Original Article

Assessing Self-care Perception among Caregivers of Dementia Patients in a Rural Medical College of Darjeeling District, West Bengal, India

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Abstract

Introduction: Dementia is a prevalent cause of morbidity and runs a downhill course. Patients progressively become completely dependent on their caregivers who are usually untrained family members. The resultant burden causes caregiver burnout making them vulnerable to diseases. The objective of this study is to assess perception and practice of self care among caregivers and assess any barriers faced. **Materials and Methods:** A cross sectional qualitative study with 18 eligible caregivers was conducted from September to December 2019 using the appropriate study tools and techniques. Content analysis was done. **Results:** Majority were aware that self care was required though only five people practiced it. Medical attention was sought by all. Barriers faced were workload and lack of knowhow. Need for comprehensive domiciliary care structured module with graded nonpharmacological interventions and capacity building was reiterated. **Conclusion:** Perception regarding self care was present, but practice lacking and barriers faced were mostly lack of training and time constraints. However, a larger study is recommended.

Keywords: Barriers, caregiver, dementia, practice, self care perception, structured module

BACKGROUND

Dementia is a neurodegenerative disease of multiple etiologies, varied phenomenology, and wide outcome. Deteriorated cognitive function in many domains and altered performance in the activities of daily living are commonly seen in dementia.[1] It has become a public health concern owing to its health-care costs and caregiver burden. Assuming low- and middle-income countries such as India are steadily entering into demographic liability phase in upcoming decades, ratio of one elderly per number of working age population is increasing alarmingly.[2] Dementia occurs in 5%–7% of the elderly population, number of people living with dementia is estimated to double by the year 2030 and treble by the year 2050 with a sizable contribution from developing countries such as India.[3]

As dementia is a progressive and irreversible entity, it offers huge expenditure and time to treat. In India, such financial and social burden is complex to calculate as it is often shared by family members and resultant decrease in the productivity of the person or caregivers and the loss of wage days become tough to quantify. The real burden is masked by families compensating while offering roles and responsibilities.[4] Family care defined as unpaid support provided by family members or other people in the immediate environment of caregiver, remains the mainstay of care for dependent elderly.[5]

With disease progression, dementia patients tend to depend increasingly for their activities of daily living on their caregivers.[6] Owing to sacrifices, concerned caregivers develop strain and burden leading to the negative impact on their physical, psychological, and social quality of life making them vulnerable to psychiatric disorders.[7] It may affect person's health in terms

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Submitted: 30-Apr-2020 **Accepted:** 20-Oct-2020 **Published:** 22-Dec-2020

Access this article online	
Quick Response Code:	**Website:** www.actamedicainternational.com
	DOI: 10.4103/ami.ami_52_20

How to cite this article: Layek AK, Ghosh N, Chakrabarti I, Bera NK. Assessing self-care perception among caregivers of dementia patients in a rural medical college of Darjeeling District, West Bengal, India. Acta Med Int 2020;7:158-61.

of subjective overload, anxiety, and depression.[8-10] Moreover, dementia caring can be more physically and emotionally demanding possibly because of high and fluctuating care demand from persons with dementia.[11,12] As few alternate facilities and welfare supports for long-standing illnesses exist, it leads to the burden of care-giving falling primarily on family members, who have to take care at every stage of illness. Social changes in India such as gradual urbanization and shrinking family are making care-giving more challenging than ever.[13]

It has been noticed that varied sociodemographic differences, social support, coping strategies, cognitive reserve of dementia, behavioral domains of dementia manifestations contribute to the layers of stress and burden perceived by caregivers.[14,15] Often emotional reciprocity between dementia patient and caregivers plays an important role in raising awareness about each other's needs.[16]

Scientific literature shows resources and interventions for family caregivers as inadequate and nonresponsive leading to their stress and burnout.[17,18] Needs perceived by caregivers are broad, multidimensional, inter-related, and integral to their process of caregiving as many studies have highlighted and often differ from perceived Indian model due to emphasis on formal versus family support.[18-20] Informal models that can be applied in the Indian perspective have been demonstrated in some studies using the Mediterranean model of care.[21-23] These are featured with positive outlook from the family members toward older relatives, greater level of family involvement, and lower level of formal caretaking in terms of services and coverage.[21] In this scenario, the family considers the care of a member as responsibility or obligation, and hence, initially restrain from seeking help from professionals.[23]

A study in the rural Indian scenario is scarce.[4,13] More studies are needed to assess caregivers' experiences to better evaluate their needs and perceptions such that strategies, programs and interventions can be formulated in accordance. Hence, the aforementioned study was conducted with the following objectives:

Objectives

1. To asses perception and practice regarding self-care among caregivers of dementia patients attending North Bengal Medical College Hospital (NBMCH)
2. To identify the barriers perceived in self-care by study subjects.

METHODS

A cross-sectional study with qualitative design was undertaken in the department of psychiatry, NBMCH for 4 months (September–December 2019) after taking ethical clearance from the Institutional Ethics Committee, NBMCH and voluntary informed consent from the study participants. All dementia patients attending outdoor of NBMCH and their accompanying caregivers in the defined study period adhering to eligibility criteria were intended to be included for the study purpose. Willing caregivers, not suffering from any disease which intercepts understanding were included for the study.

A total of only 18 eligible study participants (caregivers) could be interviewed as many chose to be nonresponders or themselves suffered from some mental health disorder. Predesigned pretested semi-structured schedule with study variables to elicit various domains, a Likert's scale to assess satisfaction and relevant records were the study tools. Techniques used were in-depth interview (IDI) and record review. The present study was conducted once a week for 3 months without hampering regular activity. Eighteen eligible candidates were interviewed and 7 people left study midway.

Background descriptors, variables eliciting perception, and practice regarding dementia were assessed for the study purpose. They were knowledge on disease course and prognosis, awareness about relevance and benefits of self-care, various methods of practicing self-care like balanced diet, regular exercise, utilizing peer groups, relaxation techniques, routine evaluations, awareness of DSR scale, nature of work (exhausting and frustrating), and course of disease (plateau, downhill). Barriers faced in accessing self-care were also evaluated in forms of work overload, lack of time, lack of knowhow, training inadequacy, and feeling of demotivation. Satisfaction of caregivers was assessed for disease prognosis, patient dependence, remuneration, and other support systems working.

Data collection procedure and analysis

Interviews were carried out by two researchers independently by IDI method, and one was male and one female. They are experts in the domains of psychiatry and public health with required training for conducting research. Participants knew about study commencement and were priorly sensitized. It was beyond conventional doctor–patient relationship. Potential biases were overcome and all queries addressed during sensitization. Content analysis was done.

Data were collected on exit interview in the hospital setting. Questions and prompts were not provided by the author. Field notes were recorded. Few responses were recorded and each interview lasted for 20 min. All information once sought was taken as data saturation, and no transcripts were handed over to caregivers. Two coders coded the data separately and then uniformly translated. Few themes and hence codes were identified. Participants were expected to be provided feedback on the study findings. Consistency in data presented existed and major themes were noted. However, description of diverse cases or discussion of minor themes was not done as many deviant cases were not elicited. Data were collected, cleaned, compiled, and decoded manually and entered in Atlas Ti. Data were analyzed and presented. It was ensured the data will be used for the academic purpose only.

RESULTS

Eighteen eligible participants were studied. Hence, the results were not expressed in the percentage in few instances to portray the exact situational analysis. 16 among 18 studied were traditional caregivers, family members became caregivers by default, and it was the first case they were handling. Two caregivers were from paid agency, who chose the profession as they felt that the job was less physically tiring and they had handled similar case prior. 88.9% caregivers were females > 50 years. 95% caregivers were residing in the rural areas and looked after the same patient for over than 2 years. Seventeen caregivers were addicted to smokeless tobacco. However, none suffered from any documented physical or mental health disorder and the 2 nontraditional caregivers had no family history of any mental health disorder. However, all 16 traditional caregivers had never received any formal training for the purpose.

Perception of self-care

All caregivers unanimously opined self-care is important but were unclear on how to enforce it in their daily lives. Majority had knowledge that it is essential and should be practiced regularly. Only one caregiver had not even heard the term "self-care." Almost all the caregivers affirmed that that they had no idea if a timely appropriate self-care would help prevent and check their anxiety and other depressive symptoms which they were much keen to develop. They had no idea if proper nutrition, rest, medication, exercises, peer group support, and emergency contacts would help them perform better at workplace.

"*Self-care is luxury, we can only aspire for a good night sleep,*" "*Please make government provisions for pension for us*" were two responses that needed mention separately.

They were aware self-care also included peer dissemination of information for techniques to other caregivers, handholding of patients who know it's a downhill course, asking the other family members to be supportive, formulation of retention laws for caregivers and formulating appropriate strategies by health care systems to safeguard interest of demented patients and taking initiatives for a dementia friendly community.

Practice of self-care

All 18 caregivers took medical help as and when required for them. As they had to accompany the patient to hospital, they sought medical attention in the same setting even for minor ailments. However, only five caregivers stated that they used to take care of their nutrition, exercises, and medications regularly despite the tiring job. They used to take balanced diet and practiced 30 min of yoga daily, especially the relaxation and breathing techniques. They talked to their friends every day and had developed a peer group and had an emergency contact number at hand for times of crisis.

Barriers of self-care

Thirteen caregivers opined they could not perform self-care due to work overload. As there was no other person to accompany the patient except them, they had no time left for themselves. Lack of sleep, fatigue was also opined. Moreover, lack of knowhow, faulty time management techniques, and absence of proper training led them to feel demotivated and not access self-care despite knowing its benefits. Four traditional caregivers said "*As my family members were suffering, didn't feel like living was worth and felt no enthusiasm to take care of myself*."

Ambiguity over patient outcome, downhill course of disease, complete mental, and physical dependence of patients over caregivers were the barriers identified in accessing self-care as these led to stress and dissatisfaction. However, majority of caregivers[14] were dissatisfied with remuneration and workload and interruption of their regular routine.

A need for training in the relevant aspects of caregiving, in areas of self-care and a structured module with clearly outlined nonpharmacological interventions for domiciliary application at the household level with appropriate management and referrals was unanimously reiterated by all study subjects and opined that they would feel more equipped with module for both patient and self-care.

DISCUSSION

Healthy and proactive dementia caregivers are of paramount importance for the management of patients, both at individual and community level. The present study assessed perception of self-care among them in terms of awareness and knowledge, right practices performed, and barriers faced. Interestingly, a dire necessity for structured module and comprehensive training was observed. The present study also found majority of caregivers to be traditional caregivers and family members who were untrained and unequipped to deal with condition. They had no idea about the disease, domiciliary care, or nonpharmacological interventions and hence just gave regular medications prescribed. Majority showed superficial knowledge on importance and methods of self-care as well as overall course and prognosis of the disorder. This followed the same trend found in the prior Indian and Mediterranean studies.[13,22,23]

Similar findings in another study concluded, untrained traditional caregivers were meting out care resulting in ineffective service delivery leading to delayed responses among patients.[16]

Further downhill course of disease, financial implications of disease burden took its toll on them and in absence of any peer group support they were often frustrated. Different studies concluded that dementia cannot be cured or progression is difficult to halt and a peer group is essential for providing support and care. Most plausible reason as found from many studies is scarce support resources and interventions at the family level often seem inadequate to their needs. Moreover, barriers to accessing self-care exist, maximally being lack of technical knowhow; hence, external trained help is welcome.[17,18]

Awareness regarding self-care was present as similar to other studies.[13-16] Various needs in varied settings concluded that more emotional care was needed. Our study did not focus on any particular perceived domain of care; however, no one was practicing self-care in true essence which is in striking contrast to other studies where caregivers follow a self-care regime and are looked after by their respective local authority for the same.[18,19]

Emphasis on informal family model over a formal and structured model is likely to contribute to its possible explanation as per one respondent.

Caregivers in our study lacked very basics of self-care and hence needed immediate attention from concerned sectors. Dissatisfaction of caregivers on remuneration and workload was similar finding to other studies on the various aspects of health-care delivery.[6,7,13,21-23]

Few studies in Europe and elsewhere concluded that timely and appropriate self-care among caregivers helped avert the development of anxiety and other depressive psychosis among them.[21-23] However, the authors with evidence from few epigenetic studies opine that as dementia preponderance is common among blood relatives, more so in female descendants, appropriate self-care, and timely identification of warning signals will help in preventing development of mental health disorders among caregivers who are mostly female blood relatives of patients.

CONCLUSION

The present study concludes that caregivers have poor knowledge and practice regarding self-care. Even those who have knowledge cannot practice it because of barriers such as logistic constraints, lack of appropriate knowhow, and complete dependence of patients on them. They were dissatisfied with workload and remuneration. However, few workers were practicing self-care despite odds. Need for structured nonpharmacological intervention module and training on patient handling techniques was reiterated.

Limitations

Caregivers suffering from some or other mental health issues could not opine in most of the cases and had to be dropped out of study. The present study in community setting would have been more realistic and generalizable. A larger study sample and a study into various aspects of dementia care will be needed in close future.

Recommendations

Dementia friendly India would need stringent and rigorous need assessment, capacity building, performance-based payments, health education, routine regular check-ups among caregivers of demented patients. The absolute necessity for an emergency contact number provided along with nonpharmacological interventions in the structured module needs to be conveyed to policy-makers. A larger study with a more representative sample is recommended.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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