

Suffering- had enough: Family caregivers of experiences of patients with terminal illness

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Date: 24/07/13

Overview of Australia



Melbourne

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Introduction

- The majority of the terminally ill patients prefer to die at home even without active treatments (Hudson, 2012).
- Palliative care is a philosophy that aims to provide optimum comfort and support for patients and family members with life threatening illness (Palliative Care Australia, 2005).
- It is predicted that the incidence of cancer will dramatically increase in the near future (WHO, 2008)
- It is important to meet the needs of the people with terminal illness and their families.

Background of the study

- 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, 2008).
- Demands of palliative care services increased
- Evidence suggests –unmet needs (Hudson, 2004)
- Evidence suggests undergraduate curricula not adequately preparing health professionals for end of life care (Block, 2002; Billings & Block, 1997; Charlton & Smith, 2000).

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.

Research design

- Constructivist grounded theory approach (Charmaz, 2006)
- Semi-structured interview guide was utilised to collect the data
- Ethics approval obtained from the study site and university



Setting of the study

- Hospital based service
- Home care service

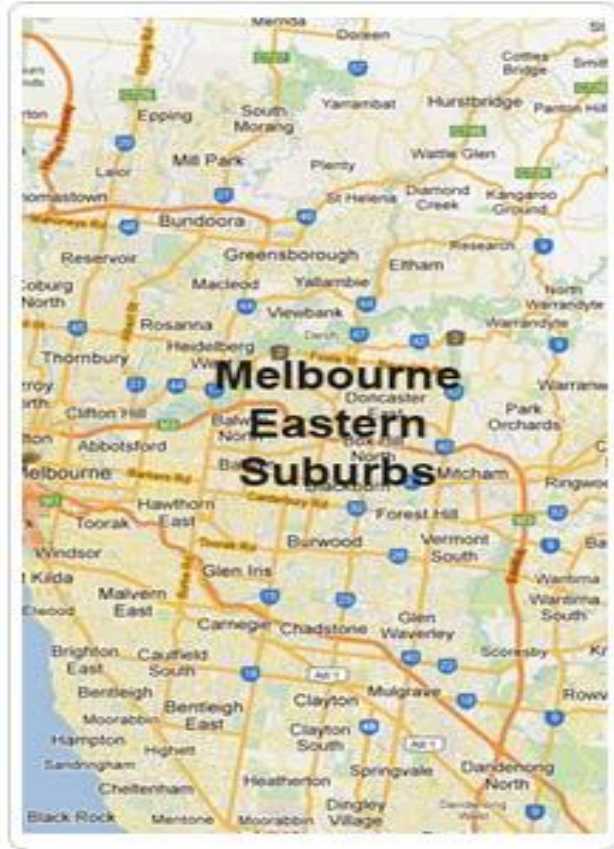


Inclusion criteria

- ✓ 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



Results

- Three major themes
 - Theme-1: Experiences of healthcare system
 - Theme-2: Cultural issues
 - Theme-3: Caring experiences



Caring experiences

- Caregivers' descriptions of their experiences tended to indicate that the nature of the caring itself was not the problem as such, but most of the caregivers perceived caregiving at some stage in the interview as '*hard work*' .
- For them 'hard work' meant being physically tired and carrying an additional burden.

Contd...

- *One participant explained*
- *“It is hard work. Because my husband is aged and I cannot toilet him or shower him, more so, he is fragile and he had a number of falls. For the past few weeks he was going down and was vomiting. I just cannot do that and really it is hard work for me” (Participant-2).*

Contd...

- *The other participant also expressed as*
- *“I was left alone. There was no one to be concerned about me. I did not receive any mental support as a husband. I was really very upset about this. That worried me too much” (Participant-1).*

Contd...

- *“I have no words to say. It is an experience. It was so painful for me. I feel so much under pressure you know, I have sleepless nights, no one to support me and no one is there to help me, so it is a lot of mental stress for me especially at the last stage of his illness. I have no time to spend with my children” (Participant-5).*

Contd...

“I just cannot relax you know...whether he wants something and... I need to do my routine work. I am waiting for him to go to toilet and shower him, so I can never be relaxed at home, I am occupied for 24 hours with his work, it is a hard job” (Participant-3).

Contd...

- *“I have not gone to friends’ parties and functions since my husband was sick and admitted to the hospital... think of leaving him alone here and go to the parties” (Participant-5).*

Future Directions

- Education, Practice and Research
- Nurses knowledge and skills
- Public health developments
- Undergraduate curricula
- Promote palliative care nursing research



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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

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THANK YOU SO MUCH

ANY ?

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