Family care-giving for CALD people living with dementia: The perspectives of family carers and health service providers

Presentation of major research findings

Research to Practice Forum
September 2011
Aims

To identify issues in dementia care giving in four CALD groups in south western Sydney: Arabic, Chinese, Italian & Spanish speaking

Increase understanding of dementia care giving in CALD communities

Improve policy and service provision for dementia care in CALD communities
Background

- Funded by NHMRC
- A research team of seven members
- Bilingual/ Bicultural facilitators
- 15 focus groups conducted – (121 Family Carers 19 Arabic, 37 Chinese, 40 Italian and 25 Spanish speaking)
- Interviews with Bilingual/bicultural workers, GPs and Geriatricians
Understanding the term Dementia and connotations

- part of normal ageing
- mental illness
- depression seen to contribute to dementia
- as a medical condition
- heredity
- a ‘return to childhood’
- managing community reaction to dementia
The term Carer

- Term carer is foreign

  - The majority of families perceived caring as normal and acceptable part of being a spouse or child in their perspective culture and family members often failed to recognise that caring is a new role or beyond normal family responsibilities.
Experience and perceptions of Family Carers

- Carers report high levels of stress and depression, sleeping problems, poor physical health and worry about the future.

- CALD carers extended role due to migration & settlement issues
Making decisions about care-giving and services

- This often involves some form of extended family.

- Cultural traditions such as filial piety and familism, where the needs of the family are put before those of the individual

- Different family members had greater involvement in the care of the PLWD than others, advocacy being a key role

- Discussions/disagreements with family overseas
Being a Family Carer

- Negotiating gender and cultural expectations about caring for older relatives with other responsibilities
- Emotional/personal reaction to loss
- Concern about PLWD safety
- Concern about their own health, including implications for PLWD

“What if she outlives me? Her life will become even more miserable. Yes, she's got our children to look after her, but it's different to the care from a husband” (Chinese FC, husband)
Role of Bilingual workers & GPs

- Provide information/education
- Working with families, building trust, cultural insights to deliver information and education effectively
- Cultural brokerage - linking the community and services
- Constantly having to maintain and negotiate the Insider/Outsider role

“by understanding the culture and what is acceptable and what not, you are able to deliver that information”
Services

- Various cultural and general influences inform preference for home care:
  - Language, religious and cultural barriers
  - Availability of Ethno specific /culturally appropriate activities
  - Mainstream meeting dementia care needs
  - Community services: respite, domestic assistance

- General reluctance for residential care, particularly Arabic community

“She sits there all day long. It is not like when she is at home and I can massage her” (Chinese FC, spouse)
Geriatricians experiences

Geriatricians only group not selected on basis of cultural background. Geriatricians identified practice variations in working with CALD communities

- Later presentations, families not aware of disease
- Need to work with extended families
- Used certain words (dementia) less
- Worked with interpreters, who assisted in how to present issues
- Identified the need to distinguish between CALD communities
- Negotiating safety issues and family expectations
Some key implications-1

- CALD FC concerned about dementia, although may not realise implications

- Existing information needs to be more widely available to CALD communities and presented in an accessible manner

- Cultural norms and expectations are intertwined with the physical and emotional work of care-giving
Some key implications-2

- Aged care service providers should consider that large numbers of family members may be involved in the care and decisions for a CALD PLWD, including family living overseas.
- It is also important for clinicians to respond to each family individually, not as a member of a cultural group.
- CALD families need much education and support to consider residential care, support should continue after placement.
Some of key implications-3

- Ethno-specific services are generally preferred, but cultural needs can be met in mainstream services by brokering bilingual/bicultural staff

- BBW play a significant role that is not well recognised

- Not all CALD families have the same needs
Thank you for listening

➢ We have reports available on the key issues for each CALD communities

➢ There are a number of papers coming out, either published or In Press:
  - Experiences and perceptions of culturally and linguistically diverse family carers of people with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 26(4), 290-297
  - Dementia information for culturally and linguistically diverse (CALD) communities: Sources, access and considerations for effective practice. *Australian Journal of Primary Health*. In Press
  - The role of the bilingual/bicultural worker in dementia education, support and care *Dementia: the International Journal of Social Research and Practice*. In Press