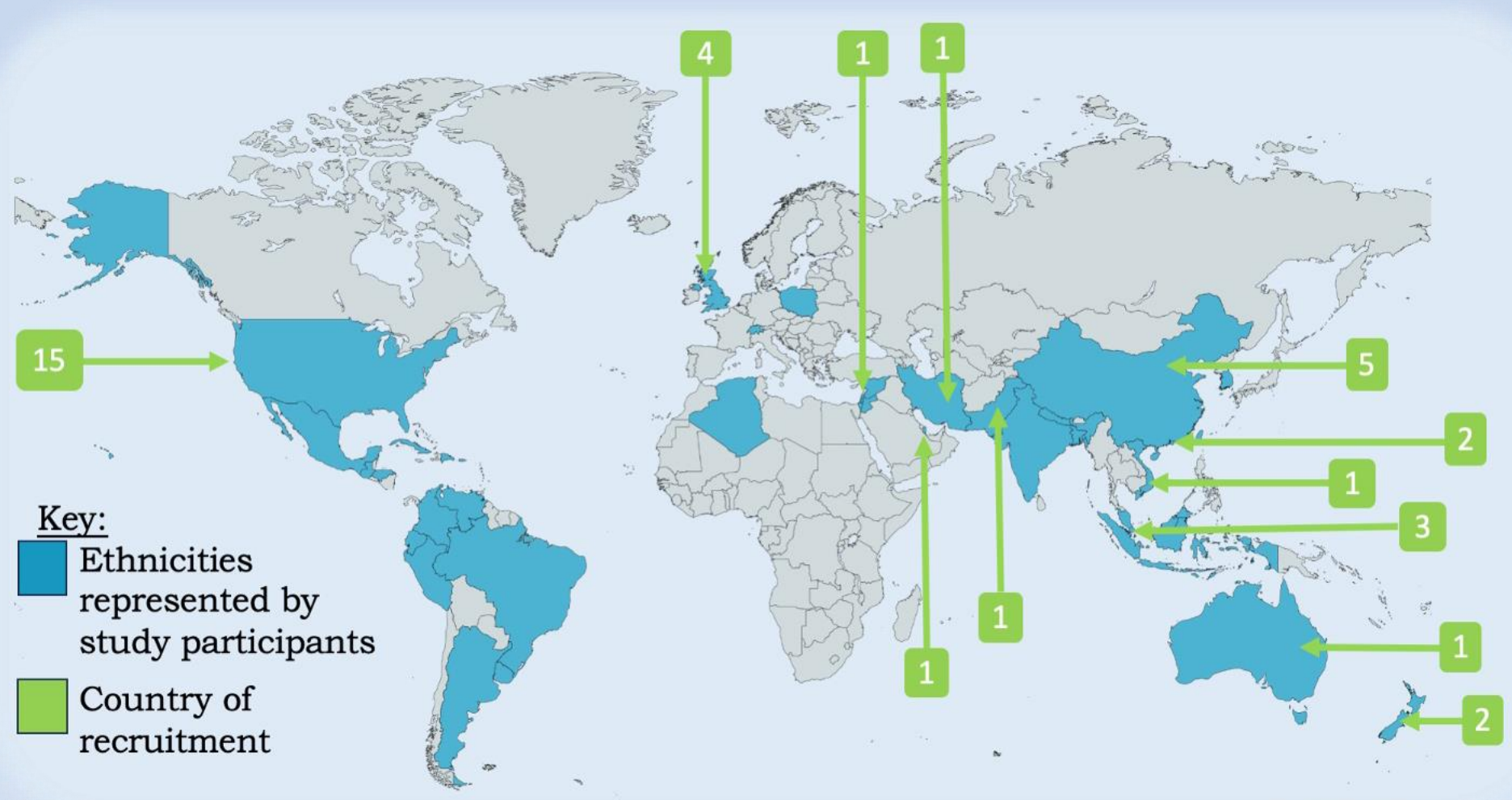
Methods

- The PRISMA guidelines were followed, with six electronic databases searched from August 2018 to January 2024.
- Titles and abstracts were screened using Machine Learning (ASReview) against eligibility criteria.
- Included studies underwent full-text screening, with a subset reviewed in duplicate by two researchers.
- A narrative synthesis was used to thematically analyze caregiving motivators, incorporating extracted quotations and demographic data.

Results

- The initial database search yielded 1,843 articles. After deduplication and screening, 37 studies were shortlisted for inclusion.

Demographics of shortlisted studies



- A total of 871 carers participated in studies, with sample sizes ranging from 7 to 200 per study.
- The majority were female, comprising 607 participants (69.7%), highlighting a greater caregiving burden on women across cultures.
- Adult child carers formed most of the sample 21%, followed by spouse carers 18% and daughters 15%

Discussion

- Caring motivations include familism, traditional beliefs, acculturation, obligation, and fulfillment.
- Barriers to formal support are limited dementia awareness, lack of culturally sensitive care, stigma fears, and quality concerns.
- Motivators are largely consistent across ethnic groups, though cultures with values like Confucianism emphasize caregiving duty more strongly.
- First and second-generation migrants in high-income countries also maintain caregiving traditions.
- While caregiving impacts are universally felt, cultural values shape caregivers' experiences and affect family acceptance of formal support^{9, 10}.
- Further research is needed to develop tailored psychosocial support for ethnically diverse caregivers and reduce family caregiving burdens.