



## Research Paper: Psychopathological Symptoms in Caregivers of Patients With Vegetative State



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**Running Title:** Caregivers of VS Patients and Psychological Symptoms

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### Bullet Points:

- Depression, somatoform and obsessive compulsive disorders are common psychological symptoms in the caregivers of Vegetative State patients.
- Female Vegetative State caregivers are at higher risk of developing psychological symptoms.

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### ABSTRACT

**Background:** Taking care of patients in a vegetative state is a great challenge and affects the mental health of the caregivers.

**Objectives:** This study aimed to determine the psychopathological symptoms in caregivers of patients with Vegetative State (VS) and determine the demographic and social predictors of the common symptoms.

**Materials & Methods:** This cross-sectional study was conducted in an educational hospital in the north of Iran from 2012 to 2013. The psychopathological symptoms of 80 caregivers of VS patients were evaluated by Symptom Checklist-Revised (SCL-90-R) questionnaire. Results were analyzed using SPSS (Version 18) by the Mann-Whitney U test. Finally, the predictors of psychopathological symptoms were determined through a simple regression model.

**Results:** The highest scores of the psychological symptoms were of the depression subscale ( $2.88 \pm 0.86$ ) and somatoform subscale ( $2.85 \pm 0.83$ ). The psychopathological symptoms including somatoform ( $P=0.012$ ), obsessive-compulsive ( $P=0.032$ ), depression ( $P=0.035$ ), anxiety ( $P=0.027$ ), phobia ( $P=0.015$ ), and paranoid ideations ( $P=0.027$ ) were significantly higher in women than in men. However, there was no significant relationship between these symptoms and marital status. The simple regression model showed that none of the sociodemographic variables could predict psychopathological symptoms in the caregivers.

**Conclusion:** A significant number of caregivers had psychopathological symptoms, especially depression and somatoform complaints.

**Keywords:** Persistent vegetative state, Caregivers, Psychology

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## Introduction

**V**egetative State (VS) refers to a comatose condition wherein patients show signs of wakefulness as demonstrated by eye opening but are unable to react to stimuli. It results from severe and usually irreversible damage to the brain [1-3] due to traumatic or non-traumatic acute cerebral events (ischemia, anoxia, hemorrhage, toxicities). VS patients show sleep-wake cycles and autonomic functions but are unable to clearly indicate awareness of the self and the environment [4]. A persistent VS can last for more than 1 month, and the number of these patients is increasing in the USA, with 14000 to 35000 cases reported annually. The VS can either be reversed by improvement in consciousness level or can last for a long time [3]. The decision to sustain the VS patients have been debated over the last 40 years [5, 6].

Usually, the burden of end-of-life care is on the families. It is estimated that more than 44 million adults are caregivers of patients with life-threatening diseases, most of whom are elderly [7]. The current therapeutic approaches toward VS include drugs, hyperbaric oxygen, nerve stimulation and stem cell transplantation [8]. Taking care of these patients at home is complicated since they require constant care even after their medical condition is stabilized. Caring for VS patients becomes more difficult when they need a tracheal canula and a pump for parenteral nutrition, and programmed mobilization every 2 hours [3].

Evidence suggests that taking care of these patients greatly affect the physical and psychological health of the caregivers. The main caregivers of VS patients spend several hours providing care, and some of them also quit their jobs because of their need to move to the cities where the specialized units of VS treatment are located [3]. Some caregivers also suffer from chronic mourning due to the affection they develop towards their patients. A study by Guarnerio et al. (2012) on 40 caregivers of VS patients showed that 65% had at least a prolonged grief disorder, depression or Post-Traumatic Stress Disorder (PTSD) [1]. The psychological symptoms vary greatly across caregivers and are related to their patients' consciousness level, emotional response, and kinship [9].

Arango-Lasprilla et al. (2011) found a low health-related quality of life in caregivers of patients with brain trauma, with significant differences in the emotional, vitality, mental health, social functioning, bodily pain, and general health subscales. They often bear the burden

of providing physical care and assistance with patients' daily activities, which can result in stress, depression, anger, anxiety, somatization, irritability, increased use of prescription and non-prescription drugs, financial problems, family role changes, poor social adjustment, and increased social isolation [10].

Many caregivers have reported changes in their lifestyle due to this burden. Some studies have reported contrary results wherein the relationship between sociodemographic and clinical variables of the caregivers of VS patients was not significant [1]. For instance, in a study on caregivers of ventilator-dependent patients at home using Caregiving Appraisal Scale, the caregivers did not report any negative experience [11]. Moreover, Findeis et al. reported that the caregivers of patients using a ventilator at home experienced a positive sense of mastery and satisfaction [12].

It is nevertheless important to study the psychological effects of caring for chronically ill patients on their family members and or caregivers, which has not been done in Iran so far. In addition, none of the studies conducted in other countries have considered all psychological symptoms in caregivers, especially those of VS patients, who exhibit mixed feelings [13] and are also statistically rare [14]. This study aimed to determine the psychopathological symptoms in caregivers of VS patients and determine the sociodemographic and social predictors of those symptoms.

## Materials and Methods

This cross-sectional study included caregivers of VS patients who had referred to Poursina Hospital, Guilan, Iran in 2013 (n=80), using available sampling method. Inclusion criteria were providing at least three months of care to patients diagnosed with post-trauma VS with GCS  $\leq 7$  for at least five days a week and a close familial relationship with the patient (e.g., father, mother, spouse, son/daughter, brother, sister, etc.). The exclusion criteria included GCS  $\geq 7$  of the VS patients and unwillingness to participate in the study.

The caregivers were subjected to Glasgow Coma Scale (GCS), the sociodemographic questionnaire, and Symptom Checklist-Revised (SCL-90-R) questionnaire. The sociodemographic questionnaire contained items related to age, sex, marital status, job, education, and economic status. The SCL-90-R is a tool designed to reflect the patterns of psychological symptoms and was first devised by Limen and Curry in 1973 to show the psychological dimensions of psychosomatic patients. In this study, we used SCL-90-R questionnaire modified by Derogatis et al. (1977) [15].

SCL-90-R is a multi-dimensional self-report inventory consisting of 90 items covering 9 dimensions of psychological distress: somatization, obsessive-compulsive behavior, interpersonal sensitivity, depression, anxiety, hostility, phobia, paranoid ideation, and psychoticism. Each question describes a physical or psychological symptom which is on a 5-point scale ranging from 0 (not at all) to 4 (very much). The patients were asked to answer the items to indicate the extent to which the symptoms of the SCL-90-R were manifested during the week preceding the day of questioning [16]. The study conducted in Iran by Bagheri et al. reported a 0.97 reliability coefficient and 0.94, 0.98, and 0.96 coefficients for sensitivity, specificity, and efficiency, respectively [17]. Furthermore, Rezaei et al. calculated the cut-off point of SCL-90-R as 0.7 in Iran, meaning that individuals with psychopathological symptoms greater than 0.7 suffer from psychological disorders [18].

After obtaining confirmation from the Ethics Committee of Guilan Road Trauma Research Center, we referred to Medical Records Department of Poursina Teaching Hospital, Guilan, Iran, which is the main center for trauma referrals in the whole province [19] and studied the records of patients with post-traumatic VS. After telephone follow-up calls and obtaining information of patients' health status, the caregivers were informed that they could be visited by a specialist (neurosurgeon) and other professionals at the Imam Reza Clinic of the hospital and were allotted visit times. A trained psychi-

atric nurse met the caregivers at the outpatient clinic of the hospital after the specialist's visit. After assuring the caregivers that their information would be kept confidential, their written consent was obtained. Based on the fulfillment of inclusion criteria, the subjects completed the sociodemographic and SCL-90-R questionnaire. The trained nurse remained with the caregivers till the end of the process and read aloud the items for illiterate or semi-literate participants. All data were analyzed using SPSS (version 18) by Mann-Whitney U test, and a simple regression model was used to determine the predictability of psychopathological symptoms as functions of sociodemographic factors.

## Results

Most of the caregivers were women (63.8%), married (91.25%), illiterate (35%), housekeepers (52.5%), and in poor economic status (60%). The mean (SD) age of the participants was 44.78(15.62) years (range: 22-75 years). The mean (SD) scores of the different psychological symptoms in caregivers were as follows: depression; 49.57(10.88), somatoform; 45.90(10.68), obsessive-compulsive; 36.68(9.00), psychosis; 35.40(9.09), anxiety; 33.88(7.44), interpersonal sensitivity; 33.43(7.98), phobia; 29.41(7.31), paranoid; 22.15(5.29), and aggression; 21.67(5.59). Since these values did not follow a normal distribution according to Shapiro Wilcoxon test, Mann-Whitney U test was used to determine the asso-

**Table 1.** Frequency of psychopathological symptoms in caregivers based on sex and marital status

Variables	Marital Statuses N (%)		P	Sex N (%)		P
	Single N=7	Married N=73		Female N=52	Male N=28	
Somatoform	5(7.2)	64(92.8)	0.145	47(68.1)	22(31.9)	0.012*
Obsessive-Compulsive	6(8.3)	66(91.7)	0.192	49(68.1)	23(31.9)	0.032*
Interpersonal sensitivity	5(7.5)	62(92.5)	0.351	45(67.2)	22(32.8)	0.056
Depression	4(6.3)	60(93.7)	0.241	46(71.9)	18(28.1)	0.035*
Anxiety	5(7.4)	63(92.6)	0.250	47(69.1)	21(30.9)	0.027*
Aggression (Hostility)	5(7.7)	60(92.3)	0.564	44(67.7)	21(32.3)	0.057
Phobia	5(7.1)	65(92.9)	0.370	48(68.6)	22(31.4)	0.015*
Paranoid Idea	4(6)	63(94)	0.470	46(68.7)	21(31.3)	0.027*
Psychosis	5(7.8)	59(92.2)	0.560	44(68.8)	20(31.2)	0.056

\* Significance level: P≤0.05; Mann-Whitney U test

**Table 2.** The regression model predicting psychopathological symptoms in caregivers of VS patients

Variable	Categories	Coefficient	P	CI	
				Lower	Upper
Age	3	-0.22	0.48	-0.85	0.40
	4	0.04	0.89	-0.68	0.78
	5	0.15	0.67	-0.58	0.90
	6	0.13	0.72	-0.63	90
	7	0.22	0.73	-1.08	1.5
Marital	Married	-0.32	0.33	-1.01	0.35
Economic	Medium	-0.15	0.53	-0.63	0.32
	Reach	0.27	0.48	-0.50	1.06
Job	Cultural	-0.80	0.27	-2.25	0.64
	House keeper	-0.27	0.49	-1.06	0.51
	Retired	-0.71	0.16	-1.72	0.30
	Self-employed	-0.18	0.65	-1.04	0.66
	Employed	-0.34	0.52	-1.44	0.74
Education	Student	0.49	0.60	-1.42	2.42
	Low literate	-0.05	0.86	-0.64	0.53
	Diploma	0.44	0.23	-0.29	1.18
	Bachelor's degree and above	0.56	0.29	-0.49	1.62

\* Significance level:  $P \leq 0.05$ ; Model simple regression



ciation between the psychopathological symptoms with sex and marital status.

A significant difference was observed in the somatoform ( $P=0.012$ ), obsessive-compulsive ( $P=0.032$ ), depression ( $P=0.035$ ), anxiety ( $P=0.027$ ), phobia ( $P=0.015$ ), and paranoid ideations ( $P=0.027$ ) behaviors between the sexes. However, no significant difference was found among individuals of different marital status (Table 1). The results of regression analysis indicated no significant relationship between the sociodemographic variables and psychopathological symptoms, suggesting that those variables cannot predict the incidence of these symptoms in caregivers of VS patients (Table 2).

## Discussion

In this study, a remarkable number of psychopathological symptoms, especially depression, somatoform and

obsessive-compulsive behaviors were observed in caregivers of patients with VS. Our findings are consistent with other studies that have reported burden of disease [20-22], strain [23], anxiety and stress [24, 25], depression and psychological distress [26], anger and potentially harmful behavior [25], and poor physical health [27] among caregivers. Individual and social limitations, in addition to the financial burden, put a lot of physical and psychological pressure on the caregivers leading to somatoform and psychological symptoms such as depression [28].

In addition, they experience a feeling of uncertainty about the survival and death of their patients which leads to anxiety and obsessive-compulsive rituals and somatoform symptoms to reduce it [29]. We found that most psychopathological symptoms in the caregivers were related to depression. This is consistent with the findings of Chiambretto et al. (2001) who reported prolonged grief

disorder, depression and post-traumatic stress disorder as the three main psychological conditions in caregivers [3]. Furthermore, in a comparative study, there was a significant difference between caregivers and non-caregivers in terms of physical health, stress, and depression [30].

In this study, somatoform symptoms were also very high, second only to depression. Chang et al. (2010) found a significant relationship between the physical and psychological health of caregivers, wherein the psychological state of caregivers had a massive effect on their physical health and, therefore, their ability to provide adequate care [31]. Furthermore, women caregivers reported more physical complaints [32], and in our study, most of the caregivers were women, and 13.8% of them had no psychological symptoms. Garlo et al. (2010) showed similar results and only 10% of the caregivers in their study had no burden disorder [33]. We observed that the frequency of psychiatric disorders, especially somatoform, obsessive-compulsive, depression, anxiety, phobia and paranoid ideations, was significantly higher in the women caregivers compared to men.

In contrast, Chiambretto et al. (2001) reported a higher level of emotional distress and neuroticism in men compared to women [3]. In the study of Garlo (2010) also, sociodemographic variables such as sex had no effect on burden disorder [33]. It is likely that low perceived control in women compared to men may be the cause of severe psychological symptoms in the former [34]. A study by Rahmani et al. (2012) on caregivers of neurological patients in Iran reported significant differences in the general health of men and women, and higher depression in women compared to men [35]. Female caregivers in various studies have reported greater stress [20-23].

However, in most of the reviewed studies in addition to the present study, most caregivers were women [20, 21, 24]; therefore, due to the low number of male caregivers, an accurate statistical comparison may not be possible. In our study, the age of the caregivers was not a significant predictor of psychopathological symptoms. Other studies have also not reported any significant association between age and psychosocial symptoms in caregivers [36].

Rahmani et al. (2012) also found no significant relationship between marital status of the caregivers and general health [35]. Another study reported that younger caregivers were more likely to research on ways to deal with stress, as they were under higher stress levels [3]. Im et al. (2004) found that more than three-quarters of the caregivers were married (77.4%) and more than half of them were the patient's spouse (52.2%), but there was

no significant relationship between the kinship with patient and caregiving [11]. We did not find any report that studied the effect of these factors on caregivers of patients with VS.

Some studies have demonstrated a correlation between caregivers' socioeconomic status and their psychological status [37], but we did not find any association between the economic situation of the caregiver and psychopathological symptoms. Although the majority of caregivers in our study were housekeepers, it was not a significant predictor of psychopathological symptoms. In Iranian society, caring for children, patients and the elderly or the disabled is often the responsibility of women, and caregiving is considered a part of housekeeping duties [38].

In the present study, most caregivers were illiterate or semi-literate. However, their education level did not predict their psychopathological symptoms. In a similar study in Iran, the majority of caregivers had high-school or lower education, but no significant correlation was seen between education level and the physical and psychological health of caregivers [35]. The economic status of most of our caregivers was poor, but poverty was also not a significant predictor of overall psychopathological symptoms. However, other studies reported that poorly trained caregivers suffered more from stress and depression [39].

Psychosocial needs of caregivers must be elucidated in order to maintain their health and provide the best possible care for the patient. In a meta-analysis of 29 clinical trials, 3 interventions had been introduced; psycho-educational counseling, skills-training, and therapeutic counseling. This study also showed that although multiple interventions had a moderate impact, they could significantly reduce the stress on the caregivers and improve their caring ability, adaptation, and quality of life by increasing their self-efficacy [40]. Therefore, giving comprehensive information to the caregivers, ensuring their active participation in treatments and helping them obtain resources and support can be highly effective [35].

## Conclusion

A significant number of caregivers of patients with post-traumatic vegetative state had psychopathological symptoms, especially depression and somatoform symptoms. Somatoform and obsessive-compulsive symptoms were more prevalent among the women compared to the men. The main limitation of our study was the small sample size since the number of VS patients is very small.

## Ethical Considerations

### Compliance with ethical guidelines

This research obtained confirmation from the Ethics Committee of Guilani Road Trauma Research Center. After assuring the caregivers that their information would be kept confidential, their written consent was obtained.

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### Conflict of interest

The authors have no conflict of interest.

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