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A Comparative Analysis of Urban and Rural Knowledge and Attitude Towards Alzheimer's Disease

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Abstract

The scarcity of awareness about Alzheimer among the Indian population, despite its increased prevalence, poses several challenges. This lack of knowledge can lead to misrepresentation and disregard of symptoms, delayed diagnosis, limited caregiving options, and increased stress for both caregivers and individuals living with Alzheimer's. Moreover, the level of awareness varies across different regions in India, including urban and rural areas. To address this issue, a study was conducted to analyze the factors influencing knowledge, attitude, and social comfort regarding Alzheimer in urban and rural regions of Rohtak Haryana. The study followed a quantitative design, collecting data from 50 respondents residing in both urban and rural areas through a Google Form. The Dementia Attitudes Scale developed by Melissa O'Connor and Susan McFadden (2010) was used as the survey tool. The findings revealed that individuals in rural areas have

limited awareness about the symptoms, progression, and treatment of Alzheimer's compared to those living in urban areas. Surprisingly, even after being caregivers for numerous years, respondents from both urban and rural regions exhibited insufficient awareness about Alzheimer. However, both groups demonstrated a positive outlook towards the disease. Based on these results, it is evident that a comprehensive approach is urgently required in both urban and rural India to address the issue of Alzheimer. This approach should include educational interventions, mass awareness campaigns, and Alzheimer screening events. By implementing such measures, the goal is to enhance knowledge and awareness among the population, ensure early detection and diagnosis, and provide appropriate care and support for individuals living with Alzheimer and their caregivers.

Introduction

Alzheimer, as defined by the World Health Organization [1], is a syndrome characterized by a chronic or progressive decline in cognitive function beyond what is expected from normal aging. It is a neurodegenerative disease that cannot be fully reversed, although timely medical intervention and trained caregivers can help delay the onset and progression of symptoms, reducing the impact on both the individual with dementia and their family [1].

In India, the second most populous country globally with 1.36 billion people, there is a significant elderly population. Approximately 138 million people in India are aged 60 or above, accounting for 8.6% of the total population, as recorded in the 2011 census. According to the Longitudinal Ageing Study of India conducted by the International Institute for Population Sciences (2020), the number of elderly individuals in India is projected to reach 319 million by 2050. This trend aligns with the global scenario, where the elderly population is expected to outnumber children under the age of ten by 2030 (UN World Population Ageing, 2017).

Regarding the types of dementia, Alzheimer's disease, Lewy Body Dementia, Vascular Dementia, and Frontotemporal Dementia collectively account for 90% of all cases. Among these, Alzheimer's disease is the most common form of [2]. While certain types of dementia cannot be reversed, early detection and appropriate interventions can help manage symptoms and provide support for individuals with dementia and their families.

According to the "Dementia in India 2020" report published by the Alzheimer's and Related Disorders Society of India [2], it is estimated that there are 5.3 million people aged 60 and above living with dementia in India. With the increasing life expectancy, this number is projected to rise to 7.6 million by 2030. The prevalence rate of dementia in India, as indicated in the report, ranges from 1% to 15%. This wide range can be attributed to the diverse population analyzed and the variations in geographical and cultural factors across different regions.

Despite the growing number of dementia cases in India, the disease has not yet become a national

healthcare priority. The cognitive decline resulting from dementia is often misunderstood as a normal consequence of aging, leading to neglect from family members, policy makers, and administrators [2]. This lack of awareness about the disease and its symptoms among the general public is a significant challenge. Consequently, services provided by entities such as care homes and Accredited Social Health Activists (ASHAs) have been stigmatized, as revealed during interactions with the respondents.

The stigma associated with dementia adds another layer of complexity to the problem, hindering the provision of appropriate care and support. Efforts to raise awareness and destigmatize dementia are crucial to ensure early diagnosis, access to services, and a supportive environment for individuals living with dementia and their families.

Knowledge about dementia, basic management strategies, and support networks comprising professionals, patients, caregivers, NGOs, and ASHAs (Accredited Social Health Activists) are crucial factors that influence the quality of care provided to individuals living with dementia (Chaudhuri & Das, 2006). The theory of planned behavior suggests that there is a direct correlation between knowledge, attitude, and action, indicating that individuals with higher levels of dementia knowledge are more likely to deliver better care for people with dementia. Implementing a person-centered approach, which has proven beneficial in other regions worldwide [3], is preferred over a reality-oriented approach.

Raising awareness about dementia is particularly vital in growing economies like India, where the elderly population has significantly increased over the past decades. In Delhi, the percentage of people aged over 60 is 8.7%, while in Haryana, it is 9.7%, which aligns with the national average of 10.7%. The prevalence of Alzheimer is also a concern, with 106 per 1000 population in Haryana and 79 per 1000 population in Delhi being affected. These numbers are projected to rise to 26 per thousand and 34 per thousand, respectively, within a year [2]. This emphasizes the urgent need to address stigma, misinformation, and the lack of information about the disease, while also learning from the experiences of caregivers and patients.

Analyzing the survey data, it becomes evident that individuals in both urban and rural regions lack sufficient knowledge about Alzheimer. However, individuals in urban areas display higher awareness regarding symptoms, disease progression (characterized by severe cognitive decline), standardized care methods, and are more likely to seek medical diagnosis. This comparative study highlights the significant awareness gap concerning Alzheimer between urban and rural India. In rural Rohtak, dementia is still predominantly seen as an age-related disease, with its symptoms associated with the natural decline of function in old age. While this belief exists among some individuals in urban areas as well, the majority of the urban population in Rohtak recognizes the distinction between Alzheimer symptoms and age-related functional decline.

Methodology

The current study focuses on analyzing the knowledge, attitude, and social comfort of individuals towards Alzheimer in both rural and urban regions. By examining these factors, the study aims to

identify areas that require attention and improvement to establish Alzheimer-friendly communities in India.

Research Design

A comparative quantitative study was conducted, which involved surveying doctors, caregivers, and individuals to gather self-reported data on their knowledge and attitude towards Alzheimer. This approach aimed to assess and compare the level of understanding and perspectives among these groups regarding the disease.

Sample

The target population for this study comprised familial caregivers, trained attendants, general physicians, neurologists, and individuals who had friends or family members diagnosed with dementia. The study was conducted in Rohtak, and three specific villages: Kanheli, Makrouli Khurd and Bohar. A total of 50 respondents participated in the study, with 26 residing in urban areas and 24 in rural areas of Rohtak.

Informed Consent

The present study adhered to ethical considerations throughout the research process. Respondents were provided the option to maintain anonymity while completing the online survey. Informed consent was obtained from all participants prior to data collection. The confidentiality and privacy of the respondents were strictly upheld, and no data was shared with any third party. Identifying information, including names, remained undisclosed in the study report and during the research conduction.

Tools Used

Demographic Questionnaire

The survey included demographic questions to gather information on various aspects of the respondents. These questions encompassed the following areas: age group, educational background, marital status, geographic location (urban, rural, peri-urban), family size, and family history of dementia. Additionally, three questions were designed to assess the respondents' experience in caring for individuals with dementia. The first question addressed personal caregiving experience, the second focused on professional caregiving experience, and the third inquired about the utilization of trained attendants for caregiving purposes.

The Dementia Attitudes Scale (DAS)

Developed by O'Connor and McFadden (2010), was utilized in the study to assess the knowledge and attitude of the respondents towards dementia. The DAS consists of two factors: "social comfort" and "dementia knowledge." The internal consistency of the DAS Total-Scale Cronbach's alpha ranged from 0.83 to 0.85, indicating good reliability. Specifically, the Cronbach's alpha for the "social comfort" factor was 0.82, and for the "dementia knowledge" factor, it was 0.75. The respondents rated their responses

on a 7-point Likert scale, ranging from 1 (strongly disagree) to 7 (strongly agree). Factor 1, which pertained to the cognitive domain, included questions such as "Difficult behaviors may be a form of communication for people with ADRD." Factor 2, focusing on behavior and perception, included questions such as "It is rewarding to work with people who have ADRD." It should be noted that respondents' prior familiarity with the disease and social desirability might have influenced the results. Reverse scored questions from the scale were appropriately corrected in this survey.

Data Collection Procedure and Analysis

The survey was developed using Google Forms and was distributed to the target population via WhatsApp during Dementia Action Week in September 2021. The survey reached individuals such as doctors of dementia patients, caregivers in both professional and personal capacities, as well as those acquainted with friends or family members living with dementia. The survey remained accessible for a duration of approximately four weeks to allow respondents ample time to complete it.

In order to assess the presence and significance of differences between the two groups in this study (urban and rural), a statistical analysis known as a t-test was employed. The t-test is a form of inferential statistics that helps determine if there are notable variations between the two groups being compared.

Result

The respondents in the study exhibited diversity in terms of age, educational background, and family size. Among the respondents, 35% belonged to the 45-54 age group, with 8 respondents from urban areas and 6 from rural areas falling within this category. More than half of the respondents (52.38%) had no prior experience in caring for individuals with dementia, and a majority of them (47.5%) were from rural regions. Out of the 24 respondents (47.5%) who did have caregiving experience, only 5 (20%) were trained in providing care for people with dementia, and all of them resided in urban areas.

Regarding family history, 95% of the respondents reported that dementia was not a recurring disease within their families. However, despite this, 10% of the respondents had hired trained attendants to assist in the care of individuals with dementia. Only 2 respondents, both from urban regions, indicated that dementia was a recurring disease in their families and had hired untrained attendants for caregiving. One of these two respondents replied "never given" when asked about the method of care provided for people living with dementia. Additionally, three participants (7.5%) from urban areas reported having hired trained attendants in the past to assist with various aspects of care, such as hygiene, medication, and mobility.

Furthermore, a significant portion of the respondents (60%) believed that memory decline due to aging is synonymous with dementia. Out of these 24 respondents, 18 were from rural areas, while 6 were from urban areas. When asked about the statement "Dementia is part of normal aging, i.e., all older people develop dementia as they age," 21 respondents (52.5%) believed the statement to be correct. Among them, 16 resided in rural areas, and 5 were from urban areas.

Discussion

The findings of the comparative study reveal a significant disparity in dementia knowledge and attitudes between rural and urban areas. Respondents from rural regions tended to associate dementia with normal aging and based their survey responses on this assumption. On the other hand, individuals in urban areas demonstrated higher levels of knowledge and more positive attitudes towards the disease, as indicated by the overall mean scores obtained from the Dementia Attitudes Scale (DAS).

While both urban and rural caregivers approached caring for elders with dementia as an act of respect and duty towards the older generation, there was a clear distinction in their knowledge of the disease. Caregivers in both settings had become accustomed to the caregiving process through years of experience, resulting in no explicit deficits in their caregiving approach, as expressed in responses such as "Life and experiences taught me." However, caregivers lacked understanding of the disease they were dealing with, including its symptoms, stages, and progression.

In rural areas, individuals predominantly associated dementia with forgetfulness and confusion regarding appropriate social behavior. This aligns with previous studies conducted in India, which have established that dementia is commonly perceived as a condition characterized by forgetfulness, attributed to normal aging [4]. The perception of dementia as a natural part of the aging process rather than a brain disorder with distinct symptoms and implications can have negative consequences for the planning and execution of care. This may lead to an increased burden on caregivers and individuals living with dementia.

It is evident that addressing the knowledge gap and misconceptions about dementia in both rural and urban areas is crucial for effective care planning and support. Educational initiatives and awareness campaigns targeted at communities, caregivers, and healthcare professionals can help dispel myths and enhance understanding of dementia as a distinct condition. This, in turn, can alleviate the burden on caregivers and improve the overall well-being of individuals living with dementia.

The significant disparity in mean scores measured by the Dementia Attitudes Scale (DAS) indicates that individuals in urban areas have a better understanding of dementia compared to their rural counterparts. People in urban regions demonstrate the ability to accurately identify the symptoms of the disease, possess knowledge about its cognitive, psychological, and behavioral effects on both patients and caregivers, and feel comfortable in the presence of individuals with dementia. They also acknowledge the challenges faced by caregivers and the emotional toll the disease can take on both the individual with dementia and their loved ones.

Moreover, respondents from urban areas recognize the need for comprehensive management and a robust social support system for individuals with dementia. They highlight the importance of proper training for doctors in effectively addressing the needs of dementia patients. These responses indicate a higher level of knowledge and awareness about the disease among urban respondents.

On the other hand, there is a notable difference in the comfort level of individuals in rural areas when it comes to interacting with people with dementia. As dementia is commonly associated with old age in rural communities, respondents generally feel comfortable spending time with elderly individuals without specifically addressing their dementia condition. In contrast, respondents from urban areas understand the specific needs of individuals with dementia and feel more confident in providing care and support, either with or without assistance from trained attendants.

While rural respondents may have some awareness of the caregiving process for individuals with dementia, they also highlight the challenges they face, such as the lack of accessible doctors and the difficulty of caring for multiple family members in large families. These responses suggest a basic understanding of the caregiving process among the rural population.

Overall, the findings emphasize the need to bridge the knowledge gap and improve awareness about dementia in rural areas. Efforts should focus on educating the rural population about the distinct symptoms and challenges associated with dementia, as well as the importance of appropriate care and support for individuals with the condition. By enhancing understanding and providing necessary training and resources, both urban and rural communities can work towards creating dementia-friendly environments that promote effective care and support for those affected by the disease.

Conclusion

The primary objective of this study was to compare the knowledge, attitude, and social comfort of individuals residing in urban and rural areas in India. While acknowledging the limitations of the study, the findings offer valuable insights into the potential blind spots that must be addressed to foster a dementia-friendly community in India. The results underscore the critical importance of raising awareness about dementia across both urban and rural regions.

The study reveals significant differences in attitude and insufficient knowledge about dementia between urban and rural India. It highlights the prevailing perception that dementia is merely an age-related condition that does not require special attention. This highlights the urgent need to organize mass awareness campaigns, memory screening events, and educational initiatives aimed at enhancing understanding of the contributing factors, symptoms, progression, and treatment of dementia. Making these efforts a national health priority is crucial.

In addition to awareness initiatives, it is imperative to prioritize proper training for caregivers. With the expected rise in dementia cases due to increased life expectancy, equipping caregivers with the necessary knowledge and skills becomes paramount. By implementing comprehensive training programs, caregivers can provide better support and care for individuals with dementia.

Overall, this study emphasizes the pressing need to enhance dementia awareness in India, irrespective of whether individuals reside in urban or rural areas. By addressing the identified gaps in

knowledge and attitudes, the country can effectively prepare for the growing number of dementia cases and work towards creating a dementia-friendly society that prioritizes the well-being and quality of life for those affected by the disease.

Limitations of the Study

Several limitations should be acknowledged regarding this study. Firstly, a notable limitation is the potential bias in the sample composition. The majority of respondents from urban regions were providers and caregivers who may have possessed prior knowledge or interest in dementia. This could have influenced their responses and resulted in an overrepresentation of individuals with greater awareness and understanding of the disease. On the other hand, respondents from rural areas exhibited more diversity, with only 42.10% having experience in caring for people with dementia. This discrepancy in caregiver representation between urban and rural areas might have influenced the observed differences in knowledge and attitudes. Furthermore, it is important to recognize that this study was conducted solely within the Delhi-NCR region. Therefore, the generalizability of the findings to a broader population may be limited. The socio-cultural and demographic characteristics of this specific region may not fully capture the diversity and variations present in other parts of India. Consequently, caution should be exercised in applying these findings to wider contexts without further research and examination. To establish a more comprehensive understanding of the knowledge, attitudes, and social comfort surrounding dementia in India, future studies should aim to incorporate a larger and more representative sample from diverse regions across the country. By expanding the scope of the study, a more accurate assessment of the prevalence and variations in knowledge and attitudes towards dementia can be obtained, leading to more targeted and effective interventions for creating dementia-friendly communities on a national scale.

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