

# **RESEARCH ARTICLE**

# The prevalence of psychological impact on caregivers of hospitalized patients: The forgotten part of the equation

Rahma Al-Zahrani<sup>1</sup>, Rahaf Bashihab<sup>1</sup>, Anwar E. Ahmed<sup>2</sup>, Reem Alkhodair<sup>1</sup>, Sultan Al-Khateeb<sup>3</sup>

#### Address for Correspondence:

#### Anwar E.Ahmed

<sup>1</sup>College of Medicine, Al-Imam Muhammad Ibn Saud Islamic University, Riyadh, Saudi Arabia <sup>2</sup>College of Public Health and Health Informatics, King Saud bin Abdulaziz University for Health Sciences,

Riyadh, Saudi Arabia

<sup>3</sup>Department of Surgery, Division of Urology, King Abdulaziz Medical City, Riyadh, Saudi Arabia Email: ahmeda5@vcu.edu

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# ABSTRACT

Introduction: Despite the large number of caregivers suffering from various psychiatric disorders, research on psychological symptoms among caregivers of hospitalized patients is lacking in Saudi populations. Objectives: The objective of this study is to determine the prevalence of depression, anxiety and stress among caregivers of hospitalized Saudi patients. Methods: A cross-sectional study of depression, anxiety and stress among caregivers of hospitalized patients was conducted. Arabic speaking caregivers (n = 353) between the ages of 14 and 80 years were included in the study. The Depression Anxiety Stress Scales (DASS-21) test (Arabic version) was used to measure the three psychological symptoms. Results: The study has shown high rates of depression, anxiety and stress among caregivers (72.8%, 76.5%, and 61.5%, respectively). Depression was found to be associated with long-term hospital stay (81.4% vs. 69.3%; p-value = 0.021) and family caregivers (75.4% vs. 46.9%, p-value = 0.001). Anxiety was found to be associated with family caregivers (78.8% vs. 53.1%; p-value = 0.001). The three psychological symptoms were higher among those with an age above 20 years old (p-value < 0.05). Multivariate logistic models show the risk of the psychological symptoms increased with low-income, higher education, immediate relation to the patient, and older caregivers.

Conclusions: The findings suggest that the prevalence of depression, anxiety and stress symptoms were very common among caregivers. The results showed that approximately 8 out of 10 caregivers suffer from at least one psychiatric disorder. Older, low socioeconomic status, and well-educated caregivers were identified as being at higher risk of developing psychiatric symptoms.

Keywords: DASS, depression, anxiety, stress, caregivers, Saudi Arabia

#### **INTRODUCTION**

Caregivers are people who devote their time helping their loved ones, including family members, friends, and others. Despite the valuable service caregivers provide to patients, many experience physical strain, emotional stress, anxiety, poor sleep, exhaustion, and depression.<sup>1 – 3</sup> The psychological symptoms such as depression, anxiety, and post-traumatic stress among caregivers of hospitalized patients are usually overlooked. Over the past decade there have been several studies on the impact of patients' hospitalization on caregivers.<sup>4,5</sup> Studies reported that caregivers are at high risk of fatigue and sleep disturbances<sup>6</sup> and also experience more negative reactions.<sup>7,8</sup>

Psychological symptoms are the most common negative outcomes of providing care for chronically ill patients.<sup>9–11</sup> A study reported the prevalence of anxiety, post-traumatic stress and depression among family members of patients in an intensive care unit to be 42%, 35% and 16%, respectively.<sup>12</sup> Estimation of depression was rated in the range of 40 to 70 percent of caregivers, closely meeting the diagnostic criteria for major depression,<sup>13</sup> especially among caregivers of patients with life threatening and psychological conditions and with long-term hospitalization. A study conducted in Tehran, Iran revealed that caregivers of children with phenylketonuria (PKU) had high levels of depression and anxiety.<sup>14</sup>

In Arab regions, most hospitals allow a patient to be accompanied by one caregiver to assist in the care of the patient and perform several daily tasks. These duties can include assisting the nurse to move the patient from the bed to a wheelchair, use the bathroom, cleaning, and accompanying the patient to the clinic, laboratory, and other medical departments, as well as feeding the patient. From an Arab cultural perspective, a caregiver would be an individual who provides care at a hospital for a family member or friend. Unlike in a hospital setting, there are several family members that provide assistance in a home setting.

Despite the increasing number of patients in need of care in hospitals, there are only two studies that

examine the psychological symptoms among Saudi caregivers. The first study compared depression, anxiety, and quality of life of the caregivers who provided care and support to oncology and chronically ill patients.<sup>15</sup> According to the study, caregivers of cancer patients suffered more from depression, anxiety, and poorer quality of life than caregivers of chronically ill patients. The second investigation evaluated the presence of depression and anxiety in caregivers of children with autistic spectrum disorders.<sup>16</sup> The second study included 100 family caregivers, 50 cases and 50 controls.<sup>16</sup> The authors note that the mean depression score and the mean anxiety score was significantly higher among cases compared to controls.<sup>16</sup> However, little research has been conducted to determine the presence of depression, anxiety and stress among caregivers of hospitalized Saudi patients. Thus, there is a great need to understand further caregivers' experiences and identify the potential hazards they might face. It is essential to provide healthcare professionals with the information they need to communicate with immediate family caregivers to increase the level of their awareness about the importance of support. The physician-family relationship is essential to prevent and control the psychological impact on caregivers. Healthcare professionals need to exceed the expectations of only saving patients' lives, extending this to saving their caregivers too. The current study is conducted to stimulate directions for future research to address and promote patient safety and quality care for caregivers in Saudi Arabia. The current study makes several unique contributions. For example, this is the first study to our knowledge that includes a large number of caregivers who provided care and support for patients with chronic illnesses and non-chronic health problems. This research was intended to determine the prevalence of psychological symptoms and to identify the associated factors contributing to negative emotional states of depression, anxiety, and stress among caregivers in Saudi Arabia. We also tested the associations between the three psychological symptoms and caregivers' characteristics.

### **METHODOLOGY**

A cross-sectional study was conducted at the King Abdulaziz Medical City (KAMC) in Riyadh, Saudi Arabia. KAMC is one of the largest tertiary hospitals in Saudi Arabia and the Middle East. It has a total of

40 wards and 1200 beds. This study was approved by King Abdullah International Medical Research Center (KAIMRC) and institutional review board, protocol number RRSC/99/2013. The participants of this study were caregivers of hospitalized Saudi patients. From an Arab cultural perspective, a caregiver is an individual who provides care at a hospital for a family member or friend. For the purpose of this study, we excluded paid caregivers. The inclusion criteria included caregivers in a hospital setting who were 14 years or older and had at least one overnight stay at the hospital and agreed to participate in the study. The study included both family caregivers (husband/ wife, son/daughter, mother/father, and brother/ sister) and non-family caregivers (friends). The current investigation assessed depression, anxiety and post-traumatic stress among caregivers of hospitalized patients using the DASS-21 (Arabic version). The Depression Anxiety Stress Scale (DASS-21) is a self-report questionnaire developed in the English language and used for assessment and evaluation of the emotional states of depression, anxiety, and stress.<sup>17</sup> The DASS-21 uses a four-point scale (0-3), the highest score of DASS-21 is 42 where lower scores are better.<sup>17</sup> The DASS-21 was developed in the Arabic language and used for the evaluation of negative emotional states of depression, anxiety, and stress in the Arabic-speaking population.<sup>18</sup> According to the authors, the Arabic DASS-21 is a reliable and valid tool for the evaluation of psychological symptoms. The Arabic DASS-21 has a good level of internal consistency. Cronbach's alpha coefficients for the three scales of depression, anxiety and stress are 0.93, 0.90 and 0.93 respectively.<sup>18</sup> In our study, the DASS-21 (Arabic version) was validated and tested in a sample of 30 caregivers. The overall internal consistency of DASS-21 (Arabic version) was found to be good, giving a Cronbach's alpha of 0.86. Additional data were collected from charts reviews such as type of illness, chronicity of the disease, and the duration of admission. The questionnaire also contained items relating to demographic data, relationship to the patient, and socioeconomic status as assessed by monthly income, along with informed consents. All questionnaires were completed anonymously to ensure confidentiality. After the researchers explained the study purpose in Arabic, caregivers were recruited for the study. Caregivers of hospitalized Saudi patients were asked verbally whether they wanted to participate in

the study. The questionnaires were only administered to those who agreed to participate. The power analysis was used to determine the sample size, based on the prevalence of 50% psychological symptoms among caregivers; the required sample size was 353 subjects. Systematic random sampling was used to select the caregivers in different wards. We systematically selected rooms at an interval of three. A total of 450 caregivers were approached and 353 agreed to participate and completed the survey giving a response rate of 78.4%.

### **STATISTICAL ANALYSIS**

Data were analyzed using Statistical Package for Social Sciences (SPSS®) version, 22.0 (Chicago, Illinois, USA). The chi-squared test was used to analyze the associations between the three psychological symptoms and categorical variables such as gender, marital status, relationship to patient, education levels and monthly income (Table 1). Means and standard deviations (mean  $\pm$  SD) were used to summarize continuous variables such as total depression anxiety stress scales (DASS). The caregiver characteristics such as gender, relationship to patient, marital status, education level, income, etc., were assessed using the t-test or ANOVA (Table 2). Multivariate logistic models were employed to identify the risk factors associated with caregivers' depression, anxiety and stress (Table 3). The strength of the associations was assessed by adjusted odds ratio (OR) and 96% confidence intervals (CI). A p-value of less than 0.05 was considered statistically significant.

# RESULTS

A total of 353 caregivers of hospitalized patients were included in the analysis. The caregivers' demographic and socio-demographic characteristics are summarized in Table 1. Of the caregivers, 53.8% were female, and 53.0% were unemployed. Only 7.9% of the caregivers were aged  $\leq 20$  years, while 92.1% were > 20 years of age. The study included 17% of the patients who were admitted to the ICU and approximately half (48.7%) of the hospitalized patients were classified as having chronic illness. When asked about the relationship to the patient, approximately half (46.2%) of caregivers were a son or daughter, 7.1% were a husband or wife, 27.2% were a father or mother, 10.5% were a brother or sister, and 9.1% were other relatives or friends.

		Ov	Overall		Depression		Anxiety		ress
		<u>n</u> =	n = 354		(72.8%)		5.5%)	(61	.5%)
		n		n		n		n	
Gender	Male	163	46.2	113	69.3	119	73	93	57.1
	Female	190	53.8	144	75.8	151	79.5	124	65.3
Age	$\leq$ 20	28	7.9	15	53.6*	17	60.7*	10	35.7*
-	> 20	325	92.1	242	74.5	253	77.8	207	63.7
Length of stay in hospital	$\leq$ 7 days	251	71.1	174	69.3*	185	73.7	143	57.0*
	> 7 days	102	28.9	83	81.4	85	83.3	74	72.5
Care unit	ICU	59	16.7	45	76.3	47	79.7	40	67.8
	Non-ICU	294	83.3	212	72.1	223	75.9	177	60.2
Disease category	Chronic	172	48.7	121	70.3	126	73.3	102	59.3
	Non-chronic	181	51.3	136	75.1	144	79.6	115	63.5
Family caregiver	Yes	321	90.9	242	75.4	253	78.8	207	64.5
	No	32	9.1	15	46.9*	17	53.1*	10	31.2*
Educational level	Uneducated	36	10.2	22	61.1	23	63.9	18	50
	High school	135	38.2	97	71.9	102	75.6	81	60
	University	182	51.6	138	75.8	145	79.7	118	64.8
Income	Low	320	90.7	237	74.1	249	77.8	200	62.5
	High	33	9.3	20	60.6	21	63.6	17	51.5

Table 1.	Caregivers'	characteristics	and its	relation	to the	three	DS\	/choloc	ical s	vmp	toms.
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\* Chi-square test shows significantly lower symptoms of disorders at  $\alpha=0.05.$ 

According to that classification, 90.9% of the caregivers were family members, while 9.1% were non-family members. The majority (72%) of the caregivers were married. Additionally, 10.2% of caregivers had not obtained a high school education,

38.2% had obtained a high school diploma, and 51.6% held a university degree. Other sample characteristics can be found in Table 1. Caregivers' ages ranged between 14 to 80 years with a mean of 34 years and standard deviation of 10.2 years. The levels of

Table 2	Differences	in	DASS	scores	by	caregivers'	characteristics.
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		Mean	± SD	P-value
Gender	Male	12.9	12.6	0.451
	Female	13.8	11.5	
Age	$\leq$ 20	8.2	8.7	0.017*
-	> 20	13.6	12.2	
Length of stay in hospital	$\leq$ 7 days	12.3	11.5	0.008*
	> 7 days	16.1	12.8	
Care unit	ICU	15.8	13.6	0.089
	Non-ICU	12.9	11.7	
Disease category	Chronic	13.0	12.3	
	Non-Chronic	13.8	11.8	
Family caregiver	Yes	14.0	12.2	0.001*
	No	7.0	8.5	
Educational level	Uneducated	9.4	8.5	0.075
	High schoo	13.2	12.1	
	University	14.4	12.4	
Income	Low	13.3	11.8	0.721
	High	14.2	14.4	

\* Independent samples t-test is significant at  $\alpha=0.05.$ 

		Depression			Anxiety		Stress			
	OR	Lower	Upper	OR	Lower	Upper	OR	Lower	Upper	
Female vs. male	1.5	0.874	2.481	1.6	0.904	2.731	1.5	0.937	2.421	
Ages (>20 vs. ≤20) years	2.6*	1.138	5.971	2.3	0.990	5.466	3.2*	1.376	7.392	
ICU vs. non-ICU	1.2	0.596	2.365	1.2	0.590	2.534	1.3	0.712	2.505	
Chronic vs. non-chronic	0.8	0.506	1.360	0.7	0.438	1.238	0.9	0.553	1.372	
Family caregiver yes vs. no	3.3*	1.536	7.181	3.1*	1.408	6.742	3.8*	1.714	8.638	
High school vs. uneducated	2.2	0.941	5.062	2.4*	1.030	5.828	2.0	0.880	4.368	
University vs. uneducated	2.8*	1.197	6.353	3.3*	1.378	7.761	2.4*	1.103	5.382	
Low vs. high income	2.5*	1.158	5.605	2.8*	1.238	6.275	2.1	0.987	4.477	
Constant	0.1			0.1			0.03			

Table 3.	Risk	factors	associated	with	caregivers'	ps	vcholog	ical s	ympt	oms
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\* Wald chi-square test shows significantly higher symptoms of disorders at  $\alpha = 0.05$ . ICU = intensive care unit.

depression, anxiety, and stress among caregivers were found to be severe (mean = 13.0, SD = 12.0 with a range from 0 - 63) in our sample.

The prevalence of depression was 72.8% (257/353) giving a 95% confidence interval of 67.8%-77.4%. Of 257 caregivers with symptoms of depression, 9.7% had mild depression, 22.6% had moderate depression, 8.9% had severe depression, and a majority of 58.8% had extremely severe depression (Figure 1). Depression was less common among young caregivers aged  $\leq$  20 years than caregivers aged > 20 years, (53.6% vs. 74.5%;

p-value = 0.017). Caregivers' depression was less common among patients with short-term hospital stay ( $\leq$ 7 days) than long-term hospital stay (>7 days), (69.3% vs. 81.4%; p-value = 0.021). Depression among non-family caregivers was less common compared to depression among family caregivers (46.9% vs. 75.4%; p-value = 0.001).

The prevalence of anxiety was 76.5% (270/353) with a 95% confidence interval of 71.7%-80.8%. Of 270 caregivers with symptoms of anxiety, 8.1% had mild anxiety, 11.5% had moderate anxiety, 11.9% had severe anxiety, and a majority of 68.5% had extremely severe anxiety (Figure 1). Anxiety was less common among young caregivers aged  $\leq$  20 years than caregivers aged > 20 years, (60.7% vs. 77.8%; p-value = 0.040). Anxiety among non-family caregivers was less common compared to family caregivers (53.1% vs. 78.8%; p-value = 0.001). The prevalence of stress was 61.5% (217/353) with a 95% confidence interval of 56.2%-66.6%. Of 217 caregivers with symptoms of stress, 14.7% had mild stress, 11.1% had moderate anxiety, 24.9%



Figure 1. Levels of depression, anxiety, and stress in the family caregivers.

had severe stress levels, and a majority of 49.3% had extremely severe stress levels (Figure 1). Young caregivers ( $\leq$  20 years) had significantly lower stress levels than older caregivers (aged > 20 years) (35.7% vs. 63.7%; p-value = 0.004). Caregivers' stress levels were less common among patients with short-term hospital stay ( $\leq$ 7 days) than long-term hospital stay (>7 days), (57% vs. 72.5%; p-value = 0.006). Stress levels among non-family caregivers was less common compared to family caregivers (31.2% vs. 64.5%; p-value = 0.001). No association was found between the gender groups, intensive care unit (ICU), education levels and the three studied disorders (p-values > 0.05). According to our findings, 83 (23.5%) caregivers had no symptoms of the studied disorders, 13 (3.7%) suffered from one symptom of the disorders, 40 (11.3%) had two symptoms of the disorders, and 217 (61.5%) had all three symptoms of the disorders. The findings suggest that 76.5% or approximately 8 out of 10 caregivers suffer from at least one psychiatric disorder.

Table 2 shows that the mean DASS subscale scores were significantly different for relationship to the patient (14.0  $\pm$  12.2 among family caregivers vs. 7.0  $\pm$  8.5 among non-family caregivers; p-value = 0.001). DASS scores increased notably with age (8.2  $\pm$  8.7 among young caregivers vs. 13.6  $\pm$  12.2 among caregivers aged > 20 years; p-value = 0.047). However, DASS scores were comparable between males (12.9  $\pm$  12.6) and females (13.8  $\pm$  11.5), (p-value = 0.451). DASS scores do not vary significantly by marital status, education levels, or monthly income (p-values > 0.05).

Table 3 shows the multivariate logistic regression of depression, anxiety, and stress. Controlling for all predictors, depression was found to be significantly more common among older caregivers, family caregivers, university degree holders, and those with low monthly income. While higher odds of anxiety were more frequent among family caregivers, those who completed high school, university degree holders, and those with low monthly income. Older caregivers, family caregivers and university degree holders were found to be predictors of stress.

### DISCUSSION

The current investigation attempted to determine the prevalence of three psychological symptoms: depression, anxiety, and stress among Saudi caregivers of hospitalized patients. We assessed symptoms of depression, anxiety and stress using the Arabic version of the Depression, Anxiety, and Stress Scale (DASS-21) in a sample of 353 caregivers. Unlike previous other studies, we found a higher prevalence of depression, anxiety, and stress among caregivers. According to our study, the prevalence of depression, anxiety, and stress were reported as 72.8%, 76.5%, and 61.5%, respectively. Mahmoudi-Gharaei et al.,<sup>14</sup> studied the prevalence of psychological symptoms in caregivers of children with PKU; 57.1%, 50.1% and 57.1% of the participants had mild to severe levels of depression, anxiety and stress scores respectively. Although this study reported high psychological symptoms among caregivers, the results reported are much lower compared to the findings of our study.

A few studies have explored gender differences in depression or stress with caregiving. A study conducted by Pöysti et al.,<sup>19</sup> revealed no differences in depression according to caregivers' gender. This is in agreement with our study that the three psychological symptoms do not correlate with gender. Our study findings suggest that the longer the patients hospital stay, the higher the level of depression and stress among caregivers. This trend could be due to the caregiver's experience of high levels of psychological symptoms as a result of long-term caring. When we looked into the effect of relationship to the patient and education, we found that family members and well-educated caregivers were significantly associated with the three psychological symptoms. The depression, anxiety, and stress disorders among family caregivers were three fold higher than nonfamily caregivers. The depression, anxiety, and stress disorders among well-educated caregivers were two fold higher than non-educated caregivers. According to our multivariate analysis, there is a significant increase in depression and anxiety among caregivers who report low monthly income, while caregivers who report high monthly income report less depression and anxiety. The study also found that depression and stress levels were approximately three times higher in caregivers who were older than 20 years of age. This age might demonstrate a high level of maturity and responsibility for caring.

The results of this study could be useful not only to caregivers but also to psychiatrists and generally to all physicians who communicate daily with their patients and caregivers in their medical practice. It is important to recognize the psychological symptoms among caregivers and provide them counseling to prevent psychological effects. We recommend providing information to family caregivers to help them understand the challenges when caring for their loved ones. Clinicians should effectively target caregivers' depression and stress to lower the prevalence rates. We believe that the outcomes of our study will help healthcare professionals to understand caregivers' needs and to encourage them to develop relationships with caregivers. The research suggests caution in using socioeconomic status and education to examine psychiatric symptoms among caregivers of hospitalized Saudi patients.

Future research is essential in order to develop a plan to help caregivers and prevent psychological effects. Intervention studies such as administering the DASS questionnaire before and after delivering educational programs to caregivers would help determine the impact of educational programs on psychological effects. There are several limitations in our study. The study was based on subjective screening tools (DASS-21). The instrument measured symptoms of psychiatric disorders and did not determine the diagnosis. The findings of this study have to be taken with caution as a control group was not employed. There is a need for further studies with different methodological designs to evaluate and compare psychological symptoms among caregivers and noncaregivers, particularly case-controlled studies. The strength of our study is that it highlights the existence of psychiatric symptoms among caregivers.

#### CONCLUSION

The study findings suggest that the prevalence of depression, anxiety and stress symptoms are very common among caregivers. According to the study, approximately 8 out of 10 caregivers suffer from at least one psychiatric disorder. Older, low socioeconomic status, and well-educated caregivers were identified as being at higher risk of developing psychiatric symptoms. The findings of this study may be useful to the Arab world.

# **COMPETING INTERESTS**

The authors declare that they have no competing interests.

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# **AUTHORS' CONTRIBUTIONS**

All authors contributed to the design and execution of this research. All authors approved the final manuscript.

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