Stigma related to dementia in India: Current status and challenges

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Introduction

There is poor dementia awareness even though approximately 5.3 million people with dementia live in India (Alzheimer's & Related Disorders Society of India, 2010). It is projected that number of people living with dementia living in India will increase to 7.61 million by 2030 and 14.32 million by 2050. The treatment gap for Dementia in India is about 90% with only 10 people out of 100 with dementia ever receives any treatment, diagnosis or care (Martin Prince et al., 2015). There are various reasons but the ones that highlights the dementia scenario in India are poor awareness in society as well as health care professionals, poor manpower and resources to provide care and lack of public health priority for dementia. Resulting in most of the care provided by family at home without any financial support additional to it with poor dementia information. The very few studies published on dementia in India suggests that people with dementia experience stigmatisation in society as well as neglect from their families (Das, Ghosal, & Pal, 2012). Dementia-related stigma can negatively affect personal relationships and quality of life which can have effects on dementia care. To date, very little research exists within India that has explored dementia-related stigma across a range of stakeholders.

Methods:

Semi structured focus group interview conducted in two cities and in local languages

Participants: 57 Participants were recruited for various categories:

- General Public (n=17)
- People living with dementia (n=8)
- Family and/or carers (n=18)
- Healthcare professionals (n=16)

Recruitment Strategy:

- Two metropolitan cities with diverse background and cultures
- Delhi recruitment through local ARDSI chapter
- Chennai recruitment through local ARDSI chapter at Sri Ramachandra Medical University
- Word of Mouth

Participant demographics across stakeholders

- **Delhi (n=16):**
    - Female- 9, Male- 7
    - Mean Age – 41.5 (Range = 23- 75 years)
- **Chennai (n=41)**
    - Female = 18, Male = 23;
    - Mean Age – 41.5 (Range = 23-78)

Analysis:

Inductive thematic analysis, applied across all stakeholder groups.

Education – illiterate to university level

Never heard of Dementia or Alzheimer's (n= 3)
Either heard of only dementia or only Alzheimer's (n= 5)

Socio- Economic background – Urban upper middle class, urban middle class, rural lower incomes

Employment - Working, part time, voluntary/social worker, house wife, student

Themes Identified

Misconceptions	• Symptoms, care and treatment, Perceived cause of dementia • Family misconceptions
Stigma	• Local, culturally used language • Addressing people with dementia
Awareness	Perceived need to raise dementia awareness among Professional, medical, care providers &general public
Service gaps	• Perceived service gaps: No treatment available, costly • Poor dementia awareness and knowledge

Theme 1: Misconceptions

Perceived cause of dementia

"One main reason (cause of dementia) is because of stress, along with stress, in Indian culture we don't have proper diet." - *Female, Delhi*

Misconception and poor knowledge

"Yes medicine has developed well in the world. By counselling (it can be cured). Even after this has caused because of accident or anything, main it is by counselling plus medical treatment (but it is) costly. Brain related things are cured." - *Male, Chennai*

Theme 2: Stigma

Stigma related to mental illness, misconception

"People also say, he has gone senile, has gone cuckoo, old man in my home who has gone Senile, the family who has a person was gone mad so it becomes a stigma with them, people don't want to who marry off their daughters in such family, should not marry here." – *Female Delhi*

Stigmatising language

"They are just like small children , so it requires to take care of them in the same manner." -*Female Delhi*

Theme 3: Need to raise dementia Awareness

"People don't even know how to combat the issue, where to go take the patient, when they go to normal doctor, who is on the street (clinic) even those people don't know about dementia, I have spoken to so many they don't know what is dementia or Alzheimer's is."- *Male, Delhi*

Perceived service gaps

Assumptions, stigma, neglect, poor understanding

"Assume that I want to keep someone there (in old age home) for 2-3 months there is no acceptance for keeping (admitting) such person, there (old age homes), as they say that this person can get violent, they will not admit that person and make some excuse and will send them back ." -*Female, Delhi*

Perceived poor access

"Actually in geriatric care, this care is available only in big hospitals. Small hospitals, Primary Health Care Centres don't have this and I think we need to make awareness in Primary Health centres about dementia. We need to talk about this to doctors in Health Care Centres too, they themselves don't know this." - *Female, Chennai*

Key findings:

- **Perceived lack of dementia awareness: Nature of the disease, symptoms, considered as normal aging**
- **Perceived lack of dementia care pathways and services**
- **Stigmatization of disease and social isolation**
- **Lack of early diagnosis due to stigma, neglect, poor knowledge of disease and available services**
- **Need for dementia training in professional curriculums**
- **Dementia care is responsibility of the government and children of people with dementia**

Conclusion: The study highlights on poor awareness of dementia, socio-cultural aspects contributing towards perceptions leading to stigma and barriers in access to dementia care in India. It also calls for need to promote dementia awareness campaigns to general public in order to help address stigma and discrimination towards dementia in India.

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