Explanatory Models of Dementia among Caregivers of Elderly Persons with Dementia – Analysis of Secondary Data

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Authors' contributions

This work was carried out in collaboration among all authors. Author NAG designed the study, performed the statistical analysis, wrote the protocol and wrote the first draft of the manuscript. Authors SL and MKSM managed the analyses of the study. Author SAH managed the literature searches. All authors read and approved the final manuscript.

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ABSTRACT

Rising life expectancy is associated with an increased prevalence of chronic diseases like dementia. The prevalence of dementia is significantly higher in low- and middle-income countries. The public's awareness of dementia in India is low. Help-seeking is largely dependent on one's socio-cultural perspective of a sickness episode and one's beliefs about the aetiology, course, and

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outcome of the illness. Dementia is still not conceptualised as a health problem, and it is believed to be a consequence of normal ageing. So carers are not concerned about seeking help. We interviewed 35 carers of persons with dementia (as per ICD-10) using the Short Explanatory Model Interview (SEMI). We explored the explanatory models of dementia given by caregivers of people with dementia. Qualitative data analysis was done using ATLAS.ti. We identified four main themes that carers expressed, namely, I) Problems of the patient: Many caregivers reported that memory loss, behavioural problems, and impaired biological functioning were their main concerns. II) Cause of problem: caregivers expressed that psychosocial stress, ageing, and black magic were causes of dementia. III) Reason to visit and expectation: most caregivers consulted doctors due to the worsening of their relatives' problems, and they were advised by others to visit. They expected medicines, better treatment, and a cure from doctors, and IV) Outcome of problem: caregivers were worried about problems with appetite, memory loss, impaired verbal communication, difficulty at work, and their relatives going missing. Caregivers have the idea that their relative had some problem that involved the brain, but most of them attribute this to the consequences of ageing due to psychosocial factors like excessive stress, bad interpersonal relationships, life events, economic crises, and black magic. There is a need for an awareness-raising campaign for dementia in the community at large concerning its cause, symptoms, course, progression, and most importantly, locally available services.

1. INTRODUCTION

World's population is aging as life expectancy is rising and the death rate is declining. Longer life has resulted in a high number of people living with non-communicable diseases, including dementia. Dementia is a syndrome usually chronic, characterized by a progressive, global deterioration in intellect including memory, learning, orientation, language, comprehension, and judgment due to a disease of the brain. Dementia is one of the major causes of disability in late life. Alzheimer's disease is the 6th leading cause of death [1] and the fifth leading cause for people aged 65 years and over [2]. This is significantly high in LMIC. Dementia has a vast impact on the mortality and morbidity of patients as well as on families, caregivers, and societies in terms of economic impact.

Help-seeking is largely dependent on one's socio-cultural perspective of sickness episodes, and one's belief of the aetiology, course, and outcome of illness. Explanatory models are ways of conceptualizing how illness is recognized, understood, and interpreted, from popular, folk, and professional perspectives [3]. Western studies explained that people do not conceptualize dementia as a health problem and it is believed as a consequence of normal aging [4] which leads to low rates of diagnosis and it is low levels of awareness and training of healthcare staff. Due to the lack of professional knowledge about treatment and care options, people may also deny access to post-diagnostic

care, treatment, and support for those who are diagnosed.

Bianca Brijnath's rich ethnography titled 'Unforgotten' is a classic study on how Indian middle-class families care for their relatives with dementia [5]. She conducted 46 interviews with 20 families over 10 months. It was observed that dementia was often not diagnosed until the second stage when behavioural symptoms become more prominent and carers were less able to ignore the social disruptions they produced. She says that there were familial and patient barriers to early diagnosis because the symptoms were initially conceived as cultural idiosyncrasies of old age and that there was a heuristic process whereby these 'normal' symptoms of aging got translated into AD. She has observed that symptoms like memory loss, and cognitive and functional decline are seen in India as normal social markers of aging. Neighbour's threats, pre-existing health conditions or sudden injuries, and stigma were reasons for help-seeking in a few families. Also, few families attributed initial symptoms of dementia to prolonged periods of grief or shock due to the loss of loved ones. According to older family members, dementia had social origins rather than neurological origins. It was due to tension, loneliness, and time. Few studies done in India [6,7] reported that people believed in too much tension was leading to dementia, depression, and psychosis. Many of them think that nothing could be done and there is no cure for dementia. So they are not concerned about

help-seeking [8]. All of this has led to a treatment gap which is certainly high in low and middle-income countries.

A study was conducted at the National Institute of Mental Health and Neurosciences by Dr.Hossein in 2015 [9] on pathways to care for dementia among 35 caregivers of dementia. Here our study is a secondary analysis of available data from that study which aims at assessing explanatory models of dementia given by caregivers of elderly people with dementia.

2. METHODOLOGY

2.1 Procedure

This is a qualitative analysis of secondary data. The study was conducted in the Geriatric Clinic Service of NIMHANS. The data from 25 interviews of caregivers which were already available and the data from 10 more interviews of caregivers which we conducted by the primary author due to missing data and to have good quality data were analysed. So, finally, 35 caregivers' interviews which were in Hindi or English were included. Caregivers of persons with dementia are taken as subjects consecutively once informed consent was obtained from them.

2.1.1 Inclusion criteria (Secondary data from an earlier study)

1. Caregivers of elderly patients aged more than 55 years attending the geriatric clinic at NIMHANS and diagnosed with dementia as per ICD 10
2. Caregivers who are living with the patient and give reliable information about the patient's illness.
3. Caregivers who speak Hindi/English.

2.1.2 Exclusion criteria (Secondary data from an earlier study)

1. Patients aged less than 55 years.
2. Caregivers who are not living with the patient and can't give adequate information.
3. Caregivers who do not speak Hindi/English.

Available audio-recorded data which was in Hindi was translated to English and transcribed. Data in English were transcribed directly. 10 more interviews were done additionally and audio recorded due to missing of data and for good quality of data and those interviews were transcribed. Transcripts were read and re-read several times. The responses were coded iteratively in Atlas.ti [10]. A qualitative analysis of translated responses was done

2.2 Assessment Tool

2.2.1 Short explanatory model interview: [11]

It is a semi-structured interview questionnaire in simple language with minimum use of medical or technical terms or phrases. The qualitative questionnaire was translated into the regional language Hindi for a better understanding of the questions by the subjects. It was modified to make it more reasonable for Indian socio-cultural background and also few modifications were done in context to the particular disease dementia. The SEMI has both the patients' and the caregivers' explanatory model of disease. Here caregivers' explanatory model was used. The caregivers were asked mostly open-ended questions about their experiences and interpretation of symptoms of their relatives to elicit their beliefs, held concepts, and social and cultural influences upon them. All responses were elicited by probing. 25 such interviews which were audio recorded were available. 10 more interviews were conducted and audio recorded. The scale is divided into a few separate parts with a group of questions. The initial part was on the subject's details, it includes name, age, sex, education, occupation, marital status, religion, and religious belief. Following which next section was the 'explanatory model for current illness episode'. It covered a person's understanding of the nature of presenting problem, the reason for consulting, the name of the problem, perceived causes, consequences, severity, and its effect on body, mind, social communication, home, and work-life in also studied. Another section was on 'Pathways to care' which examined help-seeking behaviour, contact with non-medical sources (e.g. traditional healers, and detail of interaction with a physician is also evaluated in terms of expectation and satisfaction which was used in the earlier study and hence was not included in our study.

2.3 Analysis

The data was analysed using qualitative data analysis. ATLAS.ti software [10] was used for qualitative data analysis. The responses of caregivers were coded iteratively in Atlas. ti. The

grounded theory coding was conducted [12]. The contents of the interviews were examined thoroughly, read and re-read several times. The data was disentangled, multiple themes were identified and each theme was coded using open coding to begin with [13]. 213 codes were derived from open coding which were closely observed. They were refined to 191 codes after merging codes with similar meanings. Those 191 codes were further refined and differentiated into 10 categories which were called Code groups/ Categories depending on themes of questionnaires in SEMI and explanatory models given by caregivers of elderly people with dementia. This was done using Axial coding by identifying and classifying the links between the substantive categories [13].

Subsequently, those 10 code groups were read, re-read, and further categorized into 4 broader groups called Super groups/ Smart groups, namely,

- Reasons for consultation
- Understanding the cause
- Expectations from the Care Centre/ NIMHANS
- Worry about the problem

The themes with more groundedness were observed and interpreted. The possible semantic network links were formulated on Grounded theory.

3. RESULTS

Caregivers who live with persons with dementia and take decisions upon help-seeking and who carry financial burdens were included. Caregivers of patients with all types of dementia which includes Alzheimer's disease, Vascular Dementia, Front temporal Dementia, and Diffuse Lewy Body Dementia were interviewed.

An explanatory model of dementia given by the caregiver of patients.

During the interview, multiple themes emerged from the responses of the caregivers in different areas of their understanding of dementia. Those constructs were categorized and responses are listed.

3.1 Reasons for Consultation

There are various problems for which the caregiver consulted a doctor. Among the heterogeneous responses, a few emerging themes are listed with responses.

3.1.1 Memory loss

Most of the responses from pointed out, there is a significant impairment in a person's memory which made them come to a health professional.

Table 1. Socio-demographic variables of caregivers (n=35)

	Frequency	Percentage
Gender		
Male	22	63
Female	13	37
Occupation		
Profession	17	49
Others	18	51
Education		
Graduate or more	21	60
Others	14	40
Religion		
Hindu	27	77
Muslim	8	23
Place		
North	15	43
South	20	57
Marital status		
Married	27	77
Single	6	17
Divorced	2	6
Age in years	**Mean**	**S.D**
	37	12.16

The response given by 38 years old male caregiver, "If I tell him to go to market, he will go to some other place. If I tell him to buy five things, he will buy any 2 or 3 items. He is forgetting. He is also forgetting the way home. He is forgetting the names of his sisters, and brothers, what has happened earlier. For example, when I asked about his close friend who expired 3 and half years back, He says that he is still alive. He does not remember that he by his hands itself has buried that person."

3.1.2 Behavioural problems

Most of the respondents reported anger, agitation, physical abuse, verbal abuse, behavioural change, hallucination, and suspicion as behavioural problems.

The response was given by a 37-year-old female caregiver, "He is hitting my mother very badly. Because of it, she got injured and fractured, he has broken all furniture."

3.1.3 Disturbance in functioning

The next common problems reported by caregivers are problems in sleep, appetite, self-care, and doing day-to-day activities.

3.1.4 Problems in thinking

Other common problems reported by caregivers are problems in thinking, making decisions, and recognizing family members.

37-year-old female caregiver reported about her father, "He was an Ex-serviceman and was working in Mumbai. He is not recognizing Kannada. He is asking my mother why children are talking in other languages and not Hindi/ Punjabi. He is not recognizing my brother–in–laws and was asking who this person with my daughter is."

3.1.5 Problems in identifying directions and routes

Persons usually have problems identifying the proper position. They often cannot find their way back home. Few caregivers mentioned this as a problem.

33yrs old female caregiver reported about his father: "He will go somewhere and we have to

search for him. If we are not there, he does not stay at home, he goes out. We have to find him."

3.1.6 Impaired verbal communication

Often the caregivers find that patients have significant difficulty in communicating using proper words. Though they have the information, they are not able to organize and make them into words. Also, few caregivers reported that their relatives have decreased verbal communication.

3.2 Understanding the Cause

After analysing the responses in the context of the cause, a few major constructs came out.

3.2.1 Ageing

Most people think that it is an illness related to aging.

3.2.2 Psycho-social factors

Though people have an idea of the biological model of causation, often they attribute this to psychosocial factors like problems in interpersonal relations, life events, loneliness, inactivity, business problem, and other stressors, etc. Most of the caregivers gave psycho-social factors as the cause of their relative's illness.

36 years old female caregiver about the cause of her mother's problem, "When her mind was normal, her in-laws who were money minded were torturing her, angry on her, talk about her. When she goes to her mother's home, they used to take care of her and feed her and she used to become normal. Later she comes back to her in-law's home. She used to tell us that because of torture in her in-law's home, she used to cry because she was getting headaches. So, we think illness is because of that."

3.2.3 Brain disease

Many of them think that this is a disorder of the brain like stroke and degeneration as the cause.

30yrs old male caregiver about the cause of her father's illness said, "Pathophysiology is unknown. It is due to age-related gradual neuro degeneration in brain. But the reason behind neuro degeneration is not known. There are many theories like some neurotic plaque etc. But the exact reason is not yet clear."

Table 2. Code groups, created codes, and grounded themes (n=35). There were multiple responses

Code groups/ Categories	Codes	Groundedness
Presenting problems	Memory loss	27
	Behavioural problem	17
	Impaired biological functions	6
	Problem in cognition	4
Most worrisome problem	Memory loss	15
	Impaired biological functions	6
	Problem in cognition	4
Affected part	Brain	28
	Mind	14
Name of problem	Memory loss	13
	Dementia	6
	Mental illness	6
Cause of problem	Ageing	21
	Psycho-social stress	34
	Black magic	5
Most important cause	Ageing	1
	Psycho-social stress	11
	Brain stroke	1
	Head injury	1
	Degeneration	1
Reason to visit	Worsening	13
	Advice	6
	Follow up	4
Expectations from health care system	Medicines	10
	Better treatment	6
	Cure	5
Fear of consequence	Problem in appetite	15
	Memory loss	12
	Missing	8
	Worsening	7
Impact on patient	Impaired verbal communication	16
	Problem in appetite	15
	Difficulty in work	9
	Difficulty at home	7

3.2.4 Substance use as the cause

Few caregivers reported substance use like alcohol and nicotine as the cause.

37 years old female caregiver about the cause of her father's illness, "He is heavily alcoholic, I can consider alcohol may be a cause, 65%. He started consuming earlier only, and nowadays he has increased consumption. He is not able to digest that. Instead of food, he is consuming alcohol."

3.2.5 Other causes

Few caregivers reported that accidents, another physical disease, evil spirits, due to karma, or punishment from God as causes of illness of their relatives.

3.3 Expectations from the Care Centre / NIMHANS

When the participants were asked the reason for coming to NIMHANS and what the expectations are, few constructs came out.

3.3.1 Better care

Most of the patients are already under treatment. But they are not satisfied as they are not getting a proper response or they are expecting even much more.

On asking the reason for coming to NIMHANS this male professional said, "I know there is no treatment for this illness. Present treatment can slow down the progression. This treatment should be continued and if there is any advanced intervention, I want to have that also."

3.3.2 Cure

Though a good percentage of people know the outcome, some of them expect a cure, which made them come to NIMHANS.
30yrs old female wants her father-in-law to get the cure, "I am expecting that problem of the brain should get cured. He should start taking food properly. He should sleep well."

3.3.3 Worsening of illness

People said that they are much worried and scared about the progression of the disease, and the aggravation of symptoms.

35 years old male caregiver about the reason to visit, "When I noticed him, I went to a local doctor. They gave medicines, but there was no change and the situation was becoming worse. So, we have come to NIMHANS."

3.3.4 Medicines

Most of the caregivers mentioned that they are expecting medicines as treatment for their relative illness.

A 22-year-old male caregiver about expectation said, "They have given tablets. I am expecting further good action on adding other tablets."

3.3.5 Others

Few caregivers reported that doctors referred them to NIMHANS and hence they visited. Also, other well-wishers advised them to visit NIMHANS. Few caregivers mentioned routine follow-up as a reason to visit.

Few caregivers are aware that the disease cannot be cured and they were expecting to delay the progression of the disease and reduce behavioural problems from doctors.

3.4 Fear of Consequences and Impact

3.4.1 Missing

Most caregivers are worried that their relatives will forget the way home and they may go missing.

A 33 years old male caregiver about his father said, "He will forget ways and may go missing. He may go out of home when the gates are open because of his absent mind. Anything can happen."

3.4.2 Memory loss

Most of the caregivers are worried about memory loss in their relatives.

3.4.3 Worsening of illness

Few caregivers mentioned that the progression of the disease was their fear.

34 years old female caregiver said, "It is a long-term problem which we all know progresses. We are worried about the aggravation of symptoms which may lead to the wrong diagnosis when the actual problem happens."

3.4.4 Impairment in biological functions

Few caregivers mentioned sleep disturbance, decreased appetite, and problems in self-care and day-to-day activities with their relatives as their fear.

3.4.5 Others

Few caregivers reported that physical abuse of their relative, fall of their relative, difficulty in interaction, responsibility, and family burden on them as their worry.

3.5 Socio-demographic Variability

In our study, 22 (63%) caregivers were male and 13 (37%) were female, 17 (49%) caregivers were in professional jobs like teachers, or engineers, and the other 18 (51%) caregivers were clerks or housewives. The majority of caregivers (21 out of 35; 60%) were graduates, three of them did not receive formal education and the remaining had completed twelfth standard. Among caregivers, 27 (77%) belonged to the Hindu religion and the remaining 8 (23%) belonged to the Muslim religion. 20 (57%) caregivers were from south India and the remaining 10 (43%) were from north India. 27 (77%) caregivers were married, 6 (17%) were single, and the remaining 2 (6%) were divorced.

We observed that 6 caregivers who know that the illness is dementia, were from professional backgrounds. Out of 6, 4 caregivers were male

and the remaining 2 were female. 3 caregivers were from south India and 2 were from north India. 5 caregivers belonged to the Hindu religion and the remaining 1 caregiver was a Muslim. 2 out of 6 caregivers who know about dementia expected delaying progression and others expected a cure and medicines.

It is also seen that 5 caregivers felt black magic was a cause of dementia. Out of 5, 3 were men and 2 were women. 4 out of 5 were from south India and belonged to the Hindu religion. Among 5 caregivers, 3 were married, 1 was single and the other was divorced. 4 caregivers were graduates, and 1 caregiver did not receive any formal education.

57% of the respondents perceived dementia as a disease of the brain, 17% thought it involved the mind and another 23% believed it involved both brain and mind. 54% thought it was a severe illness. 43% thought it was moderate and as per 3%, it was mild.

A good number of the respondent (48.6%) believes that without treatment this illness would worsen but won't be fatal. Many of them (51.4%) perceived that with treatment there will be partial improvement.

60% of respondents attributed aging as a cause. 23% felt these symptoms are due to disease.

4. DISCUSSION

Here our study explored the explanatory models given by the caregivers of elderly people with dementia. Dementia is often understood as a normal part of aging and people do not know about or recognize the symptoms of dementia. In our study, we came across multiple themes from caregivers' interviews regarding their understanding of dementia.

4.1 Reasons for Consultation

In our study, we have explored the major problems that initiated help-seeking. Many of the caregivers would recognize cognitive symptoms in their relatives like impaired memory, impaired verbal ability, or impaired visuospatial orientation as the reasons for consultation. These symptoms usually interfere with one's activities of daily living. So the family members felt the need for help. Other symptoms noted by the caregiver were behavioural problems like agitation and irritability, and impaired biological functions like

decreased sleep and appetite that affect the activities of another family member at home. It was observed that dementia was often not diagnosed until behavioural symptoms become more prominent and carers were less able to ignore social disruptions they produced. And finally, when a person with dementia becomes a burden on family members for their ADL they try to find a solution for that. Behavioural and psychological symptoms of dementia (BPSD) are an integral part of dementia syndrome. These symptoms increase morbidity and burden, affect the quality of life and impact the cost of care [14]. Caregivers' satisfaction with their relationship with the patient and the patient's functional independence predicted the direct impact of caregiving on caregivers' lives.

4.2 Understanding the Cause

The main finding in this part of our study is that we have got three major causal models of dementia.

1) Psychosocial stress, 2) Age-related problems, 3) Black magic. Caregivers have the idea that their relative had some problem that involved the brain (Table 2) but most of them attributed this to consequences of aging, due to psychosocial factors like excessive stress, bad interpersonal relation, life event or economic crisis, and black magic. A few caregivers also told that head injury, degeneration, and substance use are also the cause of their patient's condition. Earlier Western studies also described people's understanding of dementia as age-related problem and as neuropsychiatric illness [15]. Inadequate detection and referral and poor management have been documented nationally and internationally, leading to people with dementia and their families being denied optimal pharmacological and psychosocial intervention. In one study people described psychosocial factors or physical health-related problem as causal factors [16]. An Indian study found the symptoms of persons with dementia are considered to be features of aging. There is a lack of knowledge that the symptoms are part of an illness and which require special care [17]. There are other studies that revealed various causative beliefs i.e. deliberately produced, acts of god [18] or bad 'Feng Shui', a Chinese philosophical system, which means improper harmonization with the environment [19]. In our study, few caregivers told that either punishment from god or karma may be the cause of dementia.
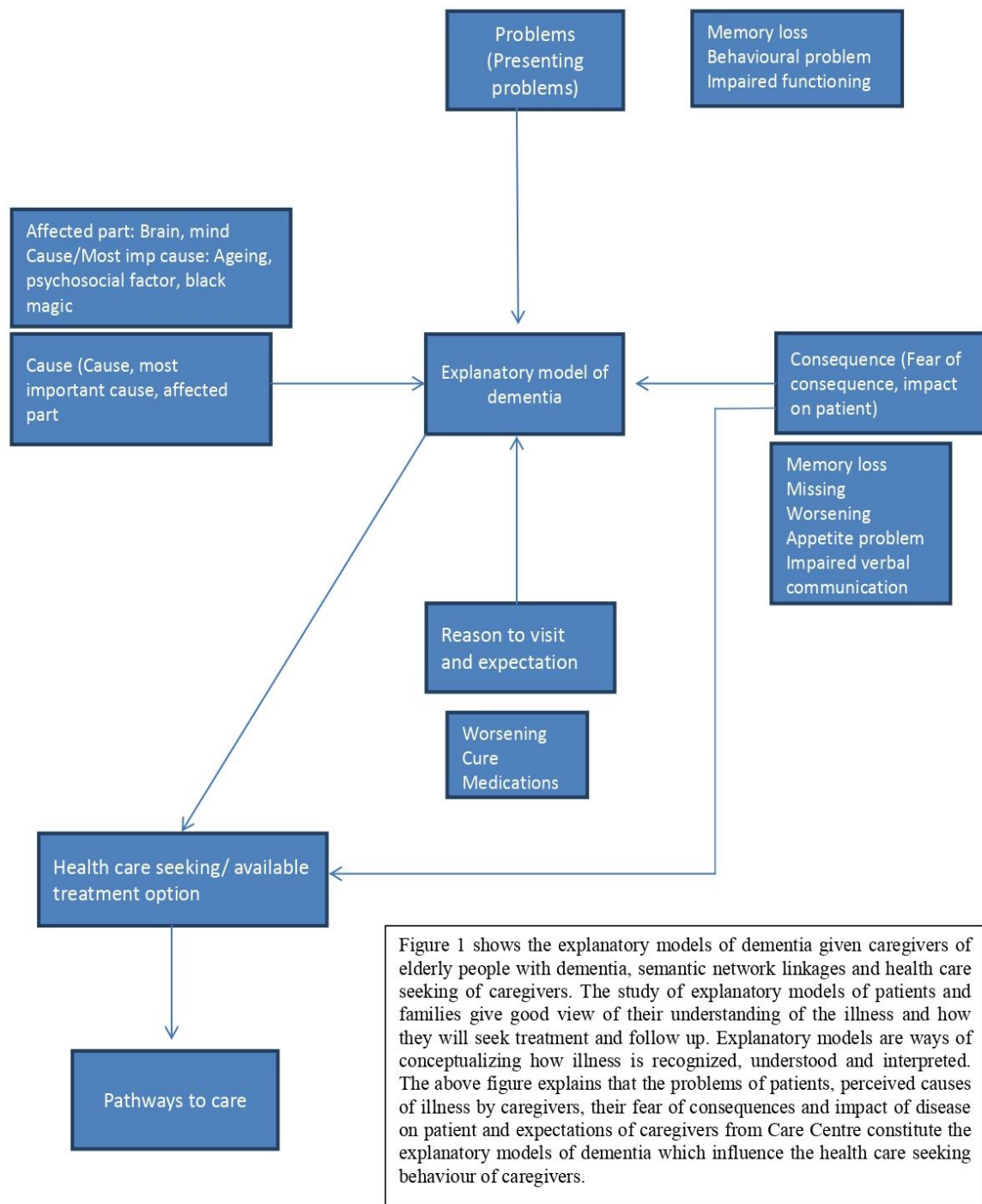
Problems (Presenting problems)

Memory loss
Behavioural problem
Impaired functioning

Affected part: Brain, mind
Cause/Most imp cause: Ageing, psychosocial factor, black magic

Cause (Cause, most important cause, affected part

Explanatory model of dementia

Consequence (Fear of consequence, impact on patient)

Memory loss
Missing
Worsening
Appetite problem
Impaired verbal communication

Reason to visit and expectation

Worsening
Cure
Medications

Health care seeking/ available treatment option

Pathways to care

Figure 1 shows the explanatory models of dementia given caregivers of elderly people with dementia, semantic network linkages and health care seeking of caregivers. The study of explanatory models of patients and families give good view of their understanding of the illness and how they will seek treatment and follow up. Explanatory models are ways of conceptualizing how illness is recognized, understood and interpreted. The above figure explains that the problems of patients, perceived causes of illness by caregivers, their fear of consequences and impact of disease on patient and expectations of caregivers from Care Centre constitute the explanatory models of dementia which influence the health care seeking behaviour of caregivers.

Fig. 1. Popular explanatory models, semantic networks, and health care seeking among caregivers of elderly patients with dementia

4.3 Reason to Visit and Expectation of Treatment Outcome

In our study, we found that worsening symptoms, and others advice were reasons to visit. Also, we found that caregivers have a belief that with treatment there will be a partial improvement or cure or it will be stable. While without treatment the disease will worsen or become fatal. Caregivers also encounter barriers when seeking a diagnosis, including the time-consuming and expensive nature of the process, not knowing where to turn for help, the patient's reluctance to go to a doctor, and a lack of consensus among

family members about how to proceed. Providing information to caregivers about what is wrong, ruling out other reversible causes of memory or behaviour problems, facilitating access to community-based information and support services, promoting adaptation and coping, helping to plan for the future, and enhancing communication during health care visits will be a great relief and help to them. They have quite a lot of expectations from a tertiary center like NIMHANS in terms of medicines, better care, and cure. Some of them expect a cure for the illness. Bianca Brijnath in her book 'Unforgotten' has mentioned that some of her participants were expecting cures from their doctors and doctor shopping has always been a part of the Indian therapeutic landscape. Many of the earlier studies described that people's perception that nothing could be done was one of the most important barriers to care [8] which is a different finding when compared to our study.

4.4 Fear of Consequences and Impact

In our study, we found that the caregivers perceived moderate to severe threat of the illness and they were worried about problems in appetite, impaired verbal communication, memory loss, missing and further worsening of illness of their relatives that will lead to worsening of quality of life of the person with dementia. According to one study [20], one of the major concerns of caregivers was their relatives' functional dependency. Patients' behavioural problems were associated with frustration/ embarrassment in caregivers according to this study. Behavioural problems have been associated with caregiver burden in several other studies and are also a strong predictor of nursing home placement. Many of them were much concerned as there is no cure for the disease and the outcome is uncertain. It was felt by the family members that eventually the person will become dependent on others. An earlier study revealed that caregivers' burden increases with the degree of cognitive impairment [21].

5. CONCLUSION

Dementia is one of the major causes of disability in late life. Public awareness about dementia in India is low. This general lack of awareness has serious consequences as families do not seek help and health services do not recognise the problem.

Caregivers have the idea that their relatives had some problems that involved the brain but most of them attributed this to the consequences of aging, due to psychosocial factors like excessive stress, bad interpersonal relation, life event or economic crisis, and black magic.

They have quite a lot of expectations from a tertiary center like NIMHANS in terms of medicines, better care, and cures. Some of them expect a cure for the illness. In our study, we found that the caregivers perceived moderate to severe threat of the illness and they were worried about problems in appetite, impaired verbal communication, memory loss, missing and further worsening of illness of their relatives that will lead to worsening of quality of life of the person with dementia. Many of them were much concerned as there is no cure for the disease and the outcome is uncertain.

There is a need for an awareness-raising campaign for dementia in the community at large about its cause, symptoms, course, progression, and most importantly locally available services. The stigma associated with dementia should be reduced using TV radio, internet so that people should not fear dementia. Earlier diagnosis can be achieved by practice-based educational programs in primary care and by the introduction of accessible diagnostic and early-stage dementia care services.

6. LIMITATIONS OF THE STUDY

- Sample size finally interviewed was small.
- Only Hindi and English-speaking persons are included in the study. It does not reflect the pathways chosen by all people with dementia. Findings cannot be generalized.
- The interviews were conducted at the hospital and hence patients' responses could have been better if the study was done at their homes.

7. THE IMPLICATIONS OF THE STUDY

- Knowledge and understanding of dementia is significantly less in public. Public understanding is mixed and there is a fear associated with dementia which contributes to the stigma attached to the syndrome and the delay or failure in seeking help.

- There is an urgent need for improving the awareness and understanding of dementia across all levels of society to improve the quality of life for people with dementia and their caregivers.
- Awareness-raising and improved understanding can reduce the stigma associated with dementia and reduce the fear of the disease. Better understanding in society generally and among those who provide the care should increase help-seeking and help-giving.
- The impact of dementia on socioeconomic conditions worldwide is enormous. Furthermore, dementia is highly stigmatized and universally feared, with studies suggesting that it is strongly associated with suffering, disability, and economic loss at all stages of a person's journey through dementia. This obscures recognition of who should take responsibility, complicates financing, and therefore hinders the process of advocacy and action.

STRENGTH OF THE STUDY

- One of the few studies on the explanatory model of dementia in India.

CONSENT

As per international standard or university standard, respondents' written consent has been collected and preserved by the author(s).

ETHICAL APPROVAL

It is not applicable.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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