Original Research Article

EXPLANATORY MODELS OF DEMENTIA AMONG CAREGIVERS OF ELDERLY PERSONS WITH DEMENTIA – ANALYSIS OF SECONDARY DATA

Abstract

Rising life expectancy is associated with increased prevalence of chronic diseases like dementia. Prevalence of dementia is significantly high in low and middle income countries. Help seeking is largely dependent on one's socio-cultural perspective of sickness episode, one's belief of aetiology, course and outcome of illness. Dementia is still not conceptualized as health problem and it is believed to be a consequence of normal aging. So they are not concerned about help seeking. We interviewed 35 caregivers 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 which caregivers expressed namely, I) Problems of patient – Many caregivers reported that memory loss, behavioural problems and impaired biological functioning as their main concerns II) Cause of problem – caregivers expressed that psychosocial stress, aging, black magic as causes of Dementia III) Reason to visit and expectation – most of caregivers consulted doctors due to worsening of their relative problems and they were advised by others to visit. They expected medicines, better treatment and cure from doctors and IV) Outcome of problem – caregivers were worried about problem in appetite, memory loss, impaired verbal communication, difficulty in work and their relatives going missing.

Keywords : Eetiology, Dementia, caregivers, Explanatory Model

1. Introduction

World's population is aging as life expectancy is rising and death rate is declining. Longer life has resulted in high number people living with non-communicable disease, including dementia. Dementia is a syndrome usually chronic, characterized by a progressive, global deterioration in intellect including memory, learning, orientation, language, comprehension and judgement due to 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 ("Alzheimer's disease facts and figures," 2013) and the fifth leading cause for people aged 65 years and over (Miniño, 2013).

Help seeking is largely dependent on one's socio-cultural perspective of sickness episode, one's belief of 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 (Kleinman 1981). Western studies explained that people do not conceptualize dementia as health problem and it is believed as a consequence of normal aging (Mukadam, Cooper, & Livingston, 2011b) which leads to low rates of diagnosis and it is due to 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 the Indian middle-class families care for their relatives with dementia (Brijnath, 2014). She had conducted 46 interviews with 20 families over 10 months. It was observed that dementia was often not diagnosed until second stage when behavioural symptoms become more prominent and carers were less able to ignore 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 ageing got translated into AD. She has observed that symptoms like memory loss, cognitive and functional decline are seen in India as normal social markers of ageing. Neighbour's threat, pre-existing health condition or sudden injury and stigma were reasons for help seeking in few families. Also few families attributed initial symptoms of dementia as prolonged period of grief or shock due to 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 like (PARKAR, FERNANDES, & WEISS, 2003), (Saravanan et al., 2007), 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 (Connell, Roberts, McLaughlin, & Carpenter, 2009). All of this has led to treatment gap which is certainly high in low and middle income countries.

A study was conducted in National Institute of Mental Health and Neurosciences by Dr. Hossein in 2015 (Hossien et al., 2017) on pathways to care in dementia among 35 caregivers of dementia. Here our study is secondary analysis of available data of 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. Study was conducted in Geriatric Clinic Service of NIMHANS. The data of 25 interviews of caregivers which was already available and the data of 10 more interviews of caregivers which we conducted due to missing of data and to have good quality of 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 irrespective of type of dementia.

Inclusion criteria (Secondary data of an earlier study)

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

Exclusion criteria (Secondary data of 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.

(This is analysis of secondary data. Data was already available)

Available audio recorded data which was in Hindi was translated to English and transcribed. Data in English was 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

Back translated to Hindi to check for accuracy.

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Transcripts were read and re-read several times.

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The responses were coded iteratively in Atlas.ti (Muhr et al., 1991)

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Qualitative analysis of translated responses was done.

2.2 Assessments tool

Short Explanatory Model Interview: (Lloyd et al., 1998)

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 in regional language Hindi for 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 in few separate parts with group of questions. The initial part was on subject's personal details, it includes name, age, sex, education, occupation, marital status, religion and religious belief. Following which next section was 'explanatory model for current illness episode'. It covered person's understanding of nature of presenting problem, reason for consulting, name of the problem, perceived cause, consequences, severity and its effect on body, mind, social communication, home and work life is also studied. Other section was on 'Pathways to care' which examined the help seeking behaviour, contact with non-medical sources (e.g. traditional healer) and detail of interaction with physician is also evaluated in terms of expectation and satisfaction which was used in earlier study and hence was not included in our study.

Another section on illness belief consisted of two vignettes. We have used vignette of dementia and depression to elicit caregivers understanding of common disorder of elderly instead of depression and somatisation disorder that were used in original SEMI.

2.3 Analysis

The audio recorded data which was in Hindi was translated to English and transcribed and back translated to Hindi to check for accuracy. Data in English was transcribed directly. The data was analyzed using qualitative data analysis. ATLAS.ti software (Muhr et al., 1991) was used for qualitative data analysis. The responses of caregivers were coded iteratively in Atlas.ti. The grounded theory coding was conducted (Charmaz, 2006). The contents of 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(Anselm L. Strauss and Juliet M. Corbin, 1990). 213 codes were derived from Open coding which were closely observed. They were refined to 191 codes after merging codes with similar meaning. Those 191 codes were further refined and differentiated into 10 categories which were called as 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 (Anselm L. Strauss and Juliet M. Corbin, 1990).

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

- Reasons for consultation
- Understanding the cause
- Expectation from the Care Center/ 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

This is a qualitative analysis of secondary data. The data of 25 interviews of caregivers which was already available and the data of 10 more interviews of caregivers which we conducted due to missing of data and to have good quality of data were analysed. So, finally 35 caregivers' interviews which were in Hindi or English were included. It is not representative of general population. Caregivers who live with the persons with dementia and take decision upon help seeking and who carry financial burden were included. Caregivers of patients with all types of dementia which includes Alzheimer's disease, Vascular Dementia, Fronto-temporal Dementia and Diffuse Lewy Body Dementia were interviewed. The mean age of the study group was 37 years. Male female ratio was approximately 2:1. Because in Indian socio-cultural background men act as major decision maker and they carry the financial burden. 60% of the sample were graduates. 77% from Hindu religious background and 23% was Muslim. Among the study group 77% were married and 17% were single (Table 1).

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

Explanatory model of dementia given by the caregiver of patients

During 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.

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

Code groups/ Categories	**Codes**	**Groundedness/Density**
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
Expectation 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

1)Reasons for consultation: There are various problems for which caregiver consulted doctor. Among the heterogeneous responses few emerging themes are listed with responses.

a) **Memory loss:**

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

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 way to home. He is forgetting names of his sisters, brothers, what has happened earlier. For ex, 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.”

b) Behavioural problems:

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

Response given by 37 years old female caregiver,“He is hitting my mother very badly. Because of it, she got injured and fractured, he has broken all furniture.”

c) Disturbance in functioning:

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

d) Problems in thinking:

Another common problems reported by caregivers are problem in thinking, making decisions and recognising family members.

37 years old female caregiver reported about her father, “He was an Ex- service man and was working in Mumbai. He is not recognising Kannada. He is asking my mother that why children are talking in other language and not Hindi/ Punjabi. He is not recognising my brother – in- laws and was asking who this person with my daughter is.”

e) Problems in identifying direction and routes:

Persons usually have problem in identifying proper position. They often cannot find way back home. Few caregivers mentioned this as 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.”

f) Impaired verbal communication:

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

2) Understanding the cause: After analysing the responses in context of cause, few major construct came out.

a) Ageing:

Most of people think that it is an illness related to ageing.

b) Psycho-social factors:

Though people have idea of biological model of causation, often they attribute this to psychosocial factor like problem in inter-personal relation, life event, loneliness, inactivity, business problem, other stressors etc. Most of caregivers gave psycho-social factors as cause of their relatives illness.

36 years old female caregiver about 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, feed her and she used to become normal. Later she comes back to in-law home. She used to tell us that because of torture in in-law home, she used to cry, she was getting headache. So, we think illness is because of that.”

c) **Brain disease**:

Many of them think that this is a disorder of brain like stroke and degeneration as 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 reason behind neuro degeneration is not known. There are many theories like some neurotic plaque etc. But exact reason is not yet clear."

d) Substance use as cause:

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

37 years old female caregiver about 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 now a days he has increased consumption. He is not able to digest that. Instead of food he is consuming alcohol."

e) Other causes:

Few caregivers reported that accident, other physical disease, evil spirit, due to karma, punishment from God as causes of illness of their relatives.

<u>3) Expectation from the Care Center / NIMHANS:</u> When the participants were asked the reason for coming to NIMHANS and what the expectations are, few construct came out.

a) Better care:

Most of the patients are already under treatment. But they are not satisfied as they are not getting 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."

b) Cure:

Though a good percentage of people have knowledge about the outcome, some of them expect cure, which made them to come them to NIMHANS.

30yrs old female wants her father in law to get cure, "I am expecting that problem of brain should get cure. He should start taking food properly. He should sleep well."

c) Worsening of illness:

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

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

d) Medicines:

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

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

e) 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 reason to visit.

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

4) Fear of consequences and impact:

a) Missing:

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

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

b) Memory loss:

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

c) Worsening of illness:

Few caregivers mentioned that progression of disease as their fear.

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

d) Impairment in biological functions:

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

e) 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.

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, engineers and other 18 (51%) caregivers were clerks, house wives. Majority of caregivers (21 out of 35; 60%) were graduates, three of them did not receive formal education and remaining had completed twelfth standard. Among caregivers, 27 (77%) belonged to Hindu religion and remaining 8 (23%) belonged to Muslim religion. 20 (57%) caregivers were from south India and remaining 10 (43%) were from north India. 27 (77%) caregivers were married, 6 (17%) were single and remaining 2 (6%) were divorced.

We observed that 6 caregivers who know that the illness is dementia, were from professional background. Out of 6, 4 caregivers were male and remaining 2 were female. 3 caregivers were from south India and 2 were from north India. 5 caregivers belonged to Hindu religion and remaining 1 caregiver was a Muslim. 2 out of 6 caregivers who know about dementia expected delaying progression and others expected cure and medicines.

It is also seen that 5 caregivers felt black magic as 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 Hindu religion. Among 5 caregivers, 3 were married, 1 was single and the other was divorced. 4 caregivers were graduates, 1 caregiver did not receive any formal education.

57% of the respondents perceived dementia as a disease of brain, 17% thought it involved 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% respondent 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. Secondary data of 25 interviews of caregivers from an earlier study was available. We interviewed 10 more caregivers due to missing of data and for good quality of data. All these interviews were analysed using qualitative data analysis tool.

Explanatory model of dementia

Dementia is often understood as normal part of ageing and people do not know about or recognize 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 caregiver would recognize cognitive symptoms in their relatives like impaired memory, impaired verbal ability or impaired visuo-spatial orientation. 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, impaired biological functions like decreased sleep and appetite that affect activities of other family member at home. And finally when the person with dementia becomes burden on family member for their ADL they try to find solution for that. These symptoms increase morbidity and burden, affect quality of life and impact cost of care (Kar, 2009).

4.2 Understanding the cause

The main finding in this part of our study is that we have got three major causal model of dementia. 1) Psychosocial stress, 2) Age related problem, 3) Black magic. Caregivers have the idea that their relative had some problem that involved brain (Table 2) but most of them attributed this to consequences of aging, due to psychosocial factor like excessive stress, bad inter-personal relation, life event or economic crisis and black magic. Earlier western studies also described people's understanding of dementia as age related problem and as neuropsychiatric illness (Downs et al., 2006). In one study people described psychosocial factor or physical health related problem as causal factor (La Fontaine et al., 2007). 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 (Emmatty et al., 2006). There are other studies which revealed various causative beliefs i.e. deliberately produced, act of god (Jett, 2006) or bad 'feng shui', a Chinese philosophical system, which means improper harmonization with the environment (Zhan, 2004). In our study few caregivers told that either punishment from god or karma may be the causes of dementia.

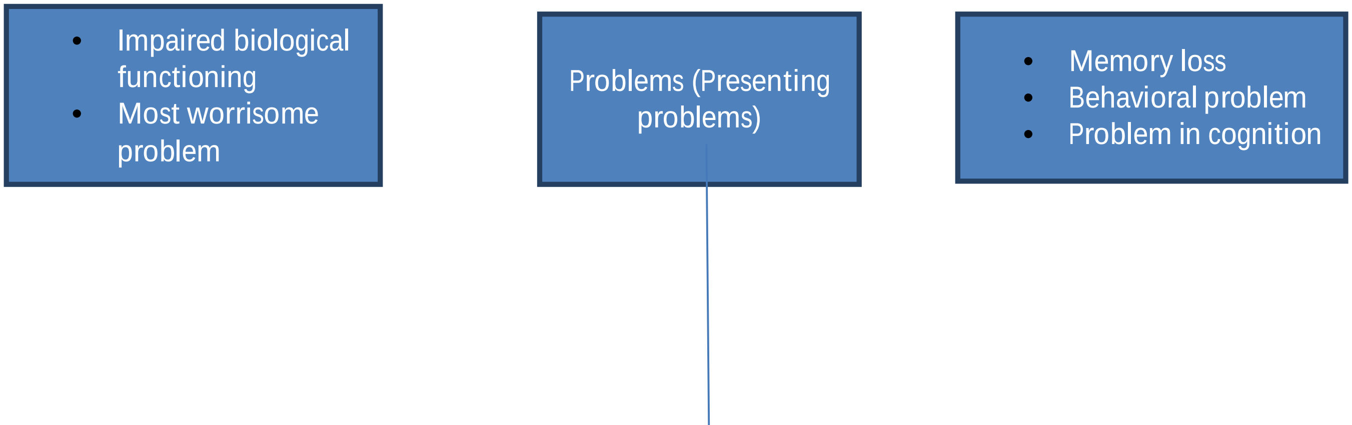
4.3 Reason to visit and expectation of treatment outcome

In our study we found that worsening of symptoms, others advice were reasons to visit. Also we found that caregivers have a belief that with treatment there will be partial improvement or cure or it will be stable. While without treatment the disease will worsen or become fatal. They have quite a lot of expectation from a tertiary center like NIMHANS in terms of medicines, better care and cure. Some of them expect cure for the illness. Bianca Brijnath in her book 'Unforgotten' has mentioned that some of her participants were expecting cure 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 (Connell et al., 2009) 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 problem 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 (Beth A et al 2014), one of the major concerns of caregivers was their relatives' functional dependency. Many of them were much concerned as there is no cure of the disease and outcome is uncertain. It was felt by the family members that eventually the person will become dependent to others. As earlier study revealed that caregivers burden increases with degree of cognitive impairment (Pattanayak, Jena, Tripathi, & Khandelwal, 2010).

Figure 1. Popular explanatory models, Semantic networks and Health Care seeking among caregivers of elderly patients with dementia



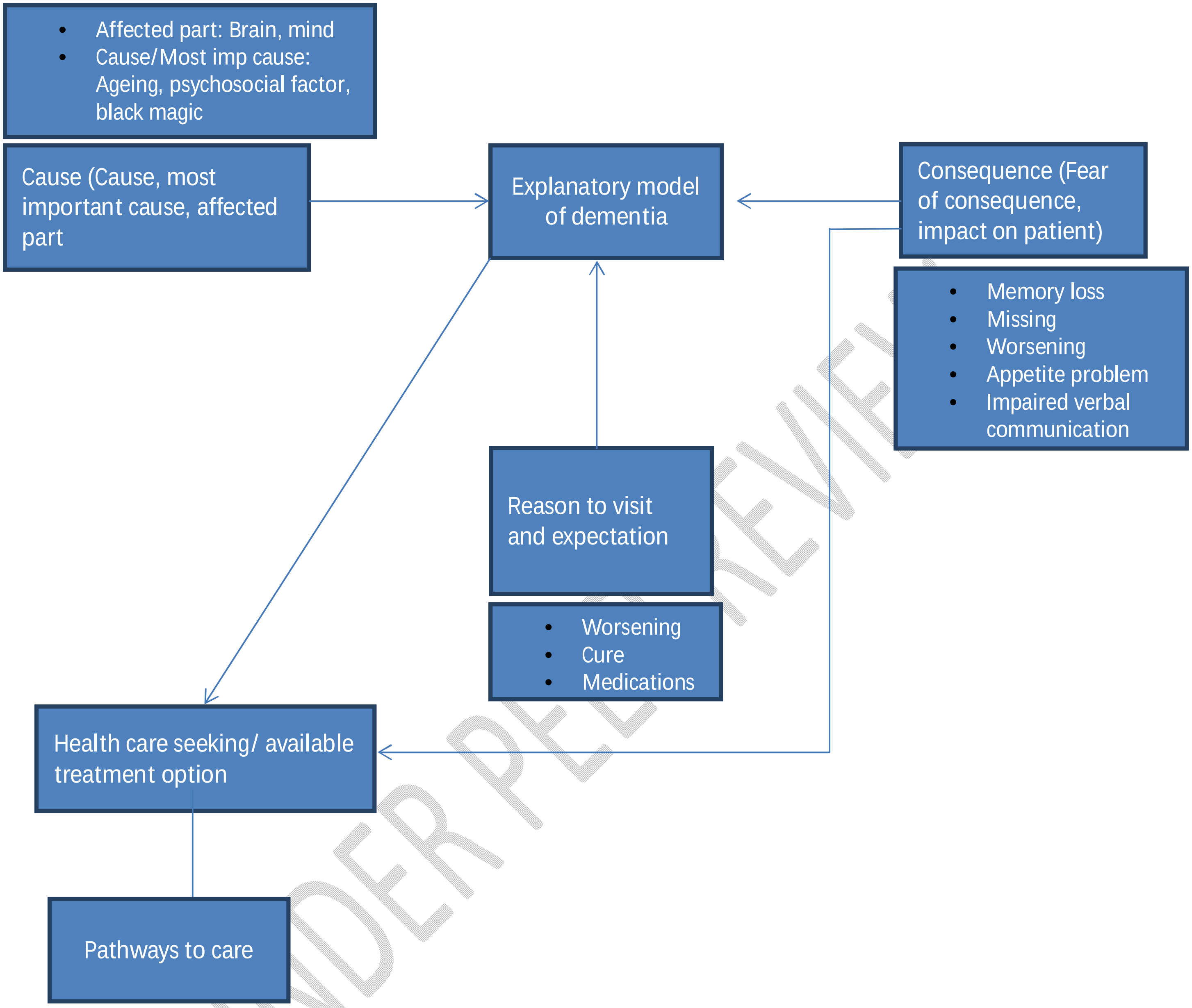


Figure 1 shows the explanatory models of dementia given caregivers of elderly people with dementia, semantic network linkages and health care seeking of caregivers. The study of explanatory models of patients and families give good view of their understanding of the illness and how they will seek treatment 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 Center constitute the explanatory models of dementia which influence the health care seeking behaviour of caregivers.

5. Conclusion

Dementia is a chronic disease with high global prevalence. This is significantly high in LMIC. Dementia has vast impact on mortality and morbidity of patients as well as on families, caregivers and societies in terms of economic impact. Dementia is one of the major causes of disability in late-life. The public awareness about dementia in India is low. In most settings, there is no awareness of dementia as an organic brain syndrome or as any kind of medical condition. Primary care doctors do not encounter many cases in their practice and there is no special emphasis on dementia diagnosis and management in the training of healthcare professionals. Media interest in dementia and related healthcare issues remain low. This general lack of awareness has serious consequences as families do not seek help and health services do not recognise the problem.

It was found that many of the caregivers would recognize cognitive symptoms in their relatives like impaired memory, impaired verbal ability or impaired visuo-spatial orientation. 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 caregivers were behavioural problems like agitation and irritability, impaired biological functions like decreased sleep and appetite that affect activities of other family member at home. And finally when symptoms worsen and the person with dementia becomes burden on family member for their ADL they try to find solution for that.

Caregivers have the idea that their relative had some problem that involved brain but most of them attributed this to consequences of aging, due to psychosocial factor like excessive stress, bad inter-personal relation, life event or economic crisis and black magic.

They have quite a lot of expectation from a tertiary centre like NIMHANS in terms of medicines, better care and cure. Some of them expect 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 problem 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 of the disease and outcome is uncertain.

There is a need for awareness raising campaign for dementia in community at large with regards to its cause, symptoms, course, progression and most importantly locally available services. Stigma associated with dementia should be reduced using TV radio, internet so that people should not fear dementia. People have to understand that though there is no cure, there are lot of things to be done for improving the quality of life of a person living with dementia. Health care strategies have to be implemented which should include sensitization and training of primary care physician and staffs to identify dementia at an early stage. 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.

Strength of the study

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

Limitation 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.

Implication 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 in order 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.

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