# Dementia Management Knowledge, Attitude and Practice of Nurses, Executive Staff and Management from Three Homes of Epoch

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**Abstract:** The study aims to assess knowledge, attitude and practice pertaining to professional caregiving and needs of elderly dealing with dementia. The study was conducted on employees of the three homes of Epoch elder care organization. (N=121). Epoch is an expert in assisted living and dementia care in India. Only participants who were employed by the Epoch elder care organization and have served for a minimum period of 6 months were included. Additionally, those staff members who were not willing to participate/or provide consent were excluded. The survey questionnaire consisted of open - ended & close - ended questions around the three domains (namely, knowledge, attitude & practice). The results of the study show that there is a moderate positive correlation of knowledge with attitude and practice. (r=.414\*\* & r=.463\*\* respectively). The years of experience at Epoch shows a statistically significant relationship with knowledge (p=.028) and the designation at Epoch as well as age shows a statistically significant relationship with attitude (p=<.001; p=.019, respectively). The study also found that the maximum number of employees ( $120.96 \sim 121$ ) showed favourable practice behaviour. Moreover, the study found that cognitive abilities were used as a demarketing factor among the majority of the employees to differentiate between normal aging & dementia. The study also indicated that employees perceived dementia management as a comprehensive team effort. Majority of the employees also emphasized the role of social and cognitive activities in slowing down the progression of dementia. Lastly, in terms of favourable behavioural practice, the majority of the employees emphasized the role of positive attributes of the professionals in dementia management.

Keywords: Dementia, dementia management, knowledge, attitude, practice, elder care, Epoch elder care, Epoch organization

### 1. Introduction

It is estimated that the prevalence of dementia is 7.4% among 60+ adults [1]. The rates of dementia are relatively low in India due to the young demographic dominance in the country, as the reverse demography took place (the elderly population will be dominant) the dementia management would be difficult to cater to the huge population [2].

Much evidence shows that Dementia is not only a neurodegenerative condition but also a crucial public health issue. Further, there are other bottlenecks like shortages in health care infrastructure, low level of awareness regarding dementia care coupled with the stigma attached to dementia care, and professional counselling [3].

In addition to that, the Indian family system is designed in a way that keeps the family together till the end of life, and thus professional care in the times of dementia and other elderly psychological conditions would be the last thing that family could think of. However, currently, India has only 10% of the population lying in the age bracket above 60 years of age. But the challenge is real in terms of future projection [4].

#### 2. Literature Review

An estimated 3.7 million Indians were thought to have dementia in 2010. By 2040, this number is anticipated to rise

by 300% [5]. Despite this, dementia is still not often recognised in India as a disease unless it is extremely advanced and it is rarely acknowledged as an organic brain ailment or a true medical condition. Early dementia symptoms are frequently misinterpreted by family members as evidence of aging normally or as depressive symptoms, which causes both the family and health policy makers to ignore the condition [8]. The Indian family structure is about to shift, even though it is still embarrassing to put parents or other family members in long - term care institutions.

In residential care facilities, a growing number of elderly dementia patients who require round - the - clock care are being looked after by medical experts. Statistics on the number of dementia patients residing in long - term care facilities are, however, lacking [9].

One reason why care staff often have a negative attitude toward dementia patients and why nursing students have reported having unpleasant experiences with these patients in clinical practice may be due to the difficulties of caring for patients with dementia. Another factor contributing to student's poor experiences caring for dementia patients may be their nursing lecturer's ignorance about the condition. These findings are troubling because it is expected that almost all nursing students in India will work with seniors who have dementia [5].

Memory loss, personality changes, sadness, and instability in everyday life are all symptoms of dementia, and patients

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become very reliant on their loved ones and caretakers. Family members must frequently check that a person taking medication for severe memory loss is doing so, and they must also remind them of the specific steps to take for daily tasks like using the bathroom and taking a shower. This high degree of dependency needs ongoing care and frequently calls for additional assistance from caregivers. Because of this, rather than the medical diagnosis, the majority of care costs are related to the need for family and social assistance. Additionally, dementia symptoms will vary based on things like personality and living conditions. Due to the complexity of the care, it is important to carefully evaluate both the dementia patient's physical and psychological capabilities as well as the competency of those delivering it. Making the best decision for the individual's care while taking into account their behavioural demands is one of the most challenging responsibilities for dementia caregivers [6].

According to studies on nursing student's attitudes about and understanding of caring for patients with dementia, they know very little about how to treat this particular population of patients. The Dementia India report notes that there is no particular emphasis on the diagnosis and management of dementia in training for healthcare professionals in India, despite studies showing that training healthcare professionals on working with people with dementia can help to effectively deal with behavioural problems and improve health care delivery. [7] Therefore, the purpose of this study is to describe the attitudes and knowledge of nursing staff working in residential care facilities for old people in India towards dementia.

Many studies have been conducted to explore dementia as a concept and its management in field settings. But there are very few investigations that have an exclusive focus on Knowledge, attitude, and practice aspects of dementia management. Therefore this study will explore dementia management as a holistic process within the assisted living settings. The attitudes and perceptions of nurses, staff, and management will also be assessed as a part of a comprehensive KAP analysis.

# 3. Rationale of Study

Knowledge, Attitudes, and Practices (KAP) study design provides a blueprint for collecting information on what is already known in relation to a particular topic — in this case, Assisted living facilities. According to the World Health Organization (WHO), KAP studies can be used to identify significant knowledge gaps, cultural beliefs, or behaviour patterns that may facilitate better understanding and evidence based intervention. The study also helps define some conceptual terms and also allows researchers to come up with an understanding based definition for conceptual measurement and also highlight issues and barriers in services delivery, and provides solutions for improving the quality and accessibility of services to larger beneficiaries.

Further the KAP also provides the organization with baseline first hand data to keep track of their progress and provides with the measurable scale to measure the program effectiveness. The aim of KAP studies is to conduct pre and post - surveys for monitoring and evaluation purposes on the awareness levels of the Epoch Assisted living Facilities in the three locations. It will also help researchers to identify gaps in knowledge about dementia care facilities as well as describe the socio - demographic component of the individuals who reside and work in the elder care homes.

The KAP study will generate information regarding the identified target groups. These include healthcare workers, management staff of the healthcare facilities, and administrative staff. The results of the KAP study will provide us with the baseline data to make informed comparison on yearly basis and will be helpful in organizational evaluation that determines the degree of effectiveness and impact of the assisted living Health Care Facilities in the three epoch homes (Vermeer, Frida and Monet).

## 4. Methods

#### 4.1 Research Objective

The objective of the study is to assess knowledge, attitude and practice pertaining to professional caregiving and needs of elderly dealing with dementia.

#### 4.2 Sample

The KAP baseline study was facilitated by Epoch elder care, as the regional champions for catering to the elderly with dementia and assisted living for more than 10 years. Given their experience of providing person - centred care at three epoch homes and the senior community in general (above 60).

The study was conducted on three homes of Epoch (Vermeer, Frida & Monet). The study has gathered data using a convenient sampling method. The total sample size was 121 (including nursing, administration, care attendants, cooking and utility staff). Only participants who were employed by the Epoch elder care organization and have served for a minimum period of 6 months were included. Additionally, those staff members who were not willing to participate/or provide consent were excluded.

#### 4.3 Methodology

The data was collected using a self - designed questionnaire which consisted of open & closed ended questions. The questionnaire was divided into three parts and assessed the knowledge, attitude, and practice of the employees. The survey items were arranged in four sections namely demographics details, knowledge, attitudes, and practices.

### 4.4 Analysis

The close - ended responses were analysed using SPSS and the open - ended responses were analysed using thematic analysis.

## 5. Findings

**Socio - economic profile of the employees:** The total sample size of this study was 121. Out of 121 employees, 65 (53.7%) are males and 56 (46.3%) are females. Mean age of the respondents is 27 years. Moreover, out of 121 employees, 76 (62.8%) are care attendant, 22 (18.2%) are cooking & utility staff, 13 (10.7%) are executive staff and 10 (8.3%) are nursing staff. Lastly, out of 121 employees, 62 employees (51.2%) have 1 to 3 years of experience, 25 employees (20.7%) have 3 to 5 years of experience, 20 employees have more than 5 years of experience and 14 employees have less than 1 year of experience in the organization. (Table 1)

Table	1:	Socio -	- economic	status
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Gender	Male=65 (53.7%)	Female=56 (46.3%)		
Designation at Epoch	Care attendant=76 (62.8%)	Executive staff=13 (10.7%)	Nursing staff=10 (8.3%)	Cooking & utility=22 (18.2%)
Years of experience at Epoch	<1 yr=14 (11.6%)	1 - 3 yr=62 (51.2%)	3 - 5 yr=25 (20.7%)	>5 yr=20 (16.5%)

Close - ended responses analysis: -

#### Knowledge of dementia care & management:

Respondents were asked about the definition, symptoms, cause, gender difference, emotional regulation, difference in comparison to normal aging, stages and wellbeing of dementia. Out of 121 respondents, 15.39 approx. (18.62% approx.) [(120.64 ~ 121) & (99.98 ~ 100%) ] were totally unaware about dementia care & management. The remaining 13.42 approx. (15.91% approx.) [(120.64 ~ 121) & (99.98 ~ 100%) ] showed some awareness and 86.11 approx. (71.17% approx.) [(120.64 ~ 121) & (99.98 ~ 100%) ] showed complete awareness of dementia care & management. Overall mean score of knowledge was found to be 20.46. It was found that years of experience in Epoch shows a statistically significant relationship with knowledge (p=.028). Knowledge shows moderate positive correlation relationship with attitude & practice (r=.414\*\* & r=.463\*\* respectively). Indicating that increase in knowledge also leads to increase in attitude & practice.

Table 2: Answers of res	pondents on knowledge related	d to dementia care & mana	igement (n=121)

Questions/statements regarding knowledge of dementia care and its management	Incorrect knowledge	Fair knowledge	Correct knowledge
Dementia is a set of symptoms that may include memory loss, difficulties with thinking. It is progressive in nature and interferes with daily life.	4 (3.3%)	4 (3.3%)	113 (93.4%)
Alzheimer's disease is the cause of dementia.	15 (12.4%)	11 (9.1%)	95 (78.5%)
Dementia affects more women than men.	11 (9.1%)	14 (11.6%)	96 (79.3%)
People with Dementia are able to control their emotions.	28 (23.1%)	18 (14.9%)	75 (62.0%)
Delirium leads to Dementia.	26 (21.5%)	25 (20.7%)	70 (57.9%)
I think normal aging is similar to Dementia.	23 (19.0%)	25 (20.7%)	73 (60.3%)
There are 7 stages of dementia.	3 (2.5%)	9 (7.4%)	109 (90.1%)
What according to you works for the well - being of individuals with Dementia?	39 (32.2%)	24 (19.8%)	58 (47.9%)

#### Attitude of dementia care & management:

Respondents were asked about their opinions and concerns related to dementia patients and their management. Out of 121 respondents, 17.07 approx. (14.11% approx.) [(120.96 ~ 121) & (99.98 ~ 100%) ] showed an unfavourable attitude towards dementia patients and their management. The remaining 23.41 approx. (19.35% approx.) [(120.96 ~ 121)

& (99.98 ~ 100%) ] showed a favourable (fair) attitude and 80.48 approx. (66.52% approx.) [(120.96 ~ 121) & (99.98 ~ 100%) ] showed a totally favourable attitude towards dementia patients and their management. Overall mean score of attitude was found to be 30.29. It was found that designation at Epoch and age shows a statistically significant relationship with attitude (p=<.001; p=.019, respectively).

Table 3: Answers of respondents on attitude related to dementia care & management (n=121	)

Questions/statements regarding attitude of dementia care and its management		Fair	Favourable
		attitude	attitude
What is your opinion of living with a person having Dementia?	4 (3.3%)	96 (79.3%)	21 (17.4%)
How concerned are you about Dementia and its management?	9 (7.4%)	35 (28.9%)	77 (63.6%)
I believe that people with Dementia are responsible for their problem?	23 (19.0%)	16 (13.2%)	82 (67.8%)
Do you see people with Dementia as violent and dangerous people to be avoided?	20 (16.5%)	22 (18.2%)	79 (65.3%)
Would you feel ashamed if people knew someone in your family has Dementia?	10 (8.3%)	2 (1.7%)	109(90.1%)
Would you avoid having a conversation with someone who has Dementia?	14 (11.6%)	5 (4.1%)	102 84.3%)
Do you think people with Dementia can live in the community?	15 (12.4%)	15 (12.4%)	91 (75.2%)
Do you think people with Dementia should live in a nursing home/assisted living?	15 (12.4)	27 (22.3%)	79 (65.3%)
On some occasions, it is okay for a staff member to use force to manage the resident.	25 (20.7%)	18 (14.9%)	78 (64.5%)
Sometimes it is justified to feel burned out during dementia management.	28 (23.1%)	25 (20.7%)	68 (56.2%)
There is nothing we can do to improve the security of the residents.	36 (29.8%)	14 (11.6%)	71 (58.7%)
Do you think that there should be a regulatory board to look into standardized protocol for	by you think that there should be a regulatory board to look into standardized protocol for		109
Dementia care homes?	6 (5.0%)	6 (5.0%)	(90.1%)

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#### Practice towards dementia residents:

Respondents were asked about how they treat residents with dementia. Out of 121 respondents, 13.99 approx. (11.57% approx.) [(120.97 ~ 121) & (99.99 ~ 100%) ] showed an unfavourable practice towards dementia residents. The remaining 7.99 approx. (6.61% approx.) [(120.97 ~ 121) &

 $(99.99 \sim 100\%)$ ] showed a favourable (fair) practice approach and 98.99 approx. (81.18% approx.) [(120.97 ~ 121) & (99.99 ~ 100\%)] showed a totally favourable practice approach towards dementia residents. Overall mean score of practice was found to be 10.81.

Table 4: Answers of respondents	n practice related to dementia care & management (n=121)
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Questions/statements regarding practice of dementia care and its management	Unfavourable practice	Fair practice	Favourable practice
I treat elders with dignity and respect.	3 (2.5%)	1 (0.8%)	117 (96.7%)
I treat elders based on my mood.	29 (24.0%)	5 (4.1%)	87 (71.9%)
I try to understand elders by giving my time.	6 (5.0%)	1 (0.8%)	114 (94.2%)
I get irritated very easily at home.	18 (14.9%)	25 (20.7%)	78 (64.5%)

Open - ended responses analysis: -

#### Answers of respondents on knowledge related question on dementia care & management (n=121)

**Differences observed in normal aging and dementia:** There were seven broad themes identified namely, 1) age, 2) cognition, 3) behavioural, 4) neurological, 5) emotional, 6) psychological and 7) biological. The most frequent response was around cognition, followed by behavioural and age. Post these responses biological, neurological, psychological and emotional were frequently occurring responses, respectively. These are the following responses listed in each of these seven themes. It is important to note that one person's response was made in more than one theme.

- 1) Age: Increase in age & 45/60/80 years above individuals
- 2) Cognition: The most popular responses were memory loss, forgetfulness, loss of cognitive functions, poor decision making & judgment skills and confusion
- Behavioural: Abnormal behaviours, wrong doings (God's punishment), inability to do daily life activities (ADL), inability to take care, repeatedly asking for information & loss of efficiency
- 4) Neurological: These included responses as neurological disorder, progressive condition and Alzheimer's disease
- 5) Emotional: Loss of emotional control & happiness
- 6) Psychological: Depression, mental activity decreased, disability & motivation
- 7) Biological: Hypertension, genetics and disease

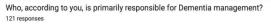
# Answers of respondents on attitude related question on dementia care & management (n=121)

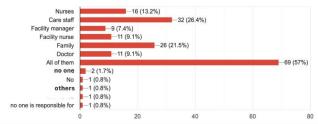
Who is primarily responsible for dementia management & why: Majority of the respondents (69 people out of 121) responded "all of them" (57%) as responsible for dementia care and management. Care staff (26.4%), Family (21.5%) and Nurses (13.2%) were respectively preferred responses. There were two broad themes around which respondents answered. These are 1) Collective care, and 2) Personal attributes. These are the following responses listed in each of these two themes. It is important to note that one person's response was made in more than one theme.

1) Collective care: Team work, community support, ecosystem services, comprehensive care, professionally trained, collaborative effort, quality care, holistic care, all of the mentioned professionals come under dementia care, medical support and humanity.

2) Personal attributes: These include the characteristic or personal traits. Handle their childlikeness, look after their needs, offer personalized care, has experience with elders, are able to identify the disease, are responsible, always look after their needs, offer care and are present at all times.

# Table 5: "Who is primarily responsible for dementia management" responses





Answers of respondents on practice related question on dementia care & management (n=121)

How can we slow the progression of dementia: There were four themes identified namely, 1) activities, 2) professional assistance, 3) lifestyle and 4) attitudes & behaviour. The most occurring theme was activities, followed by professional assistance, lifestyle and attitudes & behaviour respectively. These are the following responses listed in each of these four themes. It is important to note that one person's response was made in more than one theme.

- Activities: It provided the benefits of activities to help slow the progression of dementia. Exercising can help divert the mind, create cognitive, social & physical engagement, helps in challenging the brain by providing mental stimulations and also assist in motor & sensory engagement.
- 2) Professional assistance: It provided the benefits of professional assistance in slowing the progression of dementia in an elderly. These include having good behaviour with the resident, taking good care, preventing onset, admitting them into assisted living, following doctor's advice, working in a team with the

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nurses & care staff, providing physiotherapy and medicines.

- 3) Lifestyle: It provides lifestyle changes & their benefits that can help slow the progression of dementia. These changes include timely eating, proper diet, eating fish, spending time with the residents, quality of sleep, family interactions, living with other healthy individuals, consuming less alcohol & cigarettes, weight management, preventing any infections or injury, stress management and keeping them happy.
- 4) Attitudes & behaviour: It includes the attitudes & behaviour of the professional that can help the resident slow the progression of dementia. These include doing what they like, talking about & reminding them of their past, understanding them and always agreeing with them always.

**Best activity for slowing down dementia in an individual:** There were five themes identified namely, 1) activities, 2) social engagement, 3) attitudes, 4) professional assistance and, 5) diet. The most occurring theme was activities, followed by attitudes, professional assistance, social engagement & diet respectively. These are the following responses listed in each of these five themes. It is important to note that one person's response was made in more than one theme.

- Activities: It helps them keep busy, mode of entertainment and offer enjoyment. The respondents suggested activities like puzzles, sudoku, memory based activities, writing, group activities, every day run, cooking, art, brain activities, exercises, music, cognitive & sensory - motor activities, in no particular order.
- 2) Social engagement: It includes activities where the resident is socially engaged with others such as outings.
- 3) Attitudes: These include attitudes on the part of the professional. These include reminding them of their past, greeting them properly, showing them their favourite thing, treating them with care, not arguing with them, doing what they want and what keeps them family and spending time with them.
- Professional assistance: These include behaviours of professional help, such as maintaining their daily routine, giving medicines on time and seeking expert advice in case of an emergency.
- 5) Diet: It includes the importance of proper diet by offering nutritious food to the resident.

What should be done during times of disturbing behaviour presented by the residents: There were two themes identified namely, 1) attitudes of the professional, and 2) mode of external assistance. The most occurring theme was attitudes of the professional followed by mode of external assistance. These are the following responses listed in each of these two themes. It is important to note that one person's response was made in more than one theme.

 Attitudes of the professional: The respondents have mentioned attitudes of the professional that helps in times of disturbing behaviour presented by the residents. These include, distracting the residents, holding one - on

 one interaction with the residents, understanding the cause of occurrence of the challenging behaviour, understanding their discomfort or pain, calming them,

 being steady, consistent and firm with them, also being near them during the time of challenging behaviour and never disagreeing with them. It also includes being calm and controlled by providing them love, comfort and care. Moreover, being away from the resident for some time, asking others to help, having patience, calming listening and engaging in care plans (for example, giving them food, checking diapers, checking the temperature of the room or for any kind of pain).

2) Mode of external assistance: These responses include assistance required by using any external thing or help. These include, distracting the residents mind by engaging in some activities, involving the resident in music or diversion therapy, providing the resident with family time, bringing the resident what they need or like and exercising with them daily.

## 6. Discussion

The study was conducted on Epoch employees who have been employed for a minimum of 6 months. The total sample size was 121 employees with 65 (53.7%) being males and 56 (46.3%) being females.

For **knowledge**, the results show that 86.11 approx. (71.17% approx.) [(120.64 ~ 121) & (99.98 ~ 100%) ] employees showed complete knowledge related to dementia care & management. Additionally, it is found that years of experience at the job can help predict the knowledge of the employee (p=.028). It is also found that as knowledge increases, a moderate increase can be visible in attitude & practice (r=.414\*\* & r=.463\*\* respectively) of the employee.

The open - ended question on knowledge was "differences observed between normal aging & dementia". The responses were made around seven themes. The most frequent response was around cognition, followed by behavioural, age, biological, neurological, psychological and emotional were frequently occurring responses, respectively.

For **attitude**, 80.48 approx. (66.52% approx.) [(120.96 ~ 121) & (99.98 ~ 100%) ] employees showed a totally favourable attitude towards dementia patients and their management. It is found that designation at the job and age can help predict the attitude of the employee (p=<.001; p=.019, respectively). The open - ended question on attitude was "who, according to you, is primarily responsible for dementia management and why". Majority of the respondents (69 people out of 121) responded "all of them" (57%) as responsible for dementia care and management. Along with this, care staff (26.4%), family (21.5%) and nurses (13.2%) were other preferred responses. The responses were made around two themes namely, collective care and personal attributes of the professionals.

For **practice**, 98.99 approx. (81.18% approx.) [(120.97  $\sim$  121) & (99.99  $\sim$  100%) ] employees showed a totally favourable practice approach towards dementia residents.

The open - ended questions on practice were "how can we

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slow the progression of dementia", "best activity for slowing down dementia in an individual" and "what should be done during times of disturbing behaviour presented by the residents". For the first question, the responses were made around four themes. The most occurring theme was activities, followed by professional assistance, lifestyle and attitudes & behaviour respectively. For the second question, the responses were made around five themes. The most occurring theme was activities, followed by attitudes, professional assistance, social engagement & diet respectively. And for the last question, the responses were made around two themes. The most occurring theme was attitudes of the professional followed by mode of external assistance.

# 7. Conclusion

The study found that there exists a moderate positive correlation between knowledge, attitude and practice. This indicates that as favourable knowledge increases, favourable attitude and favourable practice behaviour also increases. It was also found that the maximum number of employees  $(120.96 \sim 121)$  showed favourable practice behaviour.

The study demonstrated that the majority of the employees differentiated between normal aging and dementia based on cognitive abilities. It was also noted that the majority of the employees agree that dementia management is a collective and comprehensive team work in which all the professionals and family members play a responsible role. Additionally, it was found that the majority of the employees responded that activities (ranging from social & cognitive engagement) can slow the progression of dementia in residents. Lastly, the majority of the employees responded that the attitude of the professional is crucial in managing resident's disturbing behaviours.

# 8. Limitation of the Study

The results of the study could not be generalized for the following reasons:

- 1) The study was limited to a specific organization and geographical area (Epoch homes).
- 2) The sample was selected only from the Epoch organization.
- 3) The sample size is relatively small which restricts the statistical inferences of the findings.

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