

Impact of Stress on Quality of Life of Caregiver's of Alzheimer's Patient in Ernakulam Dist., Kerala

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ABSTRACT

Introduction: A quantitative study with a descriptive correlational design the present study was conducted in selected ARDSI society, Kerala.

Aim: to assess the stress and quality of life of caregivers of Alzheimer's patients.

Materials and Method: 100 caregivers of Alzheimer's patients were selected through purposive sampling technique. The study was conducted in ARDSI society for a period of 4 weeks. Modified Caregiver Stress Self-Assessment Questionnaire and Modified Caregiver Quality of life Scale was used to assess the stress and quality of life of caregivers. Data were analysed using descriptive and inferential statistics.

Results: Revealed majority (99%) of caregivers had moderate stress with 85% of caregivers leading average quality of life. On correlating stress and quality of life of caregivers a negative correlation (-0.09) was found. It was statistically not significant at 0.05 level of significance.

Based on the findings it was concluded care givers involved in caring for Alzheimer's patients at home undergo a significant amount of stress; which has a negative impact on their quality of life. Therefore, measures to reduce the stress of care givers and improve their quality of life should be taken which in turn will enhance the quality of life of patients.

Keywords: Caregiver, Stress, Quality of life, Alzheimer's patients.

INTRODUCTION

Alzheimer's disease poses real challenges for both the person diagnosed with AD and to those who assume caregiving responsibilities. It is estimated that 8.9 million caregivers provide care to someone fifty years or older with AD or a related dementia. Seventy percent of people with Alzheimer disease (AD) live at home and are cared for by family and friends.

Alzheimer's disease (AD) has a major impact on everyday living of families, placing an emotional burden on the whole family unit. AD can cause changes in family structure and roles: Children become caregivers of their ill parents, looking after them and taking on the duties of carer - a situation which may create conflict if not handled properly. With the progression of disease, patients become progressively more dependent on caregivers.¹

For the successful treatment and care of the patient, family assistance is extremely valuable and often of major importance as family members are the primary source of care and support for people with Alzheimer's.²

Caregivers must provide various levels of care for the person with Alzheimer's disease. At the beginning of the disease, responsibilities frequently include shopping, meal preparation, transportation, oversight of medication, and assistance with financial and legal affairs. With progression of the disease, the person with Alzheimer's disease may require assistance with activities of daily living including bathing, feeding, dressing, and toileting. As AD progresses, caregivers watch their loved ones deteriorate at the same time as they are called upon to perform an increasing range of tasks that ultimately include helping loved ones with basic activities.

Being a family caregiver, is a situation that demands daily responsibility and transforms individuals' life. It demands time, energy, work, affection, effort and good will. Gradual cognitive losses, behavioural and emotional changes, and even changes in the patients' personality require great capacity to adapt with a view to living together satisfactorily. Numerous daily arrangements are necessary to meet progressive and irreversible patient demands.³

The changes that take place in the life of caregivers, such as: lack of time, reduction of intimacy, deterioration in social life, a sense of loss of control over their own lives, may cause physical and emotional burden (anxiety, stress, and depression), acute and chronic diseases, as well as financial deterioration, affecting all activities.⁴

Studies of caregivers, caring for persons with chronic illnesses suggest that the experience of care giving can affect their physical and mental health. Physical health outcomes as suggested in various studies of caregivers caring for person with chronic illness include a decrease in immune system response, increased risk of cardiovascular disease, high blood pressure and interruption in sleep. The psychological health of the family caregiver is negatively affected by providing care. Higher levels of stress, anxiety, depression and other mental health effects are common among family members who care for an older relative or friend, often leading to a poor quality of life.⁵

Several studies demonstrate that caregiving has a strong impact on caregiver's physical and mental health and well-being, due to many factors. The major life impact of AD on the family means that care giving can be a very difficult and physically demanding activity that encompasses all of the caregiver's life. Caregivers not only lose their relationship, spare time, have problems with their job, but experience depression, anxiety, and social isolation, leading to poor health impact as a caregiver of AD.⁶

Alzheimer's disease is a family disease, because the chronic stress of watching a loved one slowly decline affects everyone. An effective treatment will address the needs of the entire family. If the needs of family caregivers can be addressed, caregivers can more effectively look after care recipients and prevent hospitalization or placement in long-term care facilities. Emotional and practical support, counselling, resource information and educational programs about Alzheimer's disease will help a caregiver provide the best possible care for a loved one.⁷

Although the care of the caregiver is always considered very important by keeping a balance of attention for both patient and caregiver, evaluation of burden and possible emotional problems of caregivers is not routinely carried out by health professionals. Nurses, while recognizing families having specific needs, often

do not have the knowledge or skills necessary to provide the appropriate assistance. A gap does exist between what families of the Alzheimer patient need to lower stress and improve coping skills and what nurses can provide.

Based on the above facts and conclusion drawn from the observations made during clinical practice, the researcher felt that primary caregivers were enveloped, with various unspoken burden involved in caring the patient resulting in a poor quality of life.

OBJECTIVES OF THE STUDY

1. Assess the level of stress among caregivers of patients with Alzheimer's disease.
2. Assess the level of quality of life among caregivers of patients with Alzheimer's disease.
3. Find the relation between stress and quality of life of caregivers of patient with Alzheimer's disease.
4. Find the association between stress and quality of life of caregivers with selected demographic variables.

Hypotheses: At <0.05 level of significance.

H₁: There will be a significant correlation between overall stress and quality of life scores of caregivers of Alzheimer's patient.

H₂: There will be a significant association between overall stress score and selected demographic variables.

H₃: There will be a significant association between overall quality of life score and selected demographic variables.

METHODOLOGY

Research approach: In view of the nature of the problem selected for the study and the objectives to be accomplished, a quantitative research approach was considered.

Research design: A non- experimental descriptive correlation design.

Setting of the study: Care Centre Ernakulam, Respite Care Centre, Guruvayoor and Dementia Day Care Centre Aluva, were selected as setting for the present study.

Population: In the present study, the population comprised of all the Caregivers of Alzheimer's patients attending the ARDSI centres.

Sample and sampling technique

100 caregivers, who met Selection criteria, were selected, using purposive sampling technique.

Inclusion criteria

Caregivers:

- Of patient diagnosed with Alzheimer's disease and other related disorders.
- Willing to participate in the study.
- Caring for Alzheimer's patients at home.
- Providing more than 6 months of care.

Exclusion criteria

Caregivers:

- Who were occasional caregivers.
- Suffering from mental illness.
- Of patients with mental illness.

Tools/instruments: The tool consisted of 3 sections as:

Part A: Socio demographic profile: Socio demographic profile consisted of 20 items aimed at collecting demographic data of caregivers and Alzheimer patient.

Part B - Modified Caregiver Stress Self-Assessment Questionnaire: The modified version of Stress Self-Assessment Questionnaire was developed. Modified scale consisted of 25 items

Scoring and Interpretation: Score ranged from 0 to 4 per item, thus for the 25 items, a minimum score was 0 and maximum score was 100.

00	No stress
<33	Mild stress
33-67	Moderate stress
>67	Severe stress

Part C: Caregivers Quality of life Scale: A self-report questionnaire on Caregiver's QOL is a 20-item instrument that measures the overall QOL of caregivers.

Scoring and interpretation: With 3 response alternatives the score ranged from 1-3 for each item, thus the minimum score was 20 and the maximum score 60.

20-33	Low Quality of Life
34-47	Average Quality of Life
47-60	High Quality of Life

FINDINGS

Table 1: Assessment of Overall Level of Stress of Caregivers

(n = 100)

Level of Stress	Range of Score	f	%
No Stress	00	00	00
Mild Stress	< 33	01	01
Moderate Stress	33-67	99	99
Severe Stress	>67	00	00

The level of stress of caregivers ranged from mild to moderate stress. Majority of the caregivers (99%) were having moderate stress.

Table 2: Assessment of quality of life of caregivers'

(n = 100)

Level of quality of life	Range of Score	f	%
Low quality of life	20-33	15	15
Average quality of life	34-47	85	85
High quality of life	47-60	10	10

Majority of caregivers (85%) were having average quality of life and only 15% were having low quality of life.

Table 3: Correlation between stress and quality of life scores among caregivers of Alzheimer's patient

(n = 100)

Variables	Mean ± SD	r value	p-value
Caregiver stress	61.60 ± 5.94	-0.09	0.40
Quality of life	37.00 ± 3.09		

The computed r value (-0.09) indicates a negative correlation existing between Stress score and Quality of life score. Based on the findings, it can be inferred that with an increase in stress, the quality of life of caregiver decreases.

On associating stress of caregivers and quality of life with selected socio-demographic characteristics of caregivers of Alzheimer's patient using ANOVA and 't' test. It is found that there was no statistically significant association between stress score and quality of life and selected variables of caregivers at 0.05 level of significance. Hence the null Hypothesis H02: "There

is no significant association between stress, quality of life and selected demographic variables at 0.05 level of significance” is accepted.

DISCUSSION

Most of the primary caregivers are unprepared to provide physical care, meet emotional demands of the patients, as they possess inadequate knowledge and resources and get very little guidance. Providing care to a disabled elderly friend or relative can have profound effects on the caregivers physical and emotional health. Caregivers are much more likely than non-caregivers to suffer from stress overload, depression, and other health problems resulting in a poor quality of life. Because being a caregiver is so hard, some doctors think of caregivers as “hidden patients.”

Assessment of stress of caregivers: In the present study it was seen that majority of caregivers (99%) were having moderate stress. None of the caregivers reported severe stress. The overall mean score was found to be 61.60 ± 5.94 (61.60%). Similar findings were reported by Vellone E, Piras G, Sansoni J.³⁴ where 54% of subjects reported stress.⁸

Assessment of quality of life of caregivers: Majority of caregivers (85%) were having average quality of life and 15 % were having low quality of life. However, none of the caregivers reported high quality of life. Overall mean score was 37.00 ± 3.09 (80.43%).

In a study by Vellone E, Piras G, Talucci C, Cohen MZ. factors that caregivers said improved their quality of life were good health of the patient, independence from the patient, and more help in caregiving. But worries about the future and progression of the patient’s illness and stress worsened caregivers’ quality of life.⁸

Correlation between stress and quality of life scores among caregivers of Alzheimer’s patient: On correlating stress and quality of life scores among caregivers of Alzheimer’s patient, a negative correlation was seen. Similar findings were reported by Divya CP⁹ where the burden negatively correlated with the quality of life of caregivers. In another study by MA Mahesh a poor quality of life was reported in relation to psychological distress.¹⁰

CONCLUSION

Based on the findings it was concluded that AD is a disease that involves not only the patient, but also affects

the whole family. The continuous commitment in caring also causes stress on the caregiver resulting in negative repercussions in the family.

Keeping this in mind, Support to caregivers through meetings, lectures and home visits with the help of multi-professional team will contribute towards reinforcing family and community bonds, encouraging caregivers to accept their limitations and to seek help which will reduce the stress imposed on the caregivers.

Nursing Implications: In this section, based on the researcher’s experience during the study, some specific implications have been highlighted for nursing in different dimensions:

Nursing education

- Create awareness among the nurses about the magnitude of AD in India, especially in Kerala.
- Educate nurses to gain in depth knowledge regarding identification of stress, anxiety, depression and its prevention.

Nursing Practice

- Provide counselling services to the caregiver.
- Provide support to families through tailored strategies aimed to reshape the dysfunctional coping styles.
- Teach stress management techniques to the caregiver.
- Emphasis to alleviate the burden among caregivers and measures to improve quality of life.

Nursing Administration

- Establishing a network of community services to alleviate the burden on families.
- Adequate resources like information booklet/ brochures/pamphlets to create awareness in them.
- Organizing and conducting caregivers meeting.

Nursing Research: Nurses can play a vital role in undertaking research to expand their body of knowledge.

- Future research should be done to investigate the potential benefits of early intervention and education among caregivers.
- Need for development of follow up package to enhance the quality of life and reduce stress among caregivers.

Limitations

- Results cannot be generalized to the wider population.
- Sample size was small.
- Setting was limited to ARDSI society.

Recommendations

- Researchers should also investigate whether different types of caregivers (spouse, adult child and friend) have different needs or problems.
- Longitudinal studies for understanding the stress and quality of life in caregivers over a period.
- Effective intervention strategies to reduce the stress and improve the quality of life among caregivers.

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REFERENCES

1. ¹¹Martin M, Rebeca LR, Anyolina N P, Natacha RC. Burden, anxiety and depression in caregivers of Alzheimer patients in the Dominican Republic. *Dement Neuropsychol* [Internet] 2014 December [cited 2015 May5]; 8(4):384-388. Available from: <http://www.scielo.br/pdf/dn/v8n4/1980-5764-dn-08-04-00384.pdf>.
2. Sansoni J, Anderson KH , Varona LM , Varela G. Caregivers of Alzheimer’s patients and factors influencing institutionalization of loved ones: some considerations on existing literature. *Ann Ig* [Internet] 2013[cited 2014 Dec 31]; 25: 235-246. Available from:http://www.seu-roma.it/riviste/annaliigiene/open_access/articoli/0c3f2676640af498e8434c85928b9def.pdf.
3. Inouye K, Pedrazzani ES, Pavarini SC, Toyoda CY. Perceived quality of life of elderly patients with dementia and family caregivers: evaluation and correlation. *Rev Lat Am Enfermagem* [Internet] 2009 Mar-Apr[cited 2015 April 5];17(2):187-93. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/19551271>.
4. Martin M, Rebeca LR, Anyolina N P, Natacha RC. Burden, anxiety and depression in caregivers of Alzheimer patients in the Dominican Republic. *Dement Neuropsychol* [Internet] 2014 December [cited 2015 May5]; 8(4):384-388. Available from: <http://www.scielo.br/pdf/dn/v8n4/1980-5764-dn-08-04-00384.pdf>.
5. Caregiver Health [Family Caregiver Alliance: National centre on caregiving] No date [cited 2014 Dec 21]. Available from: <https://caregiver.org/caregiver-health>.
6. Alzheimer’s disease and Caregiving [Family Caregiving Alliance: National Centre on caregiving].No date [cited 2014 Dec 31]. Available from: <https://caregiver.org/alzheimers-disease-caregiving>.
7. Quang TT. The Quality of life and Caregiving burden among caregivers of people with Dementia in Hanoi, Bac ninh and Hai phong, Vietnam. [PhD thesis].Australia: Queensland University of Technology;2015 [cited 2015 April 24]. Available from: http://eprints.qut.edu.au/82287/1/Quang%20Trung_Truong_Thesis.pdf.
8. Vellone E, Piras G, Talucci C, Cohen MZ. Quality of life for caregivers of people with Alzheimer’s disease. *J Adv Nurs*.[Internet] 2008 Jan [cited 2015April 5];61(2):222-31. Available from <http://www.ncbi.nlm.nih.gov/pubmed/18186913>.
9. Divya CP. A quality of life of Elderly with dementia and their primary caregivers.[M.Sc Thesis]. Bangalore: NIMHANS Deemed University; 2012.
10. Mahesh MA. A study of quality of life and burden in caregivers of elderly with dementia and other psychiatric disorders. [M.Sc Thesis].Bangalore: NIMHANS;2010.