

CAREGIVERS' STRESS OF CANCER PATIENTS IN A TERTIARY CARE HOSPITAL

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ABSTRACT

Objective: To see psychological stress in caregiver's of cancer patients and also to find out association of stress with demographic variable of caregiver.

Material and Methods: This cross sectional study was conducted at oncology department of Aga Khan University Hospital Karachi from July 2006 to December 2006. Sample size was 200 caregivers of cancer patients. General Health Questionnaire 12th version (GHQ-12) was used to measure the mental distress

Results: Out of 200 caregivers 166 (83%) were females and among females 56.02% (n=93/166) were house wives. Parents and wives as caregivers constituted 34.5% and 22.5% of the sample respectively. Mean age was 52 years. Mean GHQ score were 11.80. The severity of stress on GHQ-12 scoring were mild (2-4) in 17%, moderate (5-9) in 34% and severe (> 10) in 49 % cases. Patients requiring care at home included patients with blood cancers (40%), gastrointestinal cancer (38.5%) and breast cancers (21%). Mean duration of illness was 3.5 years. Majority of the of patients (65%) were with <1 year and 35% of patients were with > 1 year of duration. Association of stress was significant with female gender (p<0.05), age more than 41 years (p< 0.03), being parent as caregiver (p<0.01) and caring for a patients with illness duration >1 year (p<0.04).

Conclusion: Significant number of caregivers has been found to be suffering from severe stress. Age of caregiver, relation with patient, female gender and duration of caregiving were found to be significantly associated with stress.

Keywords: Caregiver, Pakistan, Cancer, GHQ-12, Stress.

INTRODUCTION

Over last decade care of cancer patients at home has increased tremendously as more and more patients with cancer are discharged early and treated at home. With this change in care model it has been observed that burden of care has been shifted to family members who have assumed role of informal caregiver.^{1,2} Responsibilities of caregivers has extended beyond the functions like transporting the patient to hospital, keeping appointment with physicians, helping patients in activities of daily life helping. More technical jobs like intravenous injections, maintaining oxygenation of patients at home and wound care are few stressful but routine jobs.³ In this way caregivers plays an important role as member of cancer team, but without being formally trained for that.⁴ They are highly susceptible to adverse

affects of caregiving, which include both physical and psychological illnesses.⁴

In a study Grunefeld et al found that caregivers of breast cancer were more distressed than the cancer patients themselves and psychological distress is directly proportion to the duration of care giving.⁵ Burden is associated with worse mental health of both the patient and the caregiver. The commonest psychiatric disorder in caregivers of cancer patients was found to be panic disorder followed by depressive disorder, post traumatic stress disorder and generalized anxiety disorder.² Burden of caregiving also increases mortality in those carers who experience psychological strain as compared who are with less psychological distress.⁶ There is some evidence that salivary cortisol of formal caregivers remain elevated as compared to control, which could be an important

CHARACTERISTICS OF CAREGIVERS OF CANCER PATIENTS

Variables	Number (%)
Gender	
Male	34 (17)
female	166 (83)
Age	
20-40	38 (19)
41-65	147 (73.5)
>65	15 (7.5)
Relationship to patients	
wife	45 (22.5)
parent	69 (34.5)
sibling	21(10.5)
in-laws	40 (20.0)
others	25 (12.5)
Occupation	
House wife	93 (46.5)
Professional	41 (20.5)
Laborers	25 (12.5)
Others	41 (20.5)
Educational status	
Educated	46 (23)
Uneducated	82 (41)
Missing	70 (35)
	2 (1)
GHQ-12severity score	
Mild	34 (17)
Moderate	68 (34)
Sever	98 (49)
Duration of caregiving	
< one year	130 (65)
> year	70 (35)
Cancer type	
Blood cancer	80 (40)
Gastrointestinal cancer	77 (38.5)
Breast cancer	42 (21)
Lung cancer	1 (0.5)

Table 1
biological marker of the caregiving.⁷

In Pakistan family members are the main source of caregiving at home and they are randomly selected. To the best of our knowledge there has been no study in Pakistan investigating psychiatric morbidity in caregivers of cancer patients.

Objectives of this study was to see psychological distress in caregivers of cancer patient and also to see association of level of

stress with demographic factors like gender, age, relation with patient and educational level of caregivers.

MATERIAL AND METHODS

This study was conducted in the oncology unit of the Aga Khan University Hospital. It follows cross sectional study design with purposive, non nonrandomized, sampling technique. About 200 caregivers of cancer patients were selected and were asked to fill the General Health Questionnaire after getting informed consent.

Study duration was 6 month with the effect from July 2006. General Health Questionnaire 12th version (GHQ-12) was used to measure the mental distress. GHQ originally developed by Goldberg in the 1970s and has been used as screening questionnaire across different settings.⁸ It has many versions but GHQ-12 is brief, simple version of original GHQ which is easy to complete, its use as screening instrument is well established⁹ and is validated in Pakistan.^{10,11} Cut off scores of 1/2 yields the best sensitivity and specificity for identifying a person with common mental disorders.¹² This instrument has been used previously in similar studies.¹³ Socio demographic data was extracted using a sheet consisting of variables like gender, age, marital status, educational status, duration of care and relationship with patient.

The data was entered and analyzed in the Statistical Package for Social Science (SPSS15.0) for windows and descriptive statistics were used to calculate frequencies. Chi-square test of association was also applied to assess association between psychological distress on GHQ-12 and socio-demographic variables like gender, marital status, educational and economic status. $P < 0.05$ was considered level of significance.

RESULTS

The characteristics of caregivers who were included in the study are listed in the table1. Out of 200 caregivers 166 (83%) were females and among females 56.02% ($n=93/166$) were house wives. Parents and wives as caregivers constituted 34.5% and 22.5% of the sample respectively. Mean age was 52 years. Mean GHQ score were 11.80. The severity of stress on GHQ-12 scoring were mild (2-4) in 17%, moderate (5-9) in 34% and severe (> 10) in 49 % cases. Patients requiring care at home included patients with blood cancers (40%), gastrointestinal cancer (38.5%) and breast cancers (21%). Mean duration of illness was 3.5 years. Majority of the of patients (65%) were with < 1 year and 35% of patients were with > 1 year of duration. By applying chi square test of

ASSOCIATION OF CAREGIVER'S STRESS AND DEMOGRAPHIC VARIABLES

Variables		STRESS SCORES ON GHQ--12		p value
		Less than 4	More than 4	
Gender	Male	16	18	0.05
	Female	40	114	
Age (in years)	20-40	16	22	0.03
	41-65	50	97	
	>65	7	8	
Relation to patients	Wife	15	25	0.01
	Parent	13	57	
	Sibling	10	11	
	In-law	13	27	
	Others	25	17	
Duration of caregiving	<1 year	29	101	0.04
	> 1 year	25	45	

Chi Square Test

Table 2

Significance = (p value<0.05)

Confidence Interval (CI) = 95%

association, we found significant association of stress with female gender ($p<0.05$), age more than 41 years ($p<0.03$), being parent as caregiver ($p<0.01$) and caring for a patients with illness duration <1 year ($p<0.04$){table 2}.

DISCUSSION

The striking finding of this study is a high level of stress among majority of caregivers on GHQ among the caregivers of cancer patients. Mean score of 11.8 on GHQ of, 33% with moderate and 48% with severe stress is an alarming figure. This finding is similar to other studies conducted previously.¹³ Such a high prevalence of stress could be secondary to anticipatory grief, being overburden and to undertake difficult and unfamiliar task at home. Apart from this the caregiver responsibility also includes over all coordination of care. Some times they have to keep record of medical and investigation documents.

In spite of being a satisfying experience some times in our culture it is still emotionally draining, physically demanding and distracting the caregiver from taking care of self.⁴

Partly the stress level among caregivers in our culture could be secondary to situational factors mentioned by Cristine et al¹⁴ and Haley.¹⁵

In Pakistan, there are no social services or respite centers along with poor health delivery system and the caregiving becomes even more important. There is scarcity of literature on caregivers stress in Pakistan. One study from

Pakistan showed that depression and anxiety have been found to be significantly associated with caregiving of chronic psychiatric patients.¹⁶

Age of care givers is an important demographic factor, mostly older age group assume the role of being an informal caregiver. In a study from India shows that 72% of care givers of schizophrenic patients were among age group of 35 and 64 years¹⁷. This is consistent with our study in which majority of the caregivers are among 51-55 years of age. This finding points toward the fact that middle age groups are assigned the role of caregivers more often.

Our findings also show that majority of carers are females, house wives and mothers of the patients, this is not different from studies conducted else where.¹⁸ Females in the role of caregivers is not uncommon, some times the role is thrust upon them under some circumstances. Similarly Guru EK et al study reported that women had significantly higher prevalence of Hospital Anxiety Depression Scale (HADS)-defined depression compared with males.¹² We also found that, female caregivers show significantly high score on GHQ-12 (Table 2). Such findings could be explained on the basis of gender differences in over all coping with stressful situation.

We found an interesting association in our study i.e role of parents as caregivers and duration of caregiving of less than one year are significantly associated with stress (table 2). This finding is in contrast with some previous research,¹³ which could be explained on the basis

of culture and traditional values of our society. Being collectivistic nature of our society caregiving is considered as satisfying experience. Secondly the initial phase is likely to be coupled with stress reaction as a result of inability to cope with the situation.

Limitations of the study:

- Cross sectional design and longitudinal study will be more appropriate to look at stress level at different interval of caregiving.
- Study has been conducted in tertiary care private hospital and the result may not be generalized.
- This is one stage study of identifying the distressed individuals, and interview based study may be more appropriate to identify cases of depression and anxiety.

CONCLUSION

Significant number of caregivers has been found to be suffering from severe stress. Age of caregiver, relation with patient, female gender and duration of caregiving were found to be significantly associated with stress. Further research is required on larger sample using longitudinal design in order to decreased biases. Attention to should be given to caregiver's mental health.

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