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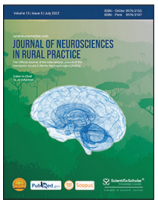

*Original Article*

# Dementia literacy and familiarity with term dementia: An exploratory study from a psychiatry outpatient setting

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## ABSTRACT

**Objectives:** Dementia, often misperceived as an inherent facet of aging, is, in fact, a progressive neurodegenerative condition. It carries a significant stigma due to its associated psychological and behavioral manifestations, leading to neglect and abuse within households. Studies reveal an alarming 90% treatment gap for dementia in India, largely due to limited knowledge about symptom recognition and accessing services. Thus, enhancing dementia literacy becomes crucial for early diagnosis and proper management. This study aims to assess dementia literacy and familiarity with the term "dementia" in a North Indian tertiary health-care setting.

**Materials and Methods:** This cross-sectional study used a case vignette method among patients and their attendants at psychiatry outpatient setting in a tertiary care hospital. A validated Hindi-translated case vignette depicting a dementia patient was employed. The study gathered sociodemographic data, the case vignette, and three related questions. Participants read the vignette and provided answers. The analysis included 200 responses collected in 1 month.

**Results:** Respondents predominantly associated the case's condition with memory issues, mental illness, and psychosocial factors. They suggested social support, a nurturing family environment, communal living, and consulting a doctor for the protagonist. Familiarity with "dementia" was at a mere 24%.

**Conclusion:** Dementia literacy and awareness of "dementia" are notably low in our sample. Urgent efforts are required to enhance dementia awareness to facilitate timely prevention, early detection, and effective management.

**Keywords:** Dementia literacy, Familiarity, Awareness, Case vignette, Psychiatry outpatient setting

## INTRODUCTION

Dementia, a relentless neurodegenerative affliction, precipitates the erosion of memory and cognitive faculties, inexorably encroaching on an individual's functional capacity. Among the litany of dementia types, Alzheimer's dementia reigns supreme, accounting for a staggering 50–70% of cases. Vascular dementia, dementia with Lewy bodies, and frontotemporal dementia stand as other prevalent variants.[1]

As our global populace ages, the specter of dementia looms larger, with its prevalence scaling precipitously. The 2016 World Alzheimer's Report paints a stark picture, indicating a worldwide dementia prevalence rate of 5.2% among individuals aged 60 and above.[2] The Global Burden of Disease Study in 2016 further underscores the magnitude of this crisis, estimating that a disconcerting 3.74 million individuals in South Asia grapple with dementia, with India bearing the brunt of this burden, encompassing 2.93 million sufferers.[3]

In light of the current therapeutic landscape, which primarily emphasizes halting disease progression rather than symptom reversal, fostering awareness of dementia symptoms and facilitating swift evaluation and diagnosis assumes paramount importance. Regrettably, a substantial segment of the populace still perceives the hallmarks of dementia as mere by products of aging or benign deviations. Tragically, dementia is occasionally ascribed to parental maltreatment, abandonment, or a lack of filial affection, further compounding the stigma that shrouds this condition. This societal stigma, combined with the complex psychological and behavioral manifestations of dementia, frequently relegates afflicted individuals to the shadows of neglect and, at times, outright mistreatment.[4]

Although precise statistics regarding the dementia treatment gap in India remain elusive, estimations suggest a dire scenario, with this chasm exceeding a staggering 90% in

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most regions of the country.[5] This gaping void can, in part, be attributed to a pervasive lack of knowledge concerning the recognition of dementia symptoms and the requisite pathways to access critical services. Consequently, elevating dementia literacy emerges as a pivotal strategy, serving as a catalyst for early diagnosis and the implementation of pertinent interventions.

Mental health literacy (MHL), introduced by Jorm *et al*. in 1997, encompasses understanding and beliefs pertaining to psychiatric disorders, facilitating their identification, control, or determent. It comprises five key facets: (a) Capability to discern particular disorders or distinct psychological agony manifestations; (b) adeptness in seeking mental health knowledge; (c) comprehension of vulnerabilities and self-help strategies; (d) awareness of available professional assistance; and (e) fostering frame of mind that foster identification and appropriate help seeking.[6]

In 2009, Low and Anstey tailored the MHL concept to the realm of dementia, conceiving dementia literacy as the knowledge and beliefs requisite for the recognition, management, and prevention of dementia.[7] Surprisingly, extant research evinces a glaring divergence in dementia education even within affluent nations.[8-10] This perplexing variability can, in part, be ascribed to the variegated assessment instruments employed to gauge dementia literacy.

Regrettably, in India, a paucity of studies exists that delve into the MHL pertinent to dementia. Consequently, this study endeavors to bridge this knowledge chasm, undertaking an evaluation of MHL as it pertains to dementia. This assessment includes an exploration of familiarity with the term "dementia." Employing a case vignette methodology, we aim to elucidate these dimensions among both patients and attendants within the hallowed precincts of a psychiatry clinic, ensconced within a tertiary care center in North India.

## MATERIALS AND METHODS

This study was conducted as a cross-sectional investigation within the confines of the outpatient department of Psychiatry in a tertiary care facility. To be eligible for participation, individuals had to meet specific criteria: They needed to be 18 years of age or older, regardless of gender; they had to willingly provide written informed consent; they were required to possess sound mental faculties; be proficient in reading and writing in the Hindi language; and they were to be free from the influence of any intoxicating substances during the cross-sectional evaluation. Ethical approval was sought and secured by the Institute's Ethical Committee.

To effectively gauge dementia awareness and comprehension, a case vignette featuring a dementia-afflicted patient was employed. Permission was sought and granted from the original author for its translation. The case vignette, initially scripted in English, underwent a translation process. Four proficient trainee psychiatrists, fluent in both English and Hindi, independently undertook the translation task. Their respective translated versions were subsequently reviewed and harmonized by the authors through deliberation and consensus, aiming to preserve the essence and fidelity of the original narrative. Feedback from the translators was incorporated into a refined Hindi version. This final version underwent reverse translation into English, vetted and deemed acceptable by ten qualified psychiatrists.

Notably, the protagonist's name underwent alteration, transitioning from "Alish" to "Kabir," a universally recognized name within this region, spanning various major religious denominations.[11]

The comprehensive study instrument encompassed an array of sociodemographic data from the participants, the case vignette itself, and a trifecta of probing questions, closely aligned with the vignette:

1. Do you think that there is anything wrong with Kabir? If you think there is a problem, then what is the problem?
2. How do you think can Kabir be best helped?
3. Have you heard of the term "dementia?" If you have heard, what do you understand by it?

To ensure the instrument's efficacy, a pilot test was conducted, involving ten volunteers. This test confirmed that the instrument was not only easily comprehensible but also elicited responses without undue difficulty. Participants were entrusted with the task of reading the vignette and furnishing their responses to the aforementioned inquiries. They were not prompted for further elaboration, and their responses were unrestricted in form and content.

The data collection effort through purposive sampling technique amassed a total of 200 responses, each of which was meticulously scrutinized. All feasible responses were distilled into individual words or clauses, subsequently organized into thematic categories that naturally emerged during this process. For instance, responses were categorized under themes such as "issues related to normal aging" or "lack of self-confidence." These thematic elements were then analyzed for their frequencies, with repeated words or phrases being counted only once.

To delve deeper into the dataset, we employed Pearson's correlation to explore potential associations between variables such as age, gender, level of education, a history of frequent interactions with hospital services, and dementia literacy.

## RESULTS

As shown in Table 1, the mean age of the study participants was 38.16 years and the majority (63%) were males. 27.5% of

participants were graduates and 50% had a history of mental illness with the affective disorder (62%) being the most common. About 24.4% had a family history of mental illness and 67.7% had a history of frequent contact with health services.

After reading the vignette, a substantial 89.5% of participants expressed a belief that something was amiss with the patient portrayed in the narrative [Table 2]. Notably, a majority (56.2%) ascribed the issues to memory problems, while a smaller fraction (13.9%) attributed them to the natural process of aging. For instance, a 34-year-old male participant remarked, "*As one ages, encountering such problems is normal.*"

**Table 1:** Sociodemographic profile of participants.

| Variable | Frequency (%) |
|---|---|
| Age, Mean (±SD) | 38.16 (±13.364) |
| Gender | |
| Males | 126 (63) |
| Females | 74 (37) |
| Others | 0 (0) |
| Education | |
| Not formally educated | 6 (3) |
| Primary school | 20 (10) |
| Middle school | 51 (25.5) |
| High school | 39 (19.5) |
| Graduate | 55 (27.5) |
| Postgraduate | 16 (8) |
| Professional | 13 (6.5) |
| History of mental illness | |
| Present | 100 (50) |
| Absent | 100 (50) |
| Category of mental illness | |
| Organic | 3 (1.5) |
| Substance-use | 10 (10) |
| Psychosis | 16 (16) |
| Affective | 62 (62) |
| Anxiety | 8 (8) |
| OCD | 1 (1) |
| Family history of mental illness | |
| Present | 49 (24.4) |
| Absent | 151 (75.5) |
| History of frequent contact with health services | |
| Yes | 136 (67.7) |
| No | 64 (32) |

SD: Standard deviation, OCD: Obsessive-compulsive disorder

**Table 2:** Response to question 1-Part 1 (*Do you think that there is anything wrong with Kabir?*).

| Do you think that there is anything wrong with Kabir? | Frequency (%) |
|---|---|
| Yes | 179 (89.5) |
| No | 19 (9.5) |
| Don't know | 2 (1) |

Mental disorders, spanning depression, dementia, schizophrenia, and others were identified by 31% of respondents as potential culprits. A minority segment (3%) acknowledged disturbances in thinking. For instance, a 46-year-old male participant opined, "*Dementia primarily pertains to thought processes rather than being an actual disease.*"

Psychosocial factors were recognized by 10.5% of respondents. A 54-year-old female participant noted, "*Issues within the home environment, family conflicts, and disputes can precipitate dementia.*" In contrast, references to factors such as inadequate diet, blood pressure, or lack of self-confidence were conspicuously rare, each garnering a mere 1.5% or less of responses [Table 3].

As shown in Table 4, in response to the vignette, participants offered diverse suggestions for aiding the patient. A substantial 46.5% recommended consulting a doctor, emphasizing the significance of medical expertise. Notably, 43.8% advocated for the invaluable support of family and kin. Some participants, constituting 16%, suggested the use of medications, while 11% proposed holistic lifestyle changes, including exercise, meditation, and dietary improvements. For instance, a 45-year-old female participant remarked, "*Exercise alone suffices for this condition; medications won't suffice.*"

Furthermore, 8.5% advised counseling as an intervention, recognizing its therapeutic value. A distinct 10% alluded to the potential benefits of reminiscing about the past. A minor fraction (0.5%) expressed faith in divine intervention, with a 51-year-old male participant stating, "*God will be the one to save from this ailment, so regular worship is imperative.*"

Comparatively, financial assistance and the perception that no external aid was needed were less frequently suggested, each accounting for a mere 1% or less of the responses.

**Table 3:** Analysis of response for Question 1- Part 2 (i.e. *If you think that there is a problem, then what is the problem?*).

| Keyword or phrase/selected vernacular equivalents | Frequency (%) |
|---|---|
| Issues related to normal aging | 28 (13.9) |
| Disorder or problems with memory | 113 (56.2) |
| Inadequate diet | 3 (1.5) |
| Mental disorders | 62 (31) |
| Uncategorized | 40 (19.9) |
| Depression | 6 (3) |
| Dementia | 3 (1.5) |
| Schizophrenia | 2 (1) |
| Insomnia | 6 (3) |
| Anxiety | 3 (1.5) |
| Substance-related issues | 2 (1) |
| Disturbance of thinking | 6 (3) |
| Psychosocial issues | 21 (10.5) |
| Blood pressure | 1 (0.5) |
| Lack of self-confidence | 3 (1.5) |

Regarding familiarity with the term "dementia," as shown in Table 5, a mere 24% of the participants had prior knowledge of the term. Interestingly, a modest 16.5% of the respondents associated dementia with memory-related issues.

As shown in Table 6, individuals with a higher level of education were more inclined to attribute the issue to memory problems and were also more familiar with the term "dementia." In addition, a notable association was observed between considering the problem as memory-related and factors such as a history of frequent hospital service interactions and a history of mental illness in oneself or within the family. Moreover, a significant gender disparity was evident, with an elevated number of women than men attributing the problem to a memory disorder.

**Table 4:** Analysis of response to item 2 (*How do you think can Kabir be best helped?*).

| Suggested intervention | Frequency (%) |
|---|---|
| No help needed | 8 (4) |
| Doctor | 93 (46.5) |
| Medications | 32 (16) |
| Counseling | 17 (8.5) |
| Faith in god/Praying | 1 (0.5) |
| Family help and support | 88 (43.8) |
| Lifestyle Modification | 22 (11) |
| Exercise/sports | 7 (3.5) |
| Meditation | 2 (1) |
| Proper diet | 13 (6.5) |
| Reminders of past | 20 (10) |
| Financial help | 2 (1) |

**Table 5:** Analysis of response to item 3 (*Have you heard of the term "dementia?" If you have heard, what do you understand by it?*).

| Variable | Frequency (%) |
|---|---|
| Heard of the term dementia | |
| Yes | 48 (24) |
| No | 152 (76) |
| Explanation of term dementia | |
| Heard but don't know | 5 (2.5) |
| Problems with memory | 33 (16.5) |
| Problems with understanding | 5 (2.5) |
| Mental illness | 2 (1) |

## DISCUSSION

To our current understanding, this study marks the pioneering effort in India to assess MHL concerning dementia and the degree of familiarity with the term "dementia." As evident from the results, approximately 56% of the respondents correctly identified the issue as a disorder related to memory, aligning with findings from a previous study in China, which reported dementia literacy rates at 55%.[8] It is worth noting that although over half of the participants recognized memory problems as a component, only a meager 24% had prior exposure to the term "dementia." On the flip side, 28.5% of participants attributed the condition to other mental illnesses, echoing a similar study where a dementia case was misdiagnosed as depression in 32% of instances.[12] In our study, a mere 13.9% of participants considered dementia as an inherent facet of normal aging, a notable contrast to prior studies where over half believed dementia to be an intrinsic part of the aging process,[13] indicating a rising awareness concerning dementia. Methodological distinctions, including our hospital-based approach, may contribute to this shift in perception compared to previous community-based studies. Moreover, our study uncovered that participants with frequent interactions with hospital services displayed higher dementia literacy levels.

Furthermore, our research revealed a gender disparity, with women exhibiting a greater comprehension of dementia in contrast to men. This observation resonates with previous studies.[8,14] Within Indian culture, women typically assume more significant roles in family caregiving, fostering heightened awareness of health issues, including dementia. Given their empathetic disposition and family-centric orientation, women are more likely to engage in community management and volunteer services, thereby creating opportunities for disseminating knowledge about dementia symptoms.

**Table 6:** Correlation of various aspects of dementia literacy with demographic and other factors.

| Variable | Problem present or not | Considers the problem is due to issues of memory | Familiarity with the term dementia | Considers dementia to be a memory problem |
|---|---|---|---|---|
| | r (*P*-value) | r (*P*-value) | r (*P*-value) | r (*P*-value) |
| Age | 0.095 (0.181) | 0.041 (0.568) | 0.015 (0.834) | 0.029 (0.684) |
| Gender | 0.142 (0.045)* | 0.044 (0.539) | 0.018 (0.796) | 0.078 (0.273) |
| Education | 0.103 (0.145) | 0.161 (0.023)* | 0.356 (0.000)** | 0.294 (0.000)** |
| History of frequent contact with hospital services | 0.084 (0.239) | 0.155 (0.029)* | 0.041 (0.563) | 0.042 (0.559) |
| History of mental illness in person or family | 0.229 (0.001)** | 0.290 (0.000)** | 0.070 (0.323) | 0.148 (0.036) |

*$P<0.05$, **$P<0.01$

Drawing on studies by Lee *et al*. and von dem Knesebeck *et al*., education emerges as a pivotal factor shaping literacy. Education inversely correlates with dementia literacy. Our findings furnish empirical support for the role of education in enhancing dementia literacy, echoing the trend where highly educated individuals tend to exhibit a better grasp of mental illness symptoms compared to those with limited education.[15,16]

It is crucial to acknowledge that this study, while a preliminary endeavor to gauge dementia awareness, has its limitations. The study's sample size is relatively modest, and it employs purposive sampling. In addition, the use of a fictitious character in the case vignette may not fully capture the ecological validity of recognizing dementia symptoms in an actual person. Moreover, given the prevalence of literate participants, the findings may not be immediately relevant to individuals with limited education or those who do not seek medical care at these hospitals. These factors collectively constrain the generalizability of the results, underscoring the imperative need for population-based surveys with more substantial sample sizes to comprehensively address these pivotal questions.

## CONCLUSION

As global life expectancy continues to rise, there is a burgeoning anticipation of a substantial surge in the prevalence of dementia. Recognizing this condition at an earlier juncture holds paramount importance as it augments the prospects for effective treatment and prognosis. Consequently, there exists an unequivocal imperative for public education initiatives tailored to dementia and related disorders. These endeavors underscore the crucial role of public health in disseminating knowledge and fostering awareness. Moreover, educational initiatives must transcend the mere understanding of symptoms; they should encompass comprehensive dementia care resources and inclusive of memory clinics.

Furthermore, it is imperative to integrate grassroots-level health-care workers into the framework, equipping them to undertake screening and offer lifestyle modification strategies specific to dementia. Their inclusion in this process can wield a transformative impact.

Furthermore, it is essential to target specific demographic cohorts, including those with lower incomes, limited educational attainment, and family members of individuals with suspected depression, for targeted health education campaigns within the community. These initiatives aim to bridge critical knowledge gaps and promote early detection and intervention in the context of dementia-related conditions.

### Author's contributions

All the authors have contributed equally in the preparation of the manuscript. YKM, AR, and SS initially composed the manuscript. Subsequently, YKM, AR, SS, and RG conducted a thorough assessment of the statistical analysis and collaboratively crafted the final manuscript.

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### Ethical approval

Ethical approval was sought and secured by the Institute's Ethical Committee, and the study complied with the Helsinki Declaration of 1964.

### Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

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### Conflicts of interest

There are no conflicts of interest.

### Use of artificial intelligence (AI)-assisted technology for manuscript preparation

The authors confirm that there was no use of artificial intelligence (AI)-assisted technology for assisting in the writing or editing of the manuscript and no images were manipulated using AI.

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