IOSR Journal Of Humanities And Social Science (IOSR-JHSS)
Volume 26, Issue 10, Series 9 (October. 2021) 01-07
e-ISSN: 2279-0837, p-ISSN: 2279-0845.
www.iosrjournals.org

A Comparative Analysis of Urban and Rural Knowledge and Attitude towards Dementia

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Abstract:
Despite the increased prevalence of Dementia in India, the awareness of the disease among the Indian population is scarce. This problem could lead to misrepresentation and disregard of the symptoms, delayed diagnosis, limit the choices to provide care for the person diagnosed and be an additional stress factor for both the caregiver and person living with dementia. In India, the degree of knowledge and awareness of the disease across geographical regions, urban and rural, are varied. The present study addresses and analyses the factors influencing knowledge, attitude and social comfort of individuals towards dementia in urban and rural regions of Delhi NCR. A quantitative design was used wherein data was collected from 40 respondents residing in urban and rural areas Delhi-NCR. A Google Form was circulated using the Dementia Attitudes Scale by Melissa O'Connor & Susan McFadden (2010). The results of the findings were that individuals in rural areas have limited awareness about the symptoms, progression and treatment of the disease, as compared to individuals residing in urban areas. While participant's awareness of dementia in both urban and rural areas is insufficient even after being caregivers for numerous years, respondents from both regions had a positive outlook towards the disease. The results suggest that a multifaceted approach consisting of education interventions, mass awareness drives and dementia screening events is urgently needed in both urban and rural India.

Key Word: Dementia, Knowledge, Attitude, Rural, Urban, Caregivers

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Date of Submission: 12-10-2021 Date of Acceptance: 27-10-2021

I. INTRODUCTION

"Dementia is a syndrome – usually of a chronic or progressive nature – that leads to deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from the usual consequences of biological ageing," according to the WHO (World Health Organisation, 1992). Alzheimer's disease, Lewy Body Dementia, Vascular Dementia, and Frontotemporal Dementia account for 90% of all cases of Dementia, out of which Alzheimer's is the most common (Alzheimer's and Related Disorders Society of India, Cochin Chapter, 2019). As it is a neurodegenerative disease, it is not possible to reverse certain types of dementia, but it is possible to delay the onset, progression of the symptoms and the impact on the family and person with dementia with timely response by doctors and trained attendants (World Health Organisation, 1992).

India is the second most populous country in the world with 1.36 billion people. Of this, 138 million are elderly people who are 60 years old or above. Accounting for 8.6% of the population, 103 million in the 2011 census, the number of elderly in India is estimated to rise to 319 million in 2050, as per the Longitudinal Ageing Study of India (International Institute for Population Sciences, 2020). Globally, the number of elderly are estimated to outnumber children under age ten by 2030 (UN World Population Ageing, 2017).

It is estimated that 5.3 million people above the age of 60 have dementia in India and with increasing life expectancy that number is expected to rise to 7.6 million by 2030. As per the data given in the Dementia in India 2020 report by ARDSI (Alzheimer's and Related Disorders Society of India, Cochin Chapter, 2019), the prevalence rate of dementia in India lies between 1% to 15%. The wide range can be attributed to the diversity of the population analysed and the geographical and cultural differences across regions. Despite the increasing cases of dementia in India, the disease is still not a national health care priority. The resulting cognitive decline due to the disease is often interpreted as effects of normal ageing, and hence is neglected by family members, policy makers and administrators (Alzheimer's and Related Disorders Society of India, Cochin Chapter, 2019). One challenge has been the absence of awareness of the disease and it's symptoms among the general public, which has led to the disease and the subsequent services offered by entities like care homes and ASHAs being stigmatised, a topic which came up during my interaction with the respondents.

A decent level of knowledge of dementia, basic management strategies, and support networks, made up of professionals, patients, caregivers, NGOs, ASHAs and so on, are the most important factors that affect the quality of care for people living with dementia (Chaudhuri & Das, 2006). The Theory of Planned Behaviour suggests that there is a direct correlation between knowledge, attitude and action, which means that individuals with higher levels of dementia knowledge would provide better care for people with dementia. They would implement a person-centered approach towards caring, which has already been proven beneficial in other regions across the world (Tay et. al, 2017) rather than a reality-oriented approach. It is imperative to raise awareness about the disease especially in growing economies like India which has witnessed several fold increase in eldery population in the past decades. The percentage of people aged over 60 is 8.7% in Delhi and 9.7% in Haryana, which is similar to the elderly population in India (10.7%). 79 per 1000 population in Delhi have dementia, while 106 per 1000 population in Haryana have Dementia. Both figures are expected to rise to 26 per thousand and 34 per thousand, respectively, in one year (ARDSI Cochin Chapter, 2019). These increasing numbers suggest an urgency to tackle stigma, false and absence of information about the disease, and learn from the lived experiences of carers and patients.

Here, by analysing the data received from the survey it is showed that comparatively, people in both urban and rural regions do not have sufficient knowledge about the disease, people in urban areas are more aware of the symptoms, progression (marked by severe cognitive decline), standardised method of care, and are more likely to approach a doctor to get a diagnosis. This comparative study is needed to establish the vast awareness gap of the disease in urban and rural India. In rural Gurgaon, dementia is still predominantly viewed as an age-related disease and its symptoms are associated with the decline of function due to old age. While this belief is held by some people in urban areas as well, the majority of the urban population in Delhi-NCR recognises the distinction between symptoms of dementia and decline of function due to old age.

II. METHODOLOGY

The present study analyses the knowledge, attitude and social comfort of individuals towards dementia in rural and urban regions, which will help highlight the areas that need to be worked upon to create dementia friendly communities in India.

Research Design

A quantitative comparative study consisting of a survey of doctors, caregivers and individuals was conducted to collect self-reported dementia knowledge and attitude.

Sample

The target population in the present study were familial caregivers, trained attendants, general physicians, neurologists and individuals with friends/family diagnosed with Dementia in Delhi, Gurgaon and three villages: Dhankot Bajghera, and Garhi Harsaru. There were 40 respondents out of which 21 were from urban areas and 19 from rural areas residing in Delhi NCR.

Informed Consent

All ethical considerations were followed for the current study. Respondents were given the opportunity to remain anonymous while filling the online survey. Informed consent was taken from the participants for data collection. Confidentiality and privacy of the respondents were maintained, and no data was distributed to a third party. Identifiers such as name were not disclosed in the paper or while conducting the study.

Tools Used

Demographic Questionnaire - Demographic questions in the survey were assessed: age group, education, marital status, geographic location (urban, rural, peri-urban), family size and family history of dementia. Three questions gauged respondent's experience of caring for individuals with dementia: first focused on personal caring, second on professional caring and third on hiring trained attendants.

The Dementia Attitudes Scale (DAS) was developed to measure the knowledge and attitude of the respondents towards dementia (O'Connor & McFadden, 2010). DAS has a two-factor structure and it's Total-Scale Cronbach's alphas (measure of internal consistency) ranged from 0.83-0.85. Cronbach's alpha for the first factor labelled "social comfort" is 0.82 and for the second factor labelled "dementia knowledge" is 0.75. The response options are scored on a 7-point Likert Scale ranging from 1 (strongly disagree) to 7 (strongly agree). Factor 1 included the cognitive domain, while factor 2 included the behaviour and perception domain. Factor 1 included questions like 'Difficult behaviours may be a form of communication for people with ADRD,' and Factor 2 included questions like 'It is rewarding to work with people who have ADRD.' Familiarity with the disease beforehand and social desirability may have influenced the results. In this survey, reverse scored questions from the scale were corrected.

Data Collection Procedure and Analysis

The survey was created using Google Forms and circulated among the target population using WhatsApp during Dementia Action Week in September 2021. The survey was distributed with doctors of dementia patients, caregivers in professional or personal capacity and people acquainted with friends/family living with dementia. The survey was accessible for approximately four weeks. T -test, a type of inferential statistics, was used to determine the presence and significance of difference between the two groups in this study: urban and rural.

III. RESULTS

The respondents were diverse in terms of age, degree of education, and size of family.

35% of the respondents belonged to the 45-54 age group, 8 respondents from urban and 6 from rural. More than half of the respondents did not have experience caring for people with dementia, out of which 52.38% were from rural regions. Out of the 19 responses (47.5%) who had experience, only 5 (26%) were trained to care for people with dementia and they all lived in urban regions. Additionally, 95% of the respondents reported that dementia was not a recurring disease in their family, yet 10% had hired trained attendants to assist in the process of caring for individuals with dementia.

Only 2 respondents reported that dementia was a recurring disease, both belonged to urban regions and had hired untrained attendants to assist in the process of caring. One of the two respondents had replied 'never given' when asked "How do you provide care for people living with Dementia?" in the survey. Three (7.5%) people reported having hired trained attendants in the past, all living in urban areas, to assist in "taking care of their hygiene (regular bath, change of clothes and diaper regularly, food at proper timings, medication on time, mobilisation)," as reported by one participant.

Furthermore, 24 respondents (60%) believed that memory decline due to aging is the same as dementia. Out of those 24, 18 were from rural areas and 6 from urban areas. Participants were also asked if the following statement was correct or incorrect: Dementia is part of normal ageing i.e all older people develop dementia as they age. 21 respondents (52.5%) believed that the statement was correct, of which 16 resided in rural areas and 5 in urban areas.

Figure 1: Is dementia a recurring disease in your family?

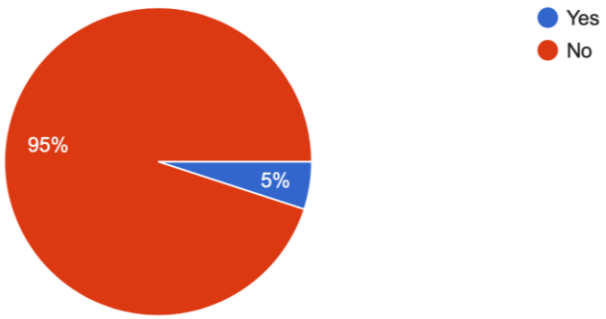


Figure 2: Memory decline due to ageing is the same as dementia.

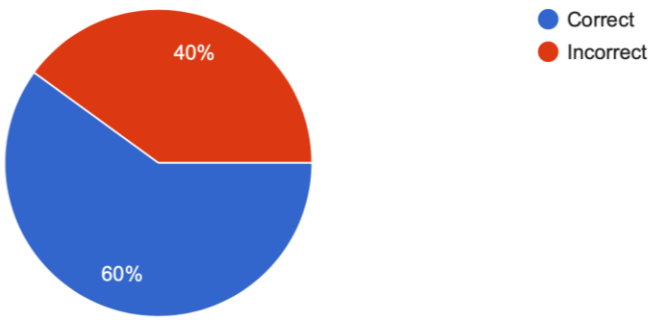
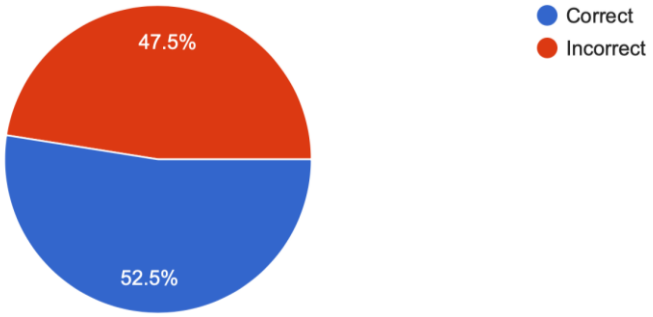


Figure 3: Dementia is part of normal ageing i.e all older people develop dementia as they age.



The overall mean score of dementia knowledge and social comfort of respondents from urban areas as measured by the DAS is (M= 117.42, SD= 11.21) where for rural areas is (M= 83, SD= 14.42) (Table 1).
To measure the presence and significance of the difference between the knowledge and attitude of people towards dementia in urban and rural areas T-test was carried out. Urban population (M= 117.42, SD= 11.21) reported significantly higher awareness about dementia than rural population (M= 83, SD= 14.42), $t(38) = 8.36$, $p < 0.05$. Hence, the results are statistically significant (Table 1).

Table 1: Summary of independent T-test analysis between respondents from urban and rural regions (N=40)

	Urban		Rural		t	p*
	M	SD	M	SD		
Dementia Attitudes Scale (O'Connor & McFadden, 2010)	117.42	11.21	83	14.42	1.69	0.000

Note. *p < .05

IV. DISCUSSION

The findings of the comparative study suggest that there is a significant gap of dementia knowledge and attitude towards the disease between rural and urban areas. Respondents from rural areas associated dementia to be part of the normal ageing process and answered the questions in the survey on the basis of this assumption.

The overall mean score of respondents as measured by DAS from urban and rural areas, suggests that individuals in urban areas have significantly more knowledge and better attitude towards the disease.

Both in urban and rural areas, caregivers cared for elders with dementia as a sign of respect and duty to the generation above, evident by this response "They should be respected and we should care for them," but there was a clear distinction about the knowledge of the disease. After years of caring for their elder, caregivers had grown accustomed to the process of caring for individuals with the disease and hence there were no explicit deficits in the process of caring, evident by this response "Life and experiences taught me." But caregivers didn't know about the disease they were fighting against. Symptoms, stages, and progression of the disease were some topics that caregivers did not have knowledge about.

Moreover, in rural rather than urban areas, individuals associated dementia with forgetfulness and confusion on how to behave appropriately in social contexts. This is in line with previous studies in India that established that dementia is commonly understood as a disease that leads to forgetfulness, which is the result of normal ageing (Benedicte et. al, 2021). The perception of dementia as part of the normal ageing process and not a brain disorder with various symptoms and implications will have negative consequences on planning and execution of care, which might lead to an increase in the burden of care on the caregivers and the person living with dementia.

As evident by the huge gap in mean scores of respondents measured by DAS, most people in urban regions seem to accurately identify the symptoms of the disease, have better knowledge about the cognitive, psychological and behavioral effects of the disease on patients and caregivers, and feel comfortable being around and taking care of individuals with dementia. In addition to this, respondents from urban areas seem to recognize the toll of the disease on caregivers and the person diagnosed as evident by the following response: "My close family member had dementia due to a medical condition. I know such patients need a lot of

encouragement and care, as along with dementia, a sense of depression also sets in. It is important for a family member to spend quality time with them and understand their emotions." Participants from urban areas also recognized some areas of improvement evident by the following two responses: "Comprehensive management with a good social support system is needed" and "Proper training of doctors." These responses suggest the presence of a higher level of knowledge of the disease by the urban respondents.

There is a clear distinction between the comfort level of individuals around people with dementia on the basis of how they perceive dementia and the low mean score of respondents from rural regions measured by DAS. In rural areas, as the disease is associated with old age, most respondents feel comfortable spending time with elders and not specifically elders with dementia whereas in urban areas, respondents realize that elders with dementia need more support and attention, and feel confident to take care of them with/ without help from external agents such as trained attendants. Respondents from rural regions have also identified problems that they face while caring for people with dementia as evident by the following responses: "Absence of doctors" and "large families hence difficulty caring for everyone by one or two members," which suggests some knowledge about the process of caring among the rural population.

V. CONCLUSION

The aim of this study was to compare the knowledge, attitude and social comfort of individuals in urban and rural settings in India. Despite the limitations of this study, the results of the study could give glimpses into the possible blindspots that need to be tackled to make a dementia friendly community in India. The findings of this comparative study emphasize the need to increase the awareness of dementia in India, in both rural and urban areas. The range of differences in attitude toward and inadequate knowledge of dementia in urban and rural India brings attention to the fact that dementia is still perceived as an age related disease that doesn't need special consideration. One important result of this study is that organising mass awareness drives, memory screening events and educating everyone about the contributing factors, symptoms, progression and treatment of the disease should be a national health priority. These initiatives together with proper training of caregivers, could help tackle the expected increase in the number of people being diagnosed with dementia due to greater life expectancy.

Limitations of the Study

This study may be limited by the fact that a majority of the respondents from urban regions were providers and caregivers who might have had prior knowledge about, or interest in, dementia. Whereas the respondents from rural areas were much more varied, only 42.10% had experience caring for people with dementia. Because the current study was conducted in the Delhi-NCR region, it is difficult to know if the results of this comparative study would hold in a wider sample.

ACKNOWLEDGEMENT

I would like to express my deep gratitude to Dr. Sandeep Miglani and Ms. Tanya Tulsyan for their guidance, enthusiastic encouragement and useful critiques of this comparative study. I would also like to thank my family and friends for their support.

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APPENDIX A. Demographic Data and respondent's relationship with dementia

Table 2: Demographic Data of the respondents (N=40)

Variables	Participant %
Age	
Less than 18	0
18-24	7.5
25-34	5
35-44	20
45-54	35
55-64	27.5
65 and above	5
Education	
Less than 10th Grade	0
10th Grade	2.5
12th Grade	20
Undergraduate	7.5
Graduate	15
Post Graduate	55
Marital Status	
Unmarried	12.5
Married	87.5
Widowed	0
Divorced	0
Engaged	0
Never married	0
Caring Experience	
Yes	52.5
No	47.5
Dementia Care Training	
Yes	12.5
No	87.5
Family Size	
1	0
2	5
3	7.5
4	15
5	22.5
6	15
More than 6	35
Hired Care	
I have hired trained attendants	7.5
I have hired untrained attendants	10
I have never hired trained/untrained attendants	82.5

Family history of dementia	
Yes	5
No	95
Geographic location	
Rural	47.5
Urban	52.5

Saumya Choudhary. "A Comparative Analysis of Urban and Rural Knowledge and Attitude towards Dementia." *IOSR Journal of Humanities and Social Science (IOSR-JHSS)*, 26(10), 2021, pp. 01-07.