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Psychological burden in inpatient relatives: the forgotten side of medical management

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Summary

Background: The burden of the hospital experience is a broad issue that has been evaluated in a particular context of intensive care unit (ICU). It is likely, however, that the load is heavy on families even in other hospital wards and not just in the ICU. The present study was designed to assess the prevalence of anxiety and depression in family members of patients admitted in a general medicine department, and to identify associated factors with those symptoms.

Methods: Patients' and relatives' socio-demographic data and information pertaining to the patients' health characteristics were collected. Family members completed the Arabic version of Hospital Anxiety and Depression Scale (HADS). Associations between anxiety or depression and covariates of interest were investigated using generalized estimating equations, for univariate and multivariate logistic regression analysis.

Results: The prevalence of anxiety (55.6%) and depression (41.1%) in family members remains high. The multivariate model identified three

groups of factors associated with these symptoms: (i) Patient related: a short length of hospital stay is associated with depression (OR 1.04, 95% CI 1.01–1.08; $P=0.02$); (ii) Family related: rural residence is associated with depression (OR 2.56, 95% CI 1.01–6.74; $P=0.04$), and female gender is associated with anxiety and depression (OR 2.60, 95% CI 1.41–4.81; $P=0.002$), (OR 3.04, 95% CI 1.62–5.70; $P=0.01$), respectively; and (iii) Caregiver related: short length of visit (OR 1.08, 95% CI 1.03–1.13; $P=0.002$) is associated with anxiety, admission to a share room (OR 2.56, 95% CI 1.25–5.23; $P=0.01$) is associated with depression and a need for more information is associated with anxiety and depression (OR 1.78, 95% CI 1.02–3.10; $P=0.04$), (OR 1.77, 95% CI 1.01–3.11; $P=0.04$), respectively.

Conclusions: The prevalence of symptoms of anxiety and depression in family members remains high at the end of acute health care. It is hoped that improving the provision of information will decrease the risk of psychological distress.

Introduction

Family members are the spokespersons, and the extension, of the incapacitated loved one. They are beset with emotional and cognitive challenges. Over the last three decades, increasing awareness of the distress experienced by families of intensive care unit (ICU) patients has kindled strong interest in family-centered care.^{1–3} Quantitative studies concerning family members mainly describe individual family members' symptoms of anxiety and depression and family members' needs.^{1–5} Qualitative studies have shown that family members' reactions involve stress, confusion and uncertainty, a search for information and attempts to fulfill the perceived needs of the patient and themselves.^{6–10} The ICU is certainly a very special environment, but the whole hospital is a special place. The burden of hospital experience is a broader issue that has been evaluated in a particular context. It is likely that the load is heavy on families even in other hospital wards and not just in the ICU. We say 'likely' because until now, this issue has never been studied. The comprehension of information given to families by caregivers, family satisfaction with both quality of care and interactions with caregivers and, finally, prevalence of anxiety and depression in family members are proposed as the three markers for quality of information. These indicators are the most used to evaluate the impact of the hospitalization experience on family members. To our knowledge, few publications concerning the measurement of psychological symptoms in family members are available, and no studies have been conducted in a general medicine department.^{2,6–10} Thus, the present study was designed to assess the prevalence of anxiety and depression in family members of patients admitted in an acute general medicine department using the Arabic version of the HADS questionnaire, and to identify associated factors with those symptoms.

Methods

Study design

This was an observational cross-sectional study based on a single interview of relatives of inpatients of an acute general medicine department of Rabat University Hospital between July and October 2010.

Study setting

Ibn Sina University Hospital in Rabat serves residents in Western-North Morocco. It is a 1028-bed tertiary-stage hospital that opened in 1955. The bed

occupancy rate is between 76% and 85%. The hospital comprises 24 departments (12 surgical, 9 medical and 3 ICUs), and admits adult patients: gynecology-obstetric and pediatric patients are treated in other facilities. The General Medical Department is a unit which supports: (i) patients with urgent medical indications of hospitalization when there is no available place at the hospital ward concerned; (ii) patients with intermediate clinical severity between medical ICUs and conventional care units; and (iii) patients with intricate medical pathologies where an indication of care in a particular service could not be determined. All patients are admitted from the medical emergency unit. The unit admits ~1200 patients annually with an average age of 40 years, and comprises seven single rooms and four shared rooms (six beds per room). The mean length of stay is 5 days.

Inclusion and exclusion criteria

The study was conducted with a convenience sample of 212 consecutive patients whose family member was >18 years old. We have included at least one family member per patient. Patients were excluded if they stayed <48 h, if they did not have visit during the hospitalization.

Data collection

The characteristics recorded for each patient included age, gender (male, female), marital status (unmarried/married), residence (urban/rural), education level (no education, primary, secondary, higher education), previous hospitalizations (none, one or more), admission room (single/shared), length of stay and reasons for admission.

Family members were defined as all relatives and friends who visited the patient in the department, regardless of their relationship to the patient.^{2,7,9} For each family member the data recorded were: age, gender (male, female), marital status (unmarried/married), residence (urban/rural), relationship with the patient (parent, child, spouse, brother or sister, other family members) and education level (no education, primary, secondary, higher educational level). Family members were asked about visiting hours per day and daily visits (yes, no), and whether they needed more information from caregivers (yes or no), and the kind of information needed (diagnostic, prognostic, therapeutic). The family members were then asked to complete the HADS (see below).

The day before discharge, family members were approached by independent, trained research assistants who explained the purpose of the study. When

they agreed to answer, the researchers asked them to take part and interviewed them face-to-face in the meetings and courses room.

Informed verbal consent was required from all participants. The study protocol and consent procedure were approved by the Moroccan Rabat University ethics committee.

Instrument

Symptoms of anxiety and depression were assessed using the HADS. This self-screening questionnaire was developed by Zigmond and Snaith for detecting and classifying the severity of anxiety and depression.¹¹ In this study, we used the Arabic version of HADS validated by El-Rufai and Absood.¹² The Cronbach alpha measures of internal consistency were 0.92 for anxiety and 0.95 for depression.

The HADS contains 14 items and consists of 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 cutoff value of 10 (score > 10) on the anxiety or depression subscale has been found reliable for discriminating between patients with and without the corresponding symptoms,¹¹ and was used in this study.

Thus, we recorded symptoms of anxiety and depression as either present or absent, at the moment of assessment, without evaluating their severity.

Statistical analysis

Continuous variables are presented as mean \pm standard deviation for variables with a normal distribution, and as median and interquartile range (IQR) for variables with skewed distributions. The normality of the distribution was tested by the Kolmogorov–Smirnov test with Lilliefors correction. For categorical variables, the percentages of patients in each category were calculated. The internal consistency of the HADS items was assessed using Chronbach's coefficient alpha: a high alpha coefficient (≥ 0.70) suggests that the items within a scale measure the same construct and support the construct validity.^{13,14} Anxiety or depression (defined as a subscale score > 10) was the dependent variable. Associations between anxiety or depression and covariates of interest were investigated using generalized estimating equations, for univariate and multivariate logistic regression analysis.¹⁵ Generalized estimating equations were used because there were several family members for the

same patient. We assumed an exchangeable correlation structure and employed the Huber–White Sandwich estimate of variance, which provides valid and robust standard error estimates, even if the correlation structure is misspecified.^{16,17} Variables with P -values ≤ 0.20 in the univariate analysis were tested in the multivariate analysis. The correlation matrix was examined in order to ascertain whether collinearity existed between variables, and collinearity was confirmed if the correlation coefficient r was above 0.5. The effects of variables on anxiety and depression were assessed separately, as measured by the estimated odds ratio and 95% CI. A two-tailed P -value < 0.05 was considered statistically significant. Statistical analyses were carried out using SPSS for Windows (SPSS, Inc., Chicago, IL, USA).

Results

Characteristics of the patients and family members

Four hundred patients were admitted during the study period. Ninety stayed < 48 h before they were discharged to their home, transferred or died. Sixty-nine did not have any family members, and family members of 54 patients rejected participation in the study, naming various reasons such as lack of time or simply unwillingness to participate in the study. Then, face-to-face interviews were carried out with 304 family members of 212 patients. The demographic, socioeconomic and health characteristics of patients and their family members are summarized in Table 1.

Characteristics of symptoms of anxiety and depression

The means of the anxiety and depression subscales scores were, respectively, 11 ± 7 and 9 ± 8 . The HADS scores indicated that 169 (55.6%) family members had symptoms of anxiety, and 125 (41.1%) had symptoms of depression. One-third, or 120 (39.5%) of the family members had symptoms of both anxiety and depression, and three-fourths, or 180 (59.2%) had symptoms of either anxiety or depression.

Factors associated with symptoms of anxiety and depression

Univariate analysis

In univariate analysis, no patient-related factors and no family-related factors were associated to anxiety. However, previous hospitalization was the only

Table 1 Characteristics of patients ($n=212$) and family members ($n=304$)

Variables	Patients ($n=212$)	Family members ($n=304$)
Age (years); mean \pm SD	52.7 \pm 21	41 \pm 11.4
Gender, n (%)		
Male	103 (48.6)	102 (33.6)
Female	109 (51.4)	202 (66.4)
Marital status, n (%)		
Married	128 (60.4)	221 (72.7)
Unmarried	84 (39.6)	83 (27.3)
Length of stay (days): median [IQR]	5[4–8]	
Residence, n (%)		
Urban	162 (76.4)	259 (85.2)
Rural	50 (23.6)	45 (14.8)
Education level, n (%)		
No education	127 (59.9)	109 (35.9)
Primary	33 (15.6)	61 (20.1)
Secondary	49 (23.1)	93 (30.6)
Higher education	3 (1.4)	41 (13.5)
Prior hospitalization, n (%)		
None	93 (43.9)	
≥ 1	119 (56.1)	
Admission diagnosis, n (%)		
Cardiovascular	80 (37.7)	
Infectious	54 (25.5)	
Hematologic	19 (9.0)	
Neurological	17 (8.0)	
Metabolic	16 (7.5)	
Respiratory	13 (6.1)	
Miscellaneous	13 (6.1)	
Relationship		
Parent		37 (12.2)
Children		128 (42.1)
Spouse		39 (12.8)
Brother/sister		53 (17.4)
Others		47 (15.5)
Admission room, n (%)		
Single	48 (22.6)	
Shared	164 (77.4)	
Daily visits		
Yes		242 (79.6)
Visiting hours: median [IQR]		3[2–6]
Need of more information		
Yes		175 (57.6)
No		129 (42.4)
Kind of information needed		
Diagnosis		155 (88.6)
Prognosis		5 (2.8)
Treatment		15 (8.6)

N , number; (%), percentage; SD, standard deviation; IQR, interquartile range; km, kilometer

patient-related factor associated with depression (OR 1.06, 95% CI 0.99–2.76; $P=0.05$). Female gender (OR 2.13, 95% CI 1.25–3.64; $P=0.01$), and rural residence (OR 1.99, 95% CI 1.02–3.88; $P=0.04$) were the family-related factors associated with depression. Patient- and family-related factors associated with symptoms of anxiety and depression in family members in univariate analysis are represented in Table 2.

Multivariate analysis

There was no collinearity between variables, and the correlation coefficient r was lower than 0.5.

In multivariate analysis, no patient-related factors were associated to anxiety. However, three family-related factors were associated with anxiety: female gender (OR 2.60, 95% CI 1.41–4.81; $P=0.002$), length of visit (per hour decrease) (OR 1.08, 95% CI 1.03–1.13; $P=0.002$) and need for more information (OR 1.78, 95% CI 1.02–3.10; $P=0.04$).

Concerning depressive symptoms, two patient-related factors—length of stay (per day decrease); (OR 1.04, 95% CI 1.01–1.08; $P=0.02$), and admission in a shared room (OR 2.56, 95% CI 1.25–5.23; $P=0.01$)—and three family-related factors—female gender (OR 3.04, 95% CI 1.62–5.70; $P=0.01$), rural residence (OR 2.56, 95% CI 1.01–6.74; $P=0.04$) and need for more information (OR 1.77, 95% CI 1.01–3.11; $P=0.04$)—were related to depression. Patient- and family-related factors associated with symptoms of anxiety and depression in family members in multivariate analysis are represented in Table 3.

Discussion

The prevalence of symptoms of anxiety (55.6%) and depression (41.1%) in family members remains high at the end of general health care. The prevalence of symptoms of depression was close to those of families of ICU patients. However, the family members of ICU patients were more anxious.^{2,9,10} To our knowledge, this was the first study establishing that symptoms of anxiety and depression are common in family members in general health care using the HADS. We found that for women family members, hospitalization in shared rooms and family need for more information were associated with both symptoms of anxiety and depression. In addition, anxiety was related to short length of visit, and depression was related to short length of hospital stay, and rural residence of family.

That women would be more predisposed to anxiety and depression is not a new result in itself, and strengthens the conclusions of previous

Table 2 Factors associated with symptoms of anxiety and depression in family members in univariate analysis

Variables	Anxiety			Depression		
	OR	95% CI	P-value	OR	95% CI	P-value
Patient-related factors						
Age (years)	0.99	0.99–1.01	0.49	1.00	0.99–1.01	0.59
Gender						
Male	0.87	0.55–1.37	0.55	0.75	0.45–1.24	0.22
Female	ref			ref		
Marital status						
Married	0.71	0.69–1.41	0.14	1.05	0.66–1.67	0.86
Unmarried	ref			ref		
Length of stay (per days decrease)	0.99	0.96–1.02	0.43	0.97	0.99–1.06	0.10
Residence						
Urban	0.96	0.57–1.63	0.80	1.67	0.93–3.01	0.06
Rural	ref			ref		
Education level						
No education	3.14	0.35–28.62	0.31	0.98	0.16–6.02	0.98
Primary	3.11	0.33–29.95	0.33	0.67	0.23–9.80	0.67
Secondary	3.67	0.39–34.50	0.26	0.97	0.15–6.15	0.97
Higher education	ref			ref		
Previous hospitalization						
None	ref			ref		
≥1	1.48	0.94–2.33	0.09	1.06	0.99–2.76	0.05
Admission diagnosis						
Cardiovascular	0.48	0.18–1.25	0.13	0.51	0.19–1.36	0.19
Infectious	0.52	0.19–1.41	0.20	0.75	0.26–2.15	0.60
Hematologic	0.43	0.14–1.40	0.16	0.66	0.20–2.18	0.51
Neurological	0.48	0.14–1.60	0.23	0.43	0.11–1.65	0.19
Metabolic	0.87	0.26–2.93	0.82	0.81	0.24–2.71	0.74
Respiratory	0.52	0.14–1.97	0.34	0.55	0.15–2.02	0.40
Miscellaneous	ref	1		ref		
Family-related factors						
Age (years)	1.01	0.99–1.3	0.28	ref	0.98–1.02	0.99
Gender						
Male	ref			ref		
Female	1.54	0.98–2.56	0.06	2.13	1.25–3.64	0.01
Marital status						
Married	1.39	0.83–2.33	0.21	0.77	0.46–1.28	0.32
Unmarried	1			ref		
Residence						
Urban	ref			ref		
Rural	1.24	0.65–2.36	0.52	1.99	1.02–3.88	0.04
Education level						
No education	1.39	0.67–2.86	0.39	2.13	0.99–4.76	0.06
Primary	0.92	0.41–2.05	0.84	2.32	1–5.55	0.05
Secondary	0.87	0.51–2.24	0.87	1.88	0.87–4.16	0.12
Higher education	ref			ref		
Relationship						
Parent	0.84	0.35–1.98	0.68	1.10	0.46–2.65	0.85
Children	0.55	0.28–1.07	0.73	1.25	0.63–2.48	0.52
Spouse	0.68	0.29–1.60	0.38	1.38	0.58–3.27	0.47
Brother/sister	0.85	0.39–1.86	0.68	0.83	0.37–1.88	0.65
Others	ref			ref		

(continued)

Table 2 Continued

Variables	Anxiety			Depression		
	OR	95% CI	P-value	OR	95% CI	P-value
Caregivers-related factors						
Admission room						
Single	ref			ref		
Shared	0.67	0.40–1.14	0.14	1.63	0.87–2.85	0.09
Daily visits	0.82	0.47–1.43	0.48	1.62	0.89–2.94	0.11
Length of visit (per hour decrease)	1.03	0.99–1.07	0.10	0.98	0.94–1.02	0.33
Need of more information	1.41	0.89–2.24	0.14	1.47	0.91–2.39	0.11

n, number; (%), percentage; OR, odds ratio; CI, confidence interval; ref, reference category; OR > 1, indicated higher degree of anxiety or depression; km, kilometer.

research.^{7,9,18–20} More appropriate behavior is required of women in the hospital areas. Women are integral of all aspects of society; the multiple roles that they fulfill in society render them at greater risk of experiencing psychological burden than others in the community.²¹ However, this result may be biased by certain risk behaviors, frequent in Arab society. In effect ‘virility’ is socially valued, and men are not able to overtly show emotions.

In agreement with an earlier study, having a place to be alone was among the factors considered very important by families.^{2,19} Patients hospitalized in room with more than one bed increased the likelihood of family symptoms of both anxiety and depression. The presence of other patients and other families disturbs their intimacy and privacy, which may prevent family members from interacting with their relative as they want.

An elevated level of anxiety and depression was associated with the need for more information, which raises questions about the quality of the information provided. The information must be accurate and provided in an understandable way; the complexity of the information for those with a low educational level, which was the case for 56% of family members in this study, makes comprehension difficult. Symptoms of anxiety and depression have been reported in up to 70% of family members of ICU patients, and the correlation between these symptoms and the lack of effective communication has been underlined.⁹ Provider inability to communicate with patients in their native dialects, patient unfamiliarity with the health care system, lack of insurance and intolerance for painfully long waiting times make patients very frustrated. Anxiety and depression are likely to affect performance in the areas of comprehension, reasoning and communication.²¹

The short length of visit does not allow time for the family members to calm their emotional turmoil or to ease their fears, which leads to persistent doubt, fear

and therefore anxiety. One important task for staff is to facilitate families’ ability to stay close to their ill family member without a sense of being in the way.

Family members who resided in rural areas were more depressive than those residing in urban areas. The distance of rural residence from medical facilities is probably a source of pessimism and depressive symptoms. Short length of stay was also associated with depression. Families believe that their loved ones are in the best place with optimal care, regular monitoring, nursing, and continuous infusion and therapy. At discharge, family members may experience fear that the patient is not fully recovered, uncertainty and pessimism about the future were sources of depressive symptoms.^{22,23}

This study has some limitations. First, the HADS scores is a self-administered questionnaire. Interview techniques may increase response rates. The alternative would have been to exclude low-literacy participants. However, the decision to include these participants was more important and better than the risk of bias, because the inclusion of the low-literacy participants was a better representation of the Moroccan population. Furthermore, the different data collection methods have advantages and disadvantages and no consensus is available concerning the problem of administering questionnaires in low-literacy populations.²⁴ Third, the staff were not blinded to the fact that a study was being done on symptoms of anxiety and depression of family members of patients. Lastly, all the family members were picked from only one service, so the results may provide useful information about only those family members’ symptoms of anxiety and depression.

Conclusion

The prevalence of symptoms of anxiety and depression in family members remains high at the end of

Table 3 Factors associated with symptoms of depression in family members ($n=304$) in multivariate analysis

Variables	Anxiety			Depression		
	OR	95% CI	<i>P</i> -value	OR	95% CI	<i>P</i> -value
Patient-related factors						
Marital status						
Married	1.07	0.40–1.08	0.84			
Unmarried	ref					
Length of stay (per days decrease)				1.04	1.01–1.08	0.02
Residence						
Urban				0.82	0.36–1.91	0.66
Rural				ref		
Previous hospitalization						
None	ref			ref		
≥ 1	1.62	0.97–2.70	0.37	1.57	0.92–2.70	0.14
Admission diagnosis						
Cardiovascular	0.40	0.15–1.08	0.17	0.95	0.16–1.53	0.22
Infectious	0.40	0.14–1.15	0.33	0.87	0.27–2.79	0.81
Hematologic	0.46	0.14–1.55	0.31	0.78	0.21–2.99	0.72
Neurological	0.27	0.08–0.98	0.49	0.45	0.11–1.82	0.26
Metabolic	0.55	0.15–2.05	0.42	0.70	0.17–2.7	0.64
Respiratory	0.44	0.11–1.76	0.82	0.84	0.19–3.78	0.82
Miscellaneous	ref			ref		
Family-related factors						
Gender						
Male	ref			ref		
Female	2.60	1.41–4.81	0.002	3.04	1.62–5.70	0.01
Residence						
Urban				ref		
Rural				2.56	1.01–6.74	0.04
Education level						
No education				1.38	1.81–3.44	0.49
Primary				1.88	0.73–4.76	0.19
Secondary				1.78	0.75–4.34	0.19
Higher education				ref		
Caregivers-related factors						
Admission room						
Single	ref			ref		
Shared	1.13	0.98–1.32	0.08	1.29	0.87–1.88	0.09
Daily visits				1.38	0.41–2.43	0.73
Length of visit (per hour decrease)	1.08	1.03–1.13	0.002			
Need of more information	1.78	1.02–3.10	0.04	1.77	1.01–3.11	0.04

OR, odds ratio; CI, confidence interval; ref, reference category; OR > 1, indicated higher degree of anxiety or depression; km, kilometer. The bold value represents the relevant variables.

acute health care. The gender (female) of the family member is a potential determinant. Studies like this one will be critical in both defining the scope of the problem and understanding risk factors and mechanisms for development of these symptoms. It is hoped that better provision of information, and more effective demonstration of empathy will decrease the risk of psychological distress.

Conflict of interest: None declared.

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