Cultural issues in end of life care: Unmet needs of a terminally ill Indians in Australia

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BACKGROUND

- World Health Organisation (WHO) estimated, 50 million deaths out of which 6 million deaths in a year due to cancer and 3 million deaths from HIV/AIDS in developing nations (WHO, 2015).
- Demands of palliative care services increased for the 10 years.
- Evidence suggests – unmet needs (Hudson, 2013).
- Evidence suggests undergraduate curricula not adequately preparing health professionals for end of life care (Block, 2002; Billings & Block, 1997; Charlton & Smith, 2000).
Australia is the most diverse cultural society in the world (Department of Immigration & Multicultural Affairs (DIMA), 2014).

It is assumed that in western countries such as UK and Australia, people of non–English speaking backgrounds have less access to end of life care (Gunaratnam, 2007; Matzo & Lyn, 2000).

Approximately, 17% of the total population is non–English speaking background (DIMA, 2014).
Study Objectives

• To explore the issues related to accessing palliative care services for Indian migrants.

• To identify the effectiveness of palliative care in supporting the patient and family.

• To recommend strategies for improving care for the family members of terminally ill Indian migrants.
METHODS & DESIGN

- Constructivist Grounded Theory Methodology was utilised (Charmaz, 2006)

- Semi– structured interview guide was developed to collect the data

- Ethics approval obtained from the study site and from the university
Setting of the study

- Hospital based service
- Home care service
- Aged care service
Inclusion criteria

✓ First generation Indian migrants residing in Australia
✓ Family members of ill relatives who already received or receiving palliative care services
✓ Family members who can understand, read and speak English.
Recruitment process
Data collection procedure

- Data was collected in 2 phases.
- Phase 1: Introductory phase
- Phase 2: Interview phase
DATA ANALYSIS

- Thematic analysis
- 3 themes emerged
  - Theme–1: Experiences of healthcare system
  - Theme–2: Cultural issues
  - Theme–3: Caring experiences
RESULTS

The study identified the major cultural issues of a terminally ill Indian patient receiving end of life care services in Australia.

These include:

- Food
- Communication barriers
- Language difficulties
- Religious beliefs
- Clothing
Language difficulties

“My mother in-law does not know English. She is always alone in her room and she does not participate in the activities. She needs interpreter to translate into Hindi or Punjabi. So she waits for the son to come in the evening”.

(Participant–3)
Communication barriers

“When my husband was admitted to the hospital, the doctor came to visit him and explained him directly that he had cancer and could not cure it because it already spread to other parts of the body, his days were counted and he would die at any time”. (Participant–5)
“My husband does not like porridge or bread for breakfast, so I had to prepare Indian dishes to give him. At least then he will be happy you know and I will be satisfied I have done something good for him” (Participant-2).
Religious beliefs

“Someone always walks into the room, there was no privacy to pray when sharing with another patient, and the Indian person did not want to disturb the other patient”.

( Participant-3)
“I know my wife is going to die soon and I visit her frequently. Every morning I pray at home and do puja on her name and bring her offerings from the temple or from home. I sit next to her bed and pray silently. On the day she was dying, I was chanting next to her”. (Participant-1)
My mother-in-law wanted to wear a traditional sari but she could not wear since she is staying in the nursing home and she feels shame in front of everyone if she wears it. But at the same time, she feels uncomfortable with the Western clothes (Participant-4).
This study had brought out significant issues of Indian migrants receiving end of life care in Australia.

Grounded theory methodology reflect participants own experiences, needs and expectations in receiving the services.

There are more research needs to be conducted in this area to explore more information relating to health care professional perspectives.
Conclusion

• Equity and access of services
• Need based care
• Patient & family centred care
• Addressing the issues of minority groups & filling the gaps
• Adequate & appropriate referral system
• Support services for all
• Culturally competent care
References


Australia icons
THANK YOU SO MUCH  ANY ?