An exploratory study to identify the stressors and coping strategies adopted by the caregivers of patients suffering from depression in the out-patient department of a tertiary hospital

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Depression is a disorder of major public health importance, in terms of its prevalence and the suffering, dysfunction, morbidity, and economic burden. Depression is more common in women than men. The report on Global Burden of Disease estimated that the point prevalence of unipolar depressive episodes was 1.9% for men and 3.2% for women, and the one-year prevalence was estimated to be 5.8% for men and 9.5% for women [1]. It is estimated that by the year 2020 if current trends for demographic and epidemiological transition continue, the burden of depression will increase to 5.7% of the total burden of disease and it would be the second leading cause of disability-adjusted life years (DALY), second only to ischemic heart disease [2]. Today the incidence of mental illness is constantly rising and the cause of this is increasing demands and burden on a person who when unable to fulfill them experiences stress. As the duration of stress gets prolonged individual efforts and resources of coping with the stress starts diminishing [3]. The care givers suffer from undue stressors like physical stressor, psychological stressors and financial stressors. Some caregivers may adapt to the stress while some may form a maladaptive functioning leading to unresolved stress and burnout. Coping strategies of caregivers has been distinguished into two broad groups: problem-focused and emotion-focused strategies. Problem-focused strategies refer to the constructive coping efforts undertaken to modify difficult situations and include measures such as problem-solving, seeking information, or using positive methods of communication [4]. In contrast, the less adaptive emotion-focused strategies are attempts at modulating the caregivers stressrelated emotional response by the measures such as avoiding or resigning themselves to the situation. The most consistent correlates of coping across quite a few studies have been caregiver-burden, patient's social functioning, expressed emotions of caregivers and social support available for caregivers [5]. High levels of burden, dysfunction, and (EE) together with low levels of available support have been associated with a number of maladaptive, principally emotion-focused styles such as avoidance, resignation, coercion, etc [6].

There are many situations and occurrences in life that can test the strength of a family unit, including environmental factors, physical factors, mental factors, biological factors and social factors. It could be one of these factors, or a combination of two or more, that affects either one or two individuals within the family unit or the entire family unit as a whole; whatever it is that impacts the family, it can have a huge impact on the families overall mental health [7]. Each individual will react to a high level of stress in their own way, but how they handle the stress can have a direct impact on the other members of their family. When depression hits the family, everyone in the unit can be affected and often it is in a negative way [8]. Millions of people throughout the world suffer from different types of depression; some of them suffer a lighter form of depression and with help they and their families are able to cope and work with it, while others suffer from more severe forms of depression that can cause a family unit to fall apart. When an individual develops depression, their family can often sense that something is making them uncomfortable; that the individual has changed and may not be quite the same person as they used to be, especially if the family was a tight-knit family [9]. The signs might not be as obvious in family that are not very close knitted. Depending on the depression that the person has and how they choose to deal with it, the family

could be adversely affected and the unit can fall apart. Rifts begin to grow into chasms, drawing each family member away from the unit they once knew. In some cases, the person's depression only becomes worse, especially if they choose to avoid help, self-medicate and then take out their frustrations on their family. It may be unfortunate, but many family units that were once strong and close have fallen apart as a result of one or more family members becoming severely depressed [10].

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When depression hits the family, everyone in the unit can be affected and often it is in a negative way. Millions of people throughout the world suffer from different types of depression; some of them suffer a lighter form of depression and with help they and their families are able to cope and work with it, while others suffer from more severe forms of depression that can cause a family unit to fall apart. When an individual develops depression, their family can often sense that something is making them uncomfortable; that the individual has changed and may not be quite the same person as they used to be, especially if the family was a tight-knit family. The signs might not be as obvious in family that are not very close knitted [12]. Depending on the depression that the person has and how they choose to deal with it, the family could be adversely affected and the unit can fall apart. Rifts begin to grow into chasms, drawing each family member away from the unit they once knew. In some cases, the person's depression only becomes worse, especially if they choose to avoid help, self-medicate and then take out their frustrations on their family [13]. It may be unfortunate, but many family units that were once strong and close have fallen apart as a result of one or more family members becoming severely depressed [14].

METHODOLOGY

This study was based on exploratory descriptive approach. The research method used in the study was the survey method. This study explored the various stressors faced by the caregivers of the patients suffering from depression and also identified the various coping strategies adopted by them.

Research Design: Survey method was used in this study to assess the various stressors and coping strategies adopted by them.

Setting: The study was conducted in the OPD of a selected Municipal Hospital in Mumbai.

Study Population: In this study population comprised of all the caregivers of patients suffering from depression in Mumbai.

Controls: In this study the samples were caregivers of patient suffering from depression attending OPD of a selected hospital in Mumbai.

Sample Size: The sample size was 150. Fifteen samples were taken each for pilot study and reliability. In this study the criteria for sample selection were as follows:

- The caregivers should be staying with the patient.
- The care giver should be the primary caregiver of the patient.

Inclusion Criteria

- The study included caregivers living with the patient.
- The study included care givers of patients diagnosed with depression.
- The study included the primary caregivers taking care of the patient and who was responsible for the patient.
- The study included care givers who could understand either English, Hindi or Marathi.
- The study included care givers who were willing to participate in the study.

Exclusion Criteria

The study excluded caregivers of patients suffering from Bipolar disorders.

In this study interviewing technique was used. A semi-structured interview schedule was used for data collection. The development of the tool was a step by step procedure for which the investigator adopted a practical approach. Prior to the preparation of the tool the investigator visited Psychiatric Outpatient Departments of different Municipal and Government Hospitals in Mumbai. The investigator observed the patients suffering from depression and their caregivers. The investigator interacted with the patients and their family members. The investigator asked the caregivers about the various problems which they are facing and what they have done to overcome it. The investigator did an extensive review of literature before developing the tool. The investigator met experts from the field and discussed the features of the study with them and incorporated their valuable suggestions in preparing the tool. The tool was finally constructed keeping in mind the actual stressors faced by the caregivers and the coping strategies adopted to relieve the stress.

The tool was divided into 2 sections. Section I dealt with the demographic details of the caregiver. Section II dealt with the various stressors and coping strategies adopted by the caregivers in the following areas as follows:

- Stressors encountered in activities of daily living
- Physical stressors.
- Psychological stressors.
- Social stressors.
- Financial stressors.
- Problems faced at workplace.

In Section II open ended questions were used for data collection. The respondents had to firstly answer either in yes or no for the presence of the particular stressor and if the answer was yes then the respondent had to elaborate on it. In a similar way coping strategies were also asked in an open ended manner. The tool was also translated in Marathi and Hindi.

A pilot study was conducted in Psychiatry OPD of a selected Hospital from 11th July 2011 to 16th July 2011. The investigator interviewed respondents after taking their consent. Fifteen samples were taken for pilot study. After getting their consent the investigator interviewed the respondent separately and the patient was made to sit comfortably in a nearby location. The samples were interviewed on a one to one basis. The investigator collected data in Hindi and Marathi. The respondents participated very well. The respondents could understand what was asked to them and it took 30-40 minutes for interviewing each respondent. The data was analysed using frequency and percentage. The investigator had no problems during the pilot study. No modification or change was required in the tool. The samples for pilot study were not included in the main study.

Data gathering process took 7 weeks. The investigator took permission from the ethical committee and the departmental heads of a selected Hospital. The investigator interviewed the caregivers as per the inclusion criteria. It took 30-40 minutes for interviewing one caregiver. On an average 4-6 patients were interviewed per day. Data gathering process continued till the desired sample size was achieved.

Data analysis was done using frequency and percentage and the formula on significance of the difference between the percentages of large uncorrelated groups.

RESULTS

Analysis of the demographic data of the caregiver

Age: It was evident that 43 (28.7%) caregivers were in the age group of 18-30yrs, 36(24%) were in the age group of 31-40yrs, 37 (24.7%) of the caregivers were in the age group of 41-50yrs and only 34 (22.7%) caregivers were above 50 years of age.

Sex: As regards to sex 91 (61%) of the caregivers were males and only 59 (39%) were females.

Religion: One hundred and thirty nine (93%) of the caregivers belonged to Hindu religion, 9 (6%) were Muslims and only 2 (1%) were Christians.

Relationship: As regards to relationship with the patient 28 (19%) were parents, 46 (31%) were offspring, 60 (40%) were spouse, 9 (6%) were siblings and only 7 (5%) were others.

Monthly income: It was evident that majority of the caregivers had a monthly family income of less than Rs 5,000.

Duration of care rendered to the patient: Eighty five (57%) caregivers had rendered care to the patient for more than 3 yrs.

Analysis of the stressors faced by the care givers of patients suffering from depression

Forty nine (33%) of the caregivers faced stressors in meeting the hygienic needs of the patient like bathing and grooming. Seventy five (50%) of the caregivers faced stressors in meeting nutritional needs of the patient. Sixty eight (45%) caregivers faced stress in relation to the treatment schedule. One hundred and four (69%) caregivers suffered from physical tiredness. Eighty two (55%) caregivers had insomnia. Ninety (60%) caregivers suffered from frequent aches. One hundred and twenty four (83%) caregivers suffered from feelings of loneliness, anger, anxiety, depression, fear and irritation when caring for the patient. One hundred and eleven (74%) caregivers suffered from feelings of helplessness when caring for the patient. Seventy three (49%) of the caregivers faced stress in attending social functions and meeting friends. Ninety six (64%) caregivers faced financial problems. Fifty eight (39%) faced stressors related to decreased concentration and work productivity.

Analysis of the coping strategies adopted by the care givers

Sixteen (33%) caregivers forced the patient to meet their hygienic needs. Twenty eight (37%) of the caregivers forced the patient to eat. Thirty two (43%) of the caregivers convinced the patient to eat. Forty six (68%) caregivers consulted the doctor themselves regarding treatment needs of the patient. To overcome physical stressors 32 (31%) planned rest and activity and 50 (48%) prayed to God. To overcome psychological stressors, 53 (43%) of the caregivers accepted the situation and 58 (47%) of the caregivers spoke to someone and ventilated their feelings. Forty eight (50%) took loan to overcome financial stressors.

DISCUSSION

The findings of the study brought in depth knowledge of the stressors faced by the caregivers of patients suffering from depression. The study brought relevant quantitative data about the caregivers. It was surprisingly found that many of the spouses of patients suffering from depression were also under treatment for conditions like Mixed anxiety Depression, Dysthymia and Major depressive disorders. Many children of patients suffering from depression were also undergoing psychiatric treatment for depression. Thus the study has put into limelight the possible association between caregivers stress culminating into mental disorders like depression.

CONCLUSION

During the study it was seen that the psychological stressors were very high in majority of the caregivers. The study has brought evidence that mental illness is still a social stigma and the family members undergo emotional turmoil due to the patient's condition. It was also noted by the investigator that many caregivers were under psychiatric treatment for depression. Thus the impact of mental illness on the family is far more greater than having a physical illness. In this era of globalisation and fast moving world and with the changing norm of nuclear families the burden on the caregivers is tremendously increasing and the caregivers have to face many challenges. Due to the patients illness they may not go to work thus the caregivers have an added responsibility of financially supporting their families. The study has explored into the stressors and the various coping strategies adopted by the caregivers in detail. The study also brought about the need for family support and counseling in Depressive disorders.

REFERENCES

- 1. Kaplan V, Sadock B. Synopsis of Psychiatry; behavioral sciences / clinical psychiatry", 10th edition, New Delhi, Wolters Kluwer; 2013.
- 2. Lopez AD Mathers D. Global Burden of Disease and Risk Factors", 1st edition, Washington, The World Bank; 2006.
- 3. Norman S. Families and mental disorders: from burden to empowerment. Psychiatr Serv 2006;57(3):424-8.
- 4. Kuipers E, Bebbington P, Barrowclough B. Research on burden and coping strategies in families of people with mental disorders: problems and perspectives. Families and mental disorders: From burden to empowerment. 2005;14:217-34.
- Budd RJ, Oles G, Hughes IC. The relationship between coping style and burden in the carers of reatives with schizophrenia. Acta Psychiatr Scand 1998;98(4):304-9.
- Scazufca M, Menezes PR, Almeida OP. Caregiver burden in an elderly population with depression in Sao Paulo, Brazil. Soc Psych Psychiatr Epidemiol 2002;37(9):416-22.
- 7. Magliano L, Fiorillo A, De Rosa C, Malangone C, Maj M, National Mental Health Project Working Group. Family burden in long-term diseases: a comparative study in schizophrenia vs. physical disorders. Soc Sci Med 2005;61(2):313-22.
- 8. Avasthi A. Preserve and strengthen family to promote mental health. Indian J Psychiatry 2010;52(2):113-23.
- 9. Magliano L, Fiorillo A, Rosa C, Maj M. Family burden and social network in schizophrenia vs. physical diseases: preliminary results from an Italian national study. Acta Psychiatr Scand 2006;113(s429):60-3.
- 10. Bromet E, Andrade LH, Hwang I, Sampson NA, Alonso J, De Girolamo G, De Graaf R, Demyttenaere K, Hu C, Iwata N, Karam AN. Cross-national epidemiology of DSM-IV major depressive episode. BMC Medicine 2011;9(1):90.
- 11. Cohen LS, Altshuler LL, Harlow BL, Nonacs R, Newport DJ, Viguera AC, Suri R, Burt VK, Hendrick V, Reminick AM, Loughead A. Relapse of major depression during pregnancy in women who maintain or discontinue antidepressant treatment. JAMA 2006;295(5):499-507.
- 12. Belden AC, Sullivan JP, Luby JL. Depressed and healthy preschoolers' internal representations of their mothers' caregiving: Associations with observed caregiving behaviors one year later. Attach Hum Dev 2007;9(3):239-54.
- 13. Beach SR Yee J. Negative and Positive Health Effects of Caring for a Disabled Spouse: Longitudinal Findings from the Caregiver Health Effects Study. J Psychol Aging 2000;15:259-71.
- 14. Beach SR, Schulz R. Risk Factors for Potentially Harmful Informal Caregiver Behavior. J Am Geriatr Soc
- 15. Metzger C, Petal B. Foundation of Nursing Theory. California, SAGE Publication; 2005

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