

Phenomenological Study on Experience of Care Givers of Patients with Dementia in Rural Kerala

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Abstract

A phenomenological study was carried out to know the experience of 10 care givers of patients with dementia in a costal rural community in Thrissur district of Kerala (India). A qualitative approach with survey design using unstructured questionnaire was employed to collect the data. After establishing rapport with the care givers, they were asked to describe what it was like a caregiver of a patient with diagnosed dementia. Interviews were recorded and transcribed verbatim before analysis by personal reflections on Giorgi's method. The study revealed that caregivers of clients with dementia in rural settings have concerns related to caring and outcome. They expressed being overwhelmed, isolated and helpless with this deteriorating condition.

Advances in modern technology, specifically in medicine and improvement in standard of living contributed greatly to the increase in elderly population across the world. It is estimated that 35.5 million people worldwide suffer from dementia. This number may double every 20 years to an estimated 65.7 million in 2030 and 115.4 million in 2050. Already 58 percent of people with dementia live in developing countries but by 2050 it may raise to 71 percent. Prevalence of dementia in urban India is 4.8 percent whereas in rural India it ranges from 0.6 percent to 3.5 percent which shows that prevalence in India is much lower than in European countries.

Symptoms of dementia are perceived differently in different countries. Some may think it as a part of normal aging, mental illness, god's curse or incurable changes in the brain. Low levels of understanding about dementia lead to various misconceptions resulting in perpetuation of stigma which is prevalent in most countries at various levels. People with dementia are often isolated or hidden, because of stigma or the possibility of negative reaction from neighbours and relatives to behavioural and psychological symptoms. The idea that nothing can be done to clients with dementia leads to hopelessness and frustration. Family members, most often adult daughters or daughters-in-law are the prime informal care givers in most families.

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According to WHO, global burden of disease in dementia is the third leading cause of contributors to years of life lost due to disability (YLD) in elderly in low income and middle income countries. Dementia is the second highest source of disease burden after tropical disease. This study sought to explore the lived experience of care givers of clients with dementia in a rural community in Kerala (India). There is a limited published material which focuses the lived experience of such care givers which need to be addressed for effective health care for such unnoticed individuals.

The main aim of this study was to present a vivid description of the lived experience of care givers related to their caring process to get a better understanding of their problems. The research questions for the present study were, "What is the lived experience of care givers of clients with dementia in home-based rural community setting?" "What is the essence of their experience?"

Methods

Researcher employed bracketing perceptions and holding them to avoid personal bias during data collection and interpretation.

After ensuring confidentiality and providing privacy, participants gave the consent to take part in the study. Criteria fixed for the study participants were fulfilled by all participants before the study. Purposive sampling technique was employed in the present study. A prevalence study for identifying dementia and other geriatric problems was conducted by Government Medical College Psychiatry Department, Thrissur

(Kerala). Clients were selected from that data and study was carried out.

Participants consisted of 10 care givers who described their experience while caring clients with dementia between age 32 and 65. Care givers were wives, daughters and daughters-in-law. All the care givers were living with the client. All participants were able to read and write Malayalam; 5 participants studied up to plus two and 2 were up to eighth standard.

Data collection and analysis

The study lasted for one month where clients were identified and interview data were collected, transcribed and analysed. Data collection was stopped when no new information was being gathered from the participants.

Data was collected from the participants from their homes using unstructured interview schedule guided by a broad question: What you feel while caring a client with dementia? Probing questions used were - What makes you made miserable? Open ended clarifying questions like tell me more about your experience?

Each participant was interviewed twice lasting for 30 to 45 minutes each. Interviews were recorded and transcribed verbatim by the investigator. Accuracy of verbatim was assured by repeated checking and further interviews with the clients.

Giorgi's method of data analysis was employed in this study. Trustworthiness, credibility, conformability or auditability and fittingness or transferability were ensured

Initially interview data was transcribed with special care on non-verbal communication. The researcher approached with openness to whatever meanings emerged. Then the researcher read the data several times to get a gestalt. Themes were identified and connections between the themes were identified. Themes were chronologically arranged and clustering of the themes was done. Master table of themes of the group was established and final themes were extracted.

Results

Care givers were astonished to see that health professionals from a tertiary care setting were visiting their home and sharing their experience. They expressed great feeling of comfort after sharing their experience.

Analysis of findings resulted in mainly 3

themes. They are problems related to symptoms, lack of knowledge and burden of care.

Theme 1: Problems related to Symptoms

Mild cognitive impairment causes a slight but noticeable and measurable decline in cognitive abilities including memory and thinking skills. But the changes may not be severe enough to interfere with daily life or independent function. In general, dementia involves three main types of symptoms: loses in cognitive capacities; difficulties in performing instrumental, daily personal activities, living and changes in mood or personality and declines in interpersonal functioning

"See she is simply lying on the floor. She is not doing anything even those which she herself can do. She suspects all her belongings are taken by somebody. Now she is angry because I am not protecting her belongings from looting. Memory loss started few years back. No special medicines are being taken for that. She is furious towards sister-in-law. With me not that much. Only thing is stand according to her demand"

Theme 2: Lack of knowledge

Care givers were aware about dementia superficially. Family care givers expressed the need to learn how to care for their relative suffering from dementia. The respondents revealed their lack of knowledge related to the service available for them in the community.

"Why sir like this? This disease has no cure? Its long time now. Regarding his memory nil. Anyway my sufferings are not so simple. Nothing can be done."

"What to do? Everybody has their own problems. Only those who suffer know his problems. Others can say anything. It was around a month since I slept properly. To whom shall I say? Some says there is someone in Tamilnadu who can cure this type of conditions."

Theme 3: Burden of care

Care giver burden means the extent to which care givers perceive their emotional or physical health, social life and financial status as suffering as a result of caring for a relative. When the care needs of the clients with dementia increases, the home care giver burden also increases. Emotionally labile and intolerable behaviours demonstrated by the individual with dementia leave the care giver with a thought of anger, resentment and anxiety. These factors contribute to family's ill health.

"I am fed up. We can go nowhere. Somebody should be there always with her. She is not satisfied with

whatever we did for her. Always blame me. My fate is like this only. Let me face it. God may be watching everything.

"...No peace of mind also. Sometime feel like going away from him. No peace of either. Repeat the same again and again."

"Fed up with this. What is this? It is impossible with me. Simply using abusive words towards me. This much is only possible by me. I am also a patient on medications. I am caring him not because I can. Caring him – otherwise I may get curse from god. Otherwise I would have gone somewhere."

Discussion

There were similarities in the participants' stories in a given time frame when they were interviewed. At another time, place, or with a more diverse sample, the data and interpretation may be different. All the study participants were willing and eager to tell their stories

The finding show that care givers had problems related to the symptoms of dementia in their loved ones. They also expressed lack of knowledge related to this disease; most importantly they expressed frustration related to the burden of care. These findings were in accordance with those of Fingerman (2001).

A qualitative study by Coeling et al (2003) looked at how care givers face the burden of care and satisfaction in the informal care giving. In grounded theory study Sheehan & Donorfio examined mother-daughter relationships in care giving. In that study a new theme namely sacrifice has emerged.

A similar theme of burden has emerged in present study. In Sheehan & Donorfio study some daughters reject the term 'care giver' to describe their roles in caring for their mothers as they reported that care giving has a negative connotation of strain and burden and that was not how they experienced what they did for their mothers. In the present study there were similar incidents where they used humour effectively during care giving process.

Limitation Implication

The present study represents only a few care givers living in a rural community in Kerala. Therefore limitations include the representation of study population because there may be care givers living in the community with much more experience to share.

Another limitation was that the interview was carried out only once. However, the finding may be useful for nurses and other health care professionals for shaping up care for dementia clients as well as their care givers.

Recommendations

Nursing Practice

Findings of the present study will definitely help the nursing community to assess, diagnose, plan, implement and evaluate care in a scientific manner. Insights from the present study may help the nurses to build a better communication among the care givers of clients with dementia in rural settings. Nurses can provide information, encouragement and supportive presence to the care givers. As advocates, nurses can provide resources and counselling to strengthen care givers' coping abilities.

Nursing education

Nurses need ongoing education in evidence-based practice, including both quantitative and qualitative current research findings. Findings enhance nurses knowledge and understanding of the science and art of caring.

Research

There is an acute shortage of research findings in case of care giving particularly with frail elderly caring. Similar studies can be carried out with care givers of clients with dementia in different parts of the state to validate the themes.

Similarly a comparison between lived experience of spouses and daughters can be carried out or even a comparison between daughters and daughters-in-law can be conducted on an extensive scale.

References

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Events of the Month

Teacher's Day: 5 September

Commemorating the birth anniversary of former President Dr Sarvapalli Radhakrishnan, Teacher's Day is celebrated in India on 5 September each year. The day highlights the seminal role of teaching community in building and grooming of students, the future custodians of the Nation. With education and teaching going hi tech and students' slackening interest in academics, the role of teacher has become rather challenging. On this day students wish their teachers in special ways. In some institutions they swap teacher's role.

World Suicide Prevention Day: 10 September

Every year, over a million persons commit suicide the world over, according to World Health Organisation (WHO). In the 15-19 years age group, suicide is among the top five causes of deaths. Further, many suicides are either not reported at all or covered up as illnesses or accidents. Factors predisposing to suicidal tendency include alcoholism, drugs and harsh parenting. In most cases, behind suicide attempt is the perceived inability of individual to attain the expected results, which may at times be unrealistic. WHO predicts that by 2020 the rate of death by suicide (presently one suicide per 40 seconds) will double to one every 20 seconds. It is therefore essential to address the issue urgently. The modalities suggested address the issue of tackling mental disorders and bridging social segregation. Certain signs need to be spotted in any suicide prevention strategy. First, see if the person is isolating himself from society and his close ones, whether he often talks about death, writes such things in his diary. More important is his habit of sharing thoughts and feelings with others, which must be inculcated in all from early stages of life.

World First Aid Day: 13 September

On Second Saturday of September every year (on 13 September in 2014), the International Federation of Red Cross and Red Crescent (IFRC) Societies organise the *World First Aid Day* the world over. With over 1.24 million people losing their lives annually in car accidents round the world, the World First Aid Day theme for 2014 is befittingly, *First Aid and Road Safety*. First aid is the application of initial care using a series of simple and sometimes, potentially life-saving techniques with minimal equipment. In fact, some self-limiting illnesses or minor injuries do not require further medical management after the first aid intervention. The IFRC pleads for making first aid training compulsory for every person driving a vehicle and also calls for making first aid training available to everyone.

World Alzheimer's Day: 21 September

One in every 10 persons above 65 is affected by Alzheimer's, a degenerative disorder of nervous system. One with Alzheimer's starts losing memory, and may even show behavioural disorders, eventually oblivious of one's identity. Of its many symptoms, dementia is most common.

Much research notwithstanding, so far only symptomatic treatment is available. In most cases the early Alzheimer's symptoms are often mistaken for age-related forgetfulness and the disease is diagnosed only in its advanced stage making its management difficult. The theme set for 2014 by the Alzheimer's and Related Disorders Society of India is, *No Time to Lose*. The number of people with dementia around the world is likely to double in the next 25 years. In India, an estimated 3.5 million plus persons are living with dementia.

World Mental Health Day: 10 October

Every year on 10 October, World Mental Health Day is celebrated at the initiative of the World Federation of Mental Health. WHO supports this initiative through raising awareness on mental health issues using its strong relationships with the Ministries of health and civil society organizations across the globe. WHO also develops technical and communication material and provides technical assistance to the countries for advocacy campaigns around the World Mental Health Day. The theme of World Mental Health Day in 2014 is, *Living with Schizophrenia*. Mental, neurological and behavioural disorders are common in all countries around the world. The affected often lead a socially isolated life, poor quality of life and have higher death rate. WHO suggests clearly defined principles and steps addressing the mental disorder problems.

Improving Mental Health in India: Government Initiatives: In our country, about 10-20 million (1-2% of population) suffer from severe mental disorders such as schizophrenia and bipolar disorder and nearly 50 million (5% of population) from common mental disorders such as depression and anxiety, yielding an overall estimate of 6.5 percent of the population, as per report of National Commission on Macroeconomics and Health. With a view to support those suffering from mental handicaps, the Mental Health Care Bill, 2013 seeks to provide following rights to them: (i) access to mental health care (ii) community living (iii) protection from cruel, inhuman and degrading treatment (iv) equality and non-discrimination (v) information (vi) confidentiality (vii) release of information in respect to mental illness (viii) access medical records (ix) personal contacts and communication (x) legal aid and (xi) to make complaints about deficiencies in provision of services.

Strengthening Mental Healthcare Facilities: To address the acute shortage of qualified mental health professionals in the field of mental health, Government of India has been implementing the National Mental Health Programme (NMHP) since 1982. Further, 11 State-run Mental Health Institutes have been upgraded as Centres of Excellence in Mental Health. Also, 27 PG training departments in mental health specialties have been supported to increase the PG training capacity in mental health improving the tertiary care treatment facility; 312 new PG seats in mental health specialties have been created in the supported Institutes. Besides, three Central Institutions viz. (i) National Institute of Mental Health and Neuro Sciences, Bangalore, (ii) Lokpriya Gopinath Bordoloi Regional Institute of Mental Health, Tezpur and (iii) Central Institute of Psychiatry, Ranchi have been strengthened in the area of mental health and for capacity building in the country.