Lived Experience of Ethnic Minority Caregivers Supporting a Family Member With Dementia: A Scoping Review

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Purpose:

Aim: To explore the lived experience of and needs of ethnic minority caregivers supporting a family member with dementia.

Background:

Many countries have an aging culturally diverse population, with increasing long-term conditions including dementia (Rosenthal Gelman 2014; Australian Bureau of Statistics 2016). The impact of cultural heritage on family members caring for a relative has been widely explored (Depp et al. 2005; Coon et al. 2004; Sharlach et al. 2006). Negative outcomes for culturally diverse family caregivers has included an increased prevalence of depression, raised blood pressure and poorer physical and mental health (Siegler et al. 2010; Lee and Farran 2004; Knight et al. 2007). However, there is a need to understand the impact of cultural heritage on the experiences and needs of ethnic minority family caregivers supporting a relative with dementia.

Methods:

Design: Scoping review

A scoping review of current literature was completed: databases searched included: Medline, CINAHL, PsycINFO and PubMed for articles published in English from 1st Jan 2006 to 31st July 2016. The aim of the scoping review was to: map all relevant literature, identify key concepts gaps in the research, sources of evidence to inform practice, inform policymaking and inform future research.

Results:

A total of 14 studies met the eligibility criteria for inclusion in the review. All explored the experiences of ethnic minority family caregivers, and applied qualitative methodology via interview and focus group data collection. Studies were conducted in: USA (n=8), Australia (n=4), England (n=1) and Netherlands (n=1). A meta-synthesis from these studies identified three themes: 1) a lack of information and knowledge 2) an emotional response, and 3) the need to adapt and change.

Discussion:
Ethnic minority caregivers needed timely information to support them and prevent the feeling of trying to navigate services and support ‘without a map’. Information needs to be provided not only in a timely manner, but also in an appropriate format. Family caregivers discussed the emotional difficulty and value of caregiving. A supportive element to enable ethnic minority family caregivers to adapt and change was that of acculturation.

**Conclusion:**

There remains a need for: the provision of timely and appropriate information for ethnic minority family caregivers, including information on: healthcare system and how to access care, social care system and how to access support, dementia skills to care for someone with dementia. There also remains the need to ensure the inclusion of resources to support family caregivers emotionally through the development of culturally including culturally competent health and social care professionals who address the emotional and cultural aspects of impact of caring for a family member with dementia. Lastly, there is a need for specific support to aid acculturation and orientation to a new culture.

**Title:**
Lived Experience of Ethnic Minority Caregivers Supporting a Family Member With Dementia: A Scoping Review

**Keywords:**
Dementia, Ethnic minority and Family caregiver

**References:**


**Abstract Summary:**
This presentation will provide information on the results of an extended scoping review which explored the lived experience of ethnic minority caregivers supporting a family member with dementia.

**Content Outline:**

**Introduction**
The introduction will include a background on the:

- prevalence of dementia in ethnic minority groups
- the aging migrant populations
- current knowledge and interventions to support ethnic minority caregivers supporting a family member with dementia
- the need and aim of this scoping review

**Body**
The body of this presentation will include:

- an overview of the process and concepts of a scoping review
- papers identified in this review
- an overview of meta-synthesis and how it has been applied to bring this body of research together
- discussion of the results of the meta-synthesis

**Conclusion**
The conclusion will include:

- the relevance of the results of the scoping review for clinical practice
- the relevance of the results of the scoping review for future research

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**Professional Experience:** Professor Jackson is a committed and experienced mentor and supervisor of developing researchers, scholars and leaders. Leading research programs in adolescent and family health, with a particular focus on parenting; and workforce development and adversity with a particular focus on leadership, workplace culture and to enhance the well-being of vulnerable and socially marginalised groups through the development of sustainable and culturally sensitive supportive interventions. An experienced writing mentor and coach, Professor Jackson and has published widely, with over 350 publications including journal articles, books and book chapters. She is Editor-in-Chief of Journal of Clinical Nursing and sits on the Editorial Boards of Journal of Child Health Care, Nursing Inquiry, and Nursing and Health Science. Named in 2016 as a Principal Fellow, NIHR Oxford Biomedical Research Centre (BRC/BRU); in recognition of the quality and volume of her internationally excellent research, and outstanding and sustained contribution, to translational clinical research.

**Author Summary:** A committed and experienced mentor and supervisor of developing researchers, scholars and leaders. She has published widely with over 350 publications including journal articles, books and book chapters and is the Editor-in-Chief of Journal of Clinical Nursing.

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**Professional Experience:** 2016- Reader in Complex Older Persons Care, Oxford Institute of Nursing and Allied Health Research (OxINAH) and Oxford Brookes University. 2015-2016 - Associate Professor in dementia, University of West London, with a focus on supporting the development of a Professional Doctorate. 2014-2015 - Nurse Consultant in dementia, Kent Community Health NHS Foundation Trust, with a focus on dementia education in practice. 2010-2014 - Senior Nurse Lecturer, University of Greenwich, with a focus on the development of evidence-based practice and research modules for undergraduate student nurses. Numerous presentations at scientific meetings. Publications in evidence-based practice from the perspectives of both student and qualified nurses.

**Author Summary:** Dr Joanne Brooke is an Adult Nurse and Health Psychologist with an interest in dementia, and the support and care of people with dementia to live well for longer in community settings. This work includes the exploration of support for family caregivers from culturally diverse populations. Dr Brooke is the Director of the International Dementia and Culture Collaborative.