Psychological Distress among Family Members of Inpatients in General Medicine Wards at a Tertiary Care Hospital: A Cross-sectional Study

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ABSTRACT

Introduction: It is now being increasingly recognised that even family members of the patients face emotional and cognitive challenges. Several studies have studied the distress experienced by family members of patients admitted in the Intensive Care Unit (ICU) setting and have identified anxiety and depression, stress, confusion, uncertainty among the family members. There is however, sparse literature available on the psychological distress experienced by family members of inpatients in general wards, globally as well as in India.

Aim: To estimate psychological distress among the family members of inpatients in General Medicine wards at a tertiary care hospital.

Materials and Methods: A cross-sectional study was conducted in General Medicine wards at a tertiary care hospital in Goa, India. Family member caregivers of the patients admitted in these wards constituted the study sample. The data was collected in predesigned format. The psychological distress was studied by using the Hospital Anxiety and Depression Scale (HADS) questionnaire and the Caregiver Self-Assessment Questionnaire (CSAQ). Statistical analysis was conducted using Statistical Package for the Social Sciences version 24.0. Chi-square was the test of significance used. Odds ratios and 95% Confidence Interval (CI) were calculated wherever the association between the variable of interest and outcome variable was statistically significant with p-value ≤0.05.

Results: Out of 150 family member caregivers, 84 were males and 66 were females with mean age of 38.87±13.08 years. Majority (43.3%) were children of the admitted patients. The most common ailments were cardiovascular (24%) followed by infectious diseases (17.3%) and neurological (16.6%) problems. The prevalence of anxiety was 42% among the family members whereas that of depression was 23.3%, on HADS scoring system. Relationship of the family member with the inpatient and marital status of the patient were the factors significantly associated with anxiety in the family member. Around 66% of the family members were experiencing high degree of distress, as measured by the CSAQ. Relationship of family member with the inpatient and the gender of the caregiver were the only factors significantly associated with psychological distress, measured by CSAQ.

Conclusion: Since family members of patients experience significant psychological distress even in general ward setting there may be a need to more actively involve family members in the hospital care of the admitted patients. This departure from the traditional patient centered care wherein a family member's role was minimal may lead to a more holistic healthcare benefiting both the patient and his family.

INTRODUCTION

Traditionally, hospital care has mainly focused on well-being of patients, their illness and their recovery. However, the patient is almost always accompanied by a family member who looks after his/her throughout the illness as a caregiver. It is now being increasingly recognised that even family member caregivers of the patients face emotional and cognitive challenges [1]. Thus, both patients and their family members require emotional support.

Several studies have studied the distress experienced by family members of patients admitted in the Intensive Care Unit (ICU) setting [2-6] and have identified anxiety and depression, stress, confusion, uncertainty among the family members. This increasing awareness of distress experienced by family caregivers of ICU patients has led to renewed interest in actively involving family members in the medical care of patients and the so-called family centered care has gained traction.

There is however sparse literature available on whether any psychological distress is also experienced by family members of inpatients in general ward setting wherein patients are less seriously ill. Belayachi J et al., in their study in Morroco, among family members of inpatients of general medical wards have reported high prevalence of anxiety and depression and have identified some factors associated with psychological distress [1]. As far as

Indian studies are concerned, few authors have reported that family caregivers experience significant psychological distress in ICU and cancer ward settings [7-9].

If indeed family members of inpatients in general medical ward setting do experience significant psychological distress, there is a need to study the associated factors to provide an evidence base for any possible strategy or solution for the same. This study was conducted to estimate prevalence of anxiety, depression and distress among the family members of inpatients in medicine general wards of a tertiary care hospital using the HADS questionnaire [10] and the CSAQ [11].

MATERIALS AND METHODS

A cross-sectional study was conducted from March 2019 to October 2019 in General Medicine wards at a tertiary care hospital in Goa Medical College, Bambolim, Goa, India. The study was approved by the Institutional Ethics Committee of the Institute (approval No: GMC/IEC/22Feb19/14 dated 22 February 2019). Informed written consent was taken before administering the questionnaire to the study participant.

Inclusion criteria: Family members of the patients admitted in the general medicine wards constituted the study sample. Family members were defined as all relatives and friends who visited the patient in the ward and were the primary caregivers, regardless of

the relationship with the patient [3,6,12]. Only one family member of an inpatient admitted for 48 hours or more and who was more than 18 years of age was recruited in the study.

Exclusion criteria: Patients transferred in the wards from a higher level e.g., ICU etc., were excluded from the study.

Sample size calculation: Considering the prevalence of depression of 41.1% as reported in a study by Belayachi J et al., in similar study settings and using the formula:

$$n=(Z_{\alpha})^2 \times pq/d^2$$

wherein, p=0.411, q=1-p, d (absolute precision)=0.08 or 8%, the minimum sample size was calculated to be 145 [1]. Considering non response it was decided to include a sample of 150.

Procedure

The data was collected in predesigned format. The demographic and personal data collected from the patient included age, sex, marital status and residence. Data collected for the family members included age, gender, marital status, education level, place of residence and relationship with the patient. In addition, details of past hospitalizations, length of stay and reasons for admission, visiting hours per day, whether daily visits were made and whether they felt need for more information from healthcare providers and the kind of information needed were collected. The psychological distress was studied by using the HADS questionnaire [10] and the CSAQ [11].

Hospital Anxiety and Depression Scale questionnaire (HADS) [10] consists of 14 items and 2 subscales: anxiety and depression. Each item is rated on a four-point scale, with 7 items evaluating depression and 7 items assessing anxiety, giving maximum scores of 21 for anxiety and for depression. Scores of 11 or more on either subscale are considered to be a significant 'case' of psychological morbidity, whereas scores of 8-10 represents 'borderline' and 0-7 'normal'. A cut-off value of 10 (score >10) on the anxiety or depression subscale has been found reliable for discriminating between patients with or without the corresponding symptoms [10]. Therefore, this cut-off was used for univariate analysis to study the associated factors.

Caregiver Self-Assessment Questionnaire (CSAQ) [11] has been developed by American Medical Association. It consists of 18 items rated as yes or no. The family member was considered to be experiencing high degree of distress if answer was 'yes' to item 4 and 11; or if total 'yes' responses score was 10 or more; or self-reported score on item 17 was 6 or higher; or if self-reported score on item 18 was six or higher.

STATISTICAL ANALYSIS

Statistical analysis was conducted using Statistical Package for the Social Sciences (SPSS) version 24.0. Continuous variables were presented as Mean and standard deviation. For categorical variables, the percentages were calculated. Anxiety or depression as per HADS questionnaire and high degree of distress as per CSAQ was the dependent variable. Associations between anxiety, depression, high degree of distress and variables of interest were studied. As far as test of significance was concerned, for tables with categorical values Chi-square test was used. Odds ratios and 95% Confidence Interval (CI) were calculated wherever the association between the variable of interest and outcome variable was statistically significant with p-value ≤0.05.

RESULTS

The background characteristics of the inpatients and their family members who were recruited in the study are summarised in [Table/Fig-1]. The patients were older compared to their caregiver family members (56.09±18.002 v/s 38.87±13.08). Total of 84 (56%) caregiver

family members were males compared to 66 (44%) females. Majority of the caregivers (43.3%) were children of the patients. More than 82% of the family members visited the patient daily. More than 60% of the family members were satisfied with the information provided to them by the healthcare providers regarding the patient in terms of diagnosis, prognosis and treatment.

Variables	Patients	Family members
Age (Years), Mean±SD	56.09±18.002	38.87±13.08
Gender, n (%)		
Male	93 (62%)	84 (56%)
Female	57 (38%)	66 (44%)
Marital status, n (%)		
Married	126 (84%)	101 (67.3%)
Unmarried	24 (16%)	49 (32.7%)
Residence, n (%)		
Urban	69 (46%)	73 (48.7%)
Rural	81 (54%)	77 (51.3%)
Relationship with patient, n (%)		
Parent	NA	8 (5.3%)
Children	NA	65(43.3%)
Spouse	NA	33 (22%)
Sibling	NA	22 (14.7%)
Others	NA	22 (14.7%)
Visiting hours/day (Mean±SD)		17.23±7.72
Daily visits, n (%)		
Yes	NA	124 (82.7%)
No	NA	26 (17.3%)
Need for more information from healthcare providers, n (%)		
Yes	NA	58 (38.7%)
No	NA	92 (61.3%)
Kind of Information needed from healthcare providers, n (%)		
Diagnosis	NA	28 (48.3%)
Prognosis	NA	9 (15.5%)
Treatment	NA	10 (17.2%)
Non response	NA	11 (19.0%)

[Table/Fig-1]: Demographic characteristics of patients and family members. (N=150)

[Table/Fig-2] describes the prevalence of anxiety and depression among the family members of the inpatients. Cut-off value of 10 (score >10) on the anxiety and depression subscale has been found to be reliable in discriminating between individuals with or without corresponding symptoms [10]. Considering the HADS score cut-off as 10, the prevalence of anxiety was found to be 42% whereas it was 23.3% for depression.

Type of distress	Hospital Anxiety and Depression Scale (HADS) score		Total
	Score >10 No. (%)	Score ≤10 No. (%)	
Anxiety	63 (42%)	87 (58%)	150 (100%)
Depression	35 (23.3%)	115 (76.7%)	150 (100%)

[Table/Fig-2]: Anxiety and Depression in Family members of inpatients.

As far as family member related factors were concerned, the relationship of the caregiver with the inpatient was found to be significantly associated with the anxiety (p-value=0.042) but not with depression. Parents of inpatients were most likely to be suffer from anxiety (OR=10.20, 95% CI 1.55-67.22) followed by spouse (OR=4.08, 95% CI 1.22-13.68), Siblings (OR=3.40, 95% CI 0.93-12.49) and children of inpatients (OR=1.86, 95% CI 0.61-5.70). Other family member related factors were not found to be significantly associated either with anxiety or depression [Table/Fig-3].

Family member factors	Anxiety (HADS score)			Depression (HADS score)		
	>10	≤10	p-value (χ^2 test)	>10	≤10	p-value (χ^2 test)
Gender						
Male	30 (47.6%)	54 (62.1%)	0.078	19 (54.3%)	65 (56.5%)	0.815
Female	33 (52.4%)	33 (37.9%)		16 (45.7%)	50 (43.5%)	
Marital status						
Married	45 (71.4%)	56 (64.4%)	0.363	21 (60.0%)	80 (69.6%)	0.291
Unmarried	18 (28.6%)	31 (35.6%)		14 (40.0%)	35 (30.4%)	
Place of residence						
Rural	33 (52.4%)	44 (50.6%)	0.827	16 (45.7%)	61 (53.0%)	0.448
Urban	30 (47.6%)	43 (49.4%)		19 (54.3%)	54 (47.0%)	
Relationship with patient						
Parent	6 (9.5%)	2 (2.3%)		2 (5.7%)	6 (5.2%)	
Children	23 (36.5%)	42 (48.3%)		16 (45.7%)	49 (42.6%)	
Spouse	18 (28.6%)	15 (17.2%)	0.042	11 (31.4%)	22 (19.1%)	0.278
Sibling	11 (17.5%)	11 (12.6%)		5 (14.3%)	17 (14.8%)	
Others	5 (7.9%)	17 (19.5%)		1 (2.9%)	21 (18.3%)	
Diagnosis at admission						
Cardiovascular	17 (27%)	19 (21.8%)		5 (14.3%)	31 (27%)	
Infectious	10 (15.9%)	16 (18.4%)		8 (22.9%)	18 (15.7%)	
Haematologic	5 (7.9%)	2 (2.3%)		2 (5.7%)	5 (4.3%)	
Neurological	9 (14.3%)	16 (18.4%)		6 (17%)	19 (16.5)	
Metabolic	5 (7.9%)	8 (9.2%)	0.812	3 (8.6%)	10 (8.7%)	0.450
Respiratory	5 (7.9%)	9 (10.3%)		5 (14.3%)	9 (7.8%)	
Gastrointestinal	6 (9.5%)	8 (9.2%)		1 (2.9%)	13 (11.3%)	
Others	6 (9.5%)	9 (10.3%)		5 (14.3%)	10 (8.7%)	

[Table/Fig-3]: Association of various family member related factors with the anxiety and depression in family members.
A p-value ≤0.05 was considered significant

Patient factors	Anxiety (HADS score)			Depression (HADS score)		
	>10	≤10	p-value (χ^2 test)	>10	≤10	p-value (χ^2 test)
Age group						
≤30	9 (14.3%)	8 (9.1%)		5 (14.3%)	12 (10.4%)	
31-60	24 (38.1%)	33 (37.8%)	0.787	12 (34.3%)	45 (39.1%)	0.857
>60	30 (47.6%)	46 (52.8%)		18 (51.4%)	58 (50.5%)	
Gender						
Male	43 (68.3%)	50 (57.5%)	0.179	23 (65.7%)	70 (60.9%)	0.605
Female	20 (31.7%)	37 (42.5%)		12 (34.3%)	45 (39.1%)	
Marital status						
Married	49 (77.8%)	77 (88.5%)	0.038	29 (82.9%)	97 (84.3%)	0.917
Unmarried	14 (22.2%)	10 (11.5%)		6 (17.1%)	18 (15.7%)	
Place of residence						
Rural	28 (44.4%)	41 (47.1%)	0.643	18 (51.4%)	51 (44.3%)	0.673
Urban	35 (55.6%)	46 (52.9%)		17 (48.6%)	64 (55.7%)	

[Table/Fig-4]: Association of various patient related factors with the anxiety and depression in family members.
A p-value ≤0.05 was considered significant

Variables	High degree of distress		p-value (χ^2 test)
	Present N (%)	Absent N (%)	
Gender			
Males	45 (45.5%)	39 (76.5%)	<0.001
Females	54 (54.5%)	12 (23.5%)	
Marital status			
Married	69 (69.7%)	32 (62.7%)	0.390
Unmarried	30 (30.3%)	19 (37.3%)	
Place of residence			
Rural	52 (52.5%)	21 (41.2%)	0.188
Urban	47 (47.5%)	30 (58.8%)	
Relationship to patient			
Parent	8 (8.1%)	0 (0%)	
Children	44 (44.4%)	21 (41.2%)	
Spouse	26 (26.3%)	7 (13.7%)	0.003
Sibling	13 (13.1%)	9 (17.6%)	
Others	8 (8.1%)	14 (27.5%)	

[Table/Fig-5]: Association of family members related factors and high level distress as per Caregiver Self-Assessment Questionnaire (CSAQ).
A p-value ≤0.05 was considered significant

As far as patient factors were concerned marital status of the inpatient was the patient related factor which was significantly associated with the anxiety among family members (p-value=0.038). Caregivers of the unmarried patients were likely to have suffer from anxiety (OR=2.20, 95% CI 0.91-5.54, p-value=0.038) compared caregivers of married patients. No other patient related factor was found to be significantly associated with either anxiety or depression [Table/Fig-4]. As far as association between anxiety and depression in family caregivers and diagnosis at admission was concerned, disease diagnosed at time of admission was also not statistically associated with either anxiety or depression [Table/Fig-3].

The recruited family members were also administered the CSAQ and their responses were recorded. Almost two thirds (66%) of the family members showed high levels of distress as per CSAQ tool. The factors which were significantly associated with high level of distress among family members of inpatients [Table/Fig-5] included the gender of the caregiver (p-value <0.001)) and relationship of family member with the inpatient (p-value=0.003). Female caregivers (OR=3.90, 95% CI 1.83-8.33) showed higher levels of distress as compared to male caregivers.

DISCUSSION

Family members face emotional and cognitive challenges during the stay of their relative in the hospital. They have to constantly stay alert to cater to all the needs of the inpatient, therefore as a result it may lead to anxiety and depression among the family members of the inpatients admitted in the hospital.

The study reported a high prevalence of anxiety (42%) as well as depression (23.3%) among family members. Only 30% of the family members tested normal on the anxiety scale whereas 36% tested normal on the depression scale. These values clearly point to high level of psychological distress among the family members even in a non ICU, non terminal or debilitating disease setting.

Belayachi J et al., studied the psychological burden among family members of patients in general wards of the study hospital [1]. They found 55.6% prevalence of symptoms for anxiety and 41.1% for depression. The study conducted by McAdam JL et al., in three ICUs in California, documented a high prevalence of psychological and physical symptoms among family members [6]. Pochard F et al., found that the prevalence of symptoms of anxiety and depression in family members was 69.1% and 35.4%, respectively [12]. A study in Karnataka, India among caregivers of inpatients with chronic

debilitating conditions and terminal illnesses [13] reported that all inpatient caregivers had some degree of anxiety and depression. Among the studies described above, only study by Belayachi J et al., was comparable to the index study in terms of study setting i.e., general wards [1]. The other studies however were in different and varied settings like ICU, patients with chronic diseases and terminal illness, which indicates that relatives of patients admitted in general medicine wards experience psychological distress similar to relatives of patients in high dependency units like ICU, cancer wards etc.

Belayachi J et al., reported that female gender of the family member is associated with anxiety and depression [1]. Similar findings were found in other studies conducted mostly in ICU settings [5,12-14]. However, in the present study no association was found between the gender of the family member and levels of significant anxiety and depression.

The study found a significant association between the marital status of the patient and anxiety levels in caregivers. Unmarried status of the patient was linked to higher anxiety in the family members. Authors believe the possible reasons could be linked to absence of financial and family support system i.e., absence of spouse etc. The other significant factor which was associated with anxiety was the relationship (parents or spouse) of the caregiver with the inpatient. Belayachi J et al., have also reported the association between relationship of the caregiver with the inpatient and the level of psychological burden [1]. Various other studies in other settings like ICU and terminal and chronic illnesses have also reported significant association between psychological distress and relationship of the caregiver to the patient [2,5,12]. The emotional bond between parents and children or between spouses could be possibly playing a role in increasing psychological distress.

Many studies have shown the association of education levels of the caregiver and burden levels but the similar association was not found in this study [1,14,15]. Higher education could possibly translate to better awareness of the disease and the processes involved during hospitalisation leading to lower psychological distress.

Caregivers are often so concerned with caring for their relative's needs that they often lose sight of their own well-being [11]. In this study, 66% (99/150) of the family members were found to be experiencing high degree of distress, as measured by the CSAQ. The present study found distress in the family member was associated with the female gender of the family member caregiver, and they are four times more likely to have psychological distress compared to men. The only other factor which was associated with high degree of distress was the relationship of the family member with the inpatient. No comparable studies were found in literature search which used the CSAQ that was used in this study.

Limitation(s)

The non availability of baseline information on anxiety and depression is a major limitation of the study. Therefore, there is a possibility, albeit small, that the study has not been able to effectively separate pre-existing anxiety and depression from what can be attributed to family member hospitalisation.

CONCLUSION(S)

It was found that the family members of the inpatients admitted in the general medicine wards in a tertiary care hospital reported significant degree of anxiety, depression and distress. Much of this psychological burden could be possibly obviated by an honest relook at the existing approach to patient care. Traditional patient care has been entirely focusing on the needs of the patients, while the family members caring for the patients remain mere bystanders. Since, family members of patients experience significant psychological distress even in general ward setting there is a need to not only actively involve family members in the hospital care of the admitted patients, but also provide access to psychological counseling to the family members within the hospital setting.

REFERENCES

[1] Belayachi J, Himmich S, Madani N, Abidi K, Dendane T, Zeggwagh AA, et al. Psychological burden in inpatient relatives: The forgotten side of medical management. Q J Med. 2014;107:115-22.

[2] Schmidt M, Azoulay E. Having a loved one in the ICU: The forgotten family. Curr Opin Crit Care. 2012;18:540-47.

[3] Rückholdt M, Tofler GH, Randall S, Buckley T. Coping by family members of critically ill hospitalised patients: An integrative review. Int J Nurs Stud. 2019;97:40-54. Doi: 10.1016/j.ijnurstu.2019.04.016.

[4] Rückholdt M, Tofler GH, Randall S, Whitfield V, Washington K, Fethney J, et al. Psychological responses and coping behaviour of visiting family members during and following unplanned hospital admission. J Clin Nurs. 2021 May 24. Doi: 10.1111/jocn.15858.

[5] Damghi N, Khoudri I, Oualili L, Abidi K, Madani N, Zeggwagh AA, et al. Measuring the satisfaction of intensive care unit patient families in Morocco: A regression tree analysis. Crit Care Med. 2008;36:2084-91.

[6] McAdam JL, Dracup KA, White DB, Fontaine DK, Puntillo KA. Symptom experiences of family members of intensive care unit patients at high risk for dying. Crit Care Med. 2010;38:1078-85.

[7] Pillai L, Aigalikar S, Vishwasrao SM, Husainy SM. Can we predict intensive care relatives at risk for posttraumatic stress disorder? Indian J Crit Care Med. 2010;14(2):83-87.

[8] Kulkarni HS, Kulkarni KR, Mallampalli A, Parkar SR, Karnad DR, Guntupalli KK. Comparison of anxiety, depression, and post-traumatic stress symptoms in relatives of ICU patients in an American and an Indian public hospital. Indian J Crit Care Med. 2011;15(3):147-56.

[9] Lukhmana S, Bhasin SK, Chhabra P, Bhatia MS. Family caregivers' burden: A hospital based study in 2010 among cancer patients from Delhi. Indian J Cancer. 2015;52(1):146-51.

[10] Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand. 1983;67:361-70.

[11] American Medical Association. The Caregiver Self-Assessment Questionnaire. Available on Url: https://www.healthinaging.org/tools-and-tips/caregiver-self-assessment-questionnaire last accessed on 20/10/2020.

[12] Pochard F, Azoulay E, Chevret S, Lemaire F, Hubert P, Canoui P, et al. Symptoms of anxiety and depression in family members of intensive care unit patients: Ethicalhypothesis regarding decision-making capacity. Crit Care Med. 2001;29:1893-97.

[13] Anandi BS, Dhadwe M. Anxiety and depression among caregivers of inpatients suffering from chronic debilitating and terminal illnesses. Int J Community Med Public Health. 2018;5:1903-08.

[14] Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: A clinical review. JAMA. 2014;311(10):1052-60.

[15] Creedle C, Leak A, Deal AM, Walton AM, Talbert G, Riff B, et al. The impact of education on caregiver burden on two inpatient oncology units. J Cancer Educ. 2012;27:250-56.

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