

# Determinants of Quality of Life in the Caregivers of Iranian War Survivors with Bilateral Lower-Limb Amputation after More than Two Decades

CME Article

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## What's Known

- Studies have shown higher physical and mental burden as a consequence of caregiving, with caregivers providing care to disable relatives at home being potentially at risk of anxiety, depression, and hopelessness.
- Limited studies have focused on the burden of caregiving to veterans with war-related disabilities.

## What's New

- QOL was significantly poorer in the caregivers than in the general Iranian female population.
- The lowest mean score of the SF-36 domains in the caregivers was observed for bodily pain.
- Hospitalization and mental health problems in the amputees constituted the most important predicting factors in the caregivers' QOL.

## Abstract

**Background:** Providing care to a disable relative at home exposes the caregiver to a potentially higher risk of physical and mental problems. We measured health-related quality of life (HRQOL) and its determinants among the caregivers of the Iranian survivors of the Iran-Iraq war (1980–1988) with bilateral lower-limb amputation.

**Methods:** Data were collected from 464 individuals comprising war-related bilateral lower-limb amputees (n=232) and their caregivers (n=232) in January 2015 in Shiraz, Iran. The 36-Item Short-Form Health Survey (SF-36) questionnaire was used to evaluate the caregivers' QOL. Logistic regression analysis was performed to determine the most significant contributing factors.

**Results:** The mean age of the caregivers and the amputees was 39.4±6.2 and 42.5±6.2 years, respectively. The mean duration of disability was 22.8±3.9 years in the amputees. Most of the caregivers were reported to be in their first marriage. The highest and lowest mean scores of the SF-36 domains in the sample population were observed for physical function (76.65±21.97) and bodily pain (53.54±24.95). QOL in the caregivers was significantly lower than that in a sample of the general Iranian female population (P<0.05). History of hospitalization during the preceding year of the study (OR: 2.23, 95% CI: 1.08 to 4.57, P=0.02) and mental health problems (OR: 1.79, 95% CI: 1.02 to 3.15, P=0.04) in the amputees constituted the most important predicting factors in the caregivers' QOL.

**Conclusion:** The caregivers of the bilateral lower-limb amputees in the current study suffered from a poor QOL. Hospitalization and mental problems were the most significant contributing factors vis-à-vis the caregivers' HRQOL. Health care and services should, therefore, be provided to both amputees and their caregivers.

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**Keywords** • Amputation • Caregivers • War survivors • Iran

## Introduction

Lower-limb amputation is life-changing surgery with great physiological strain on the individuals.<sup>1</sup> This can result in health problems such as decreased physical activity, obesity, and psychological and social disturbances.<sup>2-6</sup>

Providing care to a family member places the caregiver at higher risk of physical and mental problems. Caregivers who provide care to a disable relative at home are potentially at risk of diminished physical and mental health. Family caregivers of individuals who live with a disability report burden and stress as a consequence of caregiving, which in turn contributes to psychiatric morbidity.<sup>7</sup> This could generate both objective and subjective family caregiving burden. Objective burden denotes the problems in family life (household routines, relationships, and leisure time) as a result of a disability in a family member. Subjective burden is more related to the emotional and mental health status (guilt, feelings of loss, and anxiety) of family caregivers. Family caregivers experience practical and emotional burden when caring for a sick family member.<sup>8,9</sup> Both caregiver and care recipient have a strong impact on caregiver burden. This burden is negatively correlated with health-related quality of life (HRQOL), mainly mental health. In addition, burden is negatively correlated with caregivers' positive concern for their interactions with their disable family members.<sup>7</sup> Amputation lies amongst the most important factors influencing QOL.<sup>10</sup> Substantial research has demonstrated a low QOL among veterans and individuals living with injuries.<sup>11-13</sup> Meanwhile, only a few studies have considered the QOL of caregivers.<sup>14,15</sup>

The physical and psychological distresses of long-term caregiving are usually accompanied by a lower QOL in caregivers.<sup>16</sup> The duration of care and its intensity as well as history of hospital admission constitute some of the factors influencing caregivers' QOL.<sup>17</sup> Higher rates of anxiety, depression, and hopelessness in caregivers,<sup>18,19</sup> especially in women,<sup>20,21</sup> have also been considered as factors contributing to the decreased QOL among caregivers.<sup>12,16,18,22</sup> Some studies have shown that caregivers' QOL is more influenced in the domains of mental health, vitality, general health,<sup>23</sup> and emotional roles.<sup>18</sup> A parallel consideration of the QOL of patients and their caregivers is of paramount importance. Throughout the 8 years of war between Iran and Iraq (1980–1988), more than 400,000 Iranian individuals (both combatants and civilians) sustained injuries leading to substantial disabilities. More than 11,500 of this population eventually underwent lower-limb amputation,<sup>24</sup> and 576 had bilateral lower-limb amputation.<sup>5</sup>

The aforementioned studies focused on evaluating the QOL of caregivers. The key novel point in the present study is its attention to the factors affecting the QOL of the caregivers

tending to war survivors. Given the dearth of data on the QOL of the caregivers of war amputees, we sought to evaluate the HRQOL of the caregivers of war survivors with bilateral lower-limb amputation and compare it to that of a sample of the general Iranian female population and also assess that factors that influence it.

## Patients and Methods

This cross-sectional (descriptive-analytic) study was performed in January 2015. The sample population of the study was selected from the veterans enrolled in a general health assessment project organized in Fars Province. The project was a collaboration between the Janbazan Medical and Engineering Research Center (JMERC) and the Department of Health of the Veterans and Martyrs Affairs Foundation (VMAF). Individuals injured during the war are covered by the VMAF, and are classified based on the nature of their injury in different groups and categories.<sup>25</sup> The inclusion criteria were comprised of being married, having a caregiving spouse, and consent to participate in the study. The only exclusion criterion was lack of desire to continue cooperation with the study. All bilateral lower-limb amputees whose wives were also their caregivers were invited to participate in this study together with their caregivers. Totally, 232 couples (amputees and caregivers) were recruited in the study. All the amputees and their respective caregiving wives gave written informed consent for participation. Two questionnaires were used in this study. A demographic information questionnaire was devised; it consisted of 2 parts: a) information regarding the caregiver consisting of age, education, marital status prior to marriage to the amputee, marrying the amputee before/after amputation, employment, and presence of any disability or disease and b) information regarding the amputee himself encompassing age, educational level, employment, duration of the war-related injury, level of amputation, use of prosthetics, any disease or additional disability related to the war, presence of psychiatric problems, and history of hospitalization during the preceding year of the study.

The 36-Item Short-Form Health Survey (SF-36) questionnaire was employed to evaluate the caregivers' QOL. The SF-36 is a generic tool that can be used for the general population and different patient groups. Scores on each of the subscales range from 0 to 100, with 0 representing the worst HRQOL and 100 representing the best.<sup>12</sup> The psychometric properties of the Farsi version of the SF-36 were examined in a previous

study, in which the internal consistency (to test reliability) for all the 8 SF-36 scales met the minimum reliability standards, with Cronbach's  $\alpha$  coefficients ranging from 0.77 to 0.90 except for the vitality scale ( $\alpha=0.65$ ).<sup>26</sup> In addition, between-group comparisons in that study showed that the SF-36 discriminated between men and women as well as between old and young subjects as was anticipated (all  $P<0.05$ ) in all the scales. Convergent validity (to test scaling assumptions) using the correlation between each item and its hypothesized scale also yielded satisfactory results.<sup>27</sup>

In the statistical analysis, in addition to the descriptive statistics, the caregivers' scores on the SF-36 were compared to those of the sample of the general Iranian female population ( $n=2,166$ ) using the one-sample t-test.<sup>26</sup> The independent t-test was utilized to compare QOL in the caregivers with different characteristics. The logistic regression analysis was performed to determine variables with the most significant contribution to HRQOL in the caregivers of the war-related bilateral lower-limb amputees. For the purposes of the logistic regression analysis, the physical component summary (PCS) and the mental component summary (QOL) were employed as dependent variables, and the factors that were significant in the independent t-test were considered as independent variables. The independent variables incorporated marriage at the time of injury, level of education, employment status for both caregiver and amputee, history of hospitalization, and mental health problems in the amputees. Based on the mean PCS and MCS scores, the study sample was divided into 2 groups: those who scored  $\geq$  the mean (PCS:  $n=174$  and MCS:  $n=131$ ) and those who scored  $<$  the mean (PCS:  $n=54$  and MCS:  $n=97$ ). As a rough guide, the mean score for any given population seems to be the best cutoff point to determine whether a group or individual scores above or below the average (Ware, 2000). The research protocol was approved by the Ethics Committee of the JMERC.

## Results

The mean age of the caregivers and the amputees was  $39.4\pm 6.2$  and  $42.5\pm 6.2$  years, respectively. The mean duration of life with disability was  $22.8\pm 3.9$  years. The caregivers' data regarding marital status prior to marriage to the amputees, living with the survivors since their injury, employment status, educational level, and morbidity are demonstrated in table 1. Education, employment status, amputation level, use of prosthetics, physical comorbidity, mental

health problems, and history of hospitalization during the preceding year of the study among the war-related amputees are also illustrated in table 1.

### Comparisons of Quality of Life

A comparison of the mean scores of the 8 domains of the SF-36 between the caregivers and the sample of the general Iranian female population revealed significant differences in the domains of physical function, role limitations as a result of physical problems, bodily pain, and general health. The mean scores of the caregivers were lower in the domains of vitality, social function, and mental health, although the

**Table 1:** Demographic characteristics of the population studied ( $n=464$ )

	Number	Percent
Characteristics in caregivers (N=232)		
Caregivers' marital status		
First marriage	214	92.2
Married before (widowed)	9	3.9
Married before (divorced)	7	3.0
Educational level		
<12 years	172	71.4
$\geq 12$ years	58	25.0
Employment status		
Employed	13	5.6
Housewife	215	92.7
Morbidity		
No	181	78.0
Yes	51	22.0
Married at the time of injury		
No	173	74.6
Yes	59	25.4
Characteristics in amputees (N=232)		
Employment status		
Employed	77	33.2
Unemployed	153	65.9
Amputation level		
Both below knee	90	38.8
Both above knee	47	20.3
Other types of amputation	86	37.1
Use of prosthetics		
No	44	19.0
Yes	169	72.8
Additional war-related injury		
No	78	33.6
Yes	152	65.5
Psychological problems		
No	144	62.1
Yes	88	37.9
History of hospitalization		
No	192	82.8
Yes	40	17.2

differences were not considered statistically significant (table 2).

#### Caregivers' Characteristics and Health-Related Quality of Life

Most of the caregivers were reported to be in their first marriage. The marital status of the caregivers prior to marriage to the amputees was not significantly associated with their QOL. The caregivers responsible for the care of the survivors from the beginning of amputation had a significantly lower score in physical functioning ( $P=0.049$ ). The caregivers who had higher educational levels ( $\geq 12$  years) had significantly higher scores in physical functioning ( $P=0.001$ ), role physical ( $P=0.005$ ), bodily pain ( $P=0.006$ ), general health ( $P=0.05$ ), and vitality ( $P=0.02$ ). Being employed was significantly associated with higher scores in vitality ( $P=0.02$ ), social functioning ( $P=0.001$ ), and mental health ( $P=0.002$ ) among the caregivers. Morbidity in the caregivers did not affect any domains of the HRQOL SF-36.

#### Characteristics of the Bilateral Lower-Limb Amputees and Quality of Life of the Caregivers

Unemployment among the amputees was significantly associated with lower HRQOL among the caregivers ( $P<0.05$ ), except for physical functioning and role emotional. The caregivers of the survivors who had a history of hospitalization during the preceding year of the study had significantly lower scores in mental health ( $P=0.01$ ) and role emotional domains ( $P=0.04$ ).

The level of amputation and use of prosthetics in the amputees were not statistically associated with lower HRQOL in the caregivers. HRQOL in the caregivers whose partners suffered from

mental health problems was significantly worse than that of their counterparts' ( $P<0.05$ ), except for physical functioning, role physical, bodily pain, and role emotional. Additional war-related injuries in the amputees did not prove to have any significant correlation with the caregivers' SF-36 domains.

#### Impact of the Variables on the Caregivers' Health-Related Quality of Life

In order to identify the predicting factors for HRQOL in both PCS and MCS, different variables including the marital status of the caregivers prior to marriage to the amputees, marrying the amputees before/after the injury, occupational status, presence of any disability or health problem in the caregivers, history of hospitalization during the preceding year of the study, and presence of mental health problems which had been proved to be statistically significant factors in the independent t test were analyzed through logistic regression. History of hospitalization during the preceding year of the study and presence of mental health disorder had the most negative influence on the MCS (table 3). Nonetheless, these variables did not influence the PCS significantly.

## Discussion

The results of the present study showed that, as compared to a sample of the general Iranian female population, the caregivers of the war veterans with lower-limb amputation had a poor QOL. The lowest scores of QOL were reported for bodily pain and general health. A similar study also reported a low score for the QOL of the caregivers of individuals with war-related spinal cord injuries as compared to the general population of women in Iran.<sup>14</sup> Amputation lies among the factors influencing the QOL of the individual.<sup>10</sup> Lower-limb amputation is usually accompanied by the need for further support to perform daily tasks and self-care, a need which certainly increases as the individual grows older.<sup>27</sup> Individuals with chronic health conditions mostly depend on their own first-degree relatives, including spouses and children.<sup>28</sup> The burden of the provision of care to these patients probably results in a decreased QOL among the caregivers as compared to the general population.

The duration of partnership and providing care to patients also influences the QOL of the caregiver.<sup>17,29</sup> In the present study, the caregivers responsible for the care of the amputees from the beginning of their condition ( $>22$  years) had a lower QOL in the domain of physical functioning.

**Table 2:** Comparison the SF-36 scores between the caregivers and the sample of the general Iranian female population

	Mean $\pm$ SD		P value
	Caregivers (N=232)	General Iranian female population (N=2,166)	
Physical functioning	76.65 $\pm$ 21.97	82.9 $\pm$ 22.1	<0.001*
Role physical	61.90 $\pm$ 27.44	66.5 $\pm$ 29.1	0.013*
Bodily pain	53.54 $\pm$ 24.95	76.4 $\pm$ 26.2	<0.001*
General health	60.42 $\pm$ 16.71	65 $\pm$ 20.8	<0.001*
Vitality	61.67 $\pm$ 23.56	62.9 $\pm$ 17.8	0.446
Social functioning	75.85 $\pm$ 25.44	74.2 $\pm$ 25.1	0.321
Role emotional	66.48 $\pm$ 26.73	62.4 $\pm$ 32.4	0.1
Mental health	62.84 $\pm$ 26.41	65 $\pm$ 18.6	0.216

\* $P<0.05$  was significant

**Table 3:** Determinants of poor physical and mental health-related quality of life in the caregivers of war-related bilateral lower-limb amputees (n=232)

	OR (95% CI)	P value
<b>Physical component summary (PCS)</b>		
Married at the time of injury		
No	1.0 (ref.)	0.723
Yes	0.876 (0.421-1.822)	
Caregivers' educational level		
<12 years	1.0 (ref.)	0.227
≥12 years	0.600 (0.262-1.374)	
Amputees' employment status		
Unemployed	ref1.0 (ref.)	
Employed	0.658 (0.313-1.380)	0.268
Caregivers' employment status		
Unemployed	1.0 (ref.)	0.189
Housewife	2.545 (0.631-10.265)	
Amputees' history of hospitalization		
No	1.0 (ref.)	0.611
Yes	1.228 (0.556-2.710)	
Amputees' psychological problem		
No	1.0 (ref.)	0.555
Yes	1.215 (0.636-2.319)	
<b>Mental component summary (MCS)</b>		
Married at the time of injury		
No	1.0 (ref.)	0.968
Yes	1.013 (0.537-1.911)	
Caregivers' educational level		
<12 years	1.0 (ref.)	0.480
≥12 years	0.785 (0.401-1.537)	
Amputees' employment status		
Employed	1.0 (ref.)	0.192
Unemployed	0.661 (0.355-1.231)	
Caregivers' employment status		
Employed	1.0 (ref.)	0.380
Housewife	1.873 (0.461-7.608)	
Amputees' history of hospitalization		
No	1.0 (ref.)	0.028*
Yes	2.229 (1.088-4.566)	
Amputees' psychological problem		
No	1.0 (ref.)	0.044*
Yes	1.791 (1.017-3.154)	

\*P&lt;0.05 was significant

Prolonged care in this group, commencing from the time of the injury and lasting for about 22 years, is indeed expected to result in limitation of physical activity. Providing care to patients with either chronic or severe health conditions is usually accompanied by a higher decline in the caregiver's QOL.<sup>16</sup>

It should be noted that in most of the cases in the current study, the caregivers were in their first marriage: This is a fact that underscores the stability of the family status, not least in a condition where the war veterans were afflicted with various health problems and relied on

their spouses for care. This highlights the great need for a simultaneous service provision to the amputee and his caregiver when dealing with the health issues of war veterans. Stable family status has also been reported by other studies.<sup>15,30</sup> This must be the influence of the culture and social values of Iranians prompting women to tend to their husbands who were injured when defending the country against a foreign country's invasion. Additionally, earlier studies reported that religious/moral beliefs were significant factors for mental health protection in war veterans.<sup>31,32</sup> Indeed, controlling distress and

overcoming post-war psychosocial problems were in tandem with a higher index of religious/moral beliefs in war veterans.<sup>31</sup> Furthermore, the negative effect of a weak faith in God on coping with psychological trauma and post-traumatic stress disorder was confirmed by a previous study.<sup>33</sup> Likewise, the present study showed that, in comparison with a similar sample of the general population, family caregivers found life more difficult due to living with disabled persons. However, religious beliefs enabled them to continue their married life in the face of a lower QOL and tougher conditions.

The results of some studies have revealed that caregivers' level of education can influence their QOL.<sup>22</sup> This is concordant with our results. Social activity among amputees also positively influences the QOL of their caregivers.<sup>17</sup> Caregivers whose patients were involved in social activities and possessed occupation proved to have a higher QOL.<sup>17</sup> Most probably, having a job and being involved in social activities accompany privileges such as more social networking and higher incomes. This was also true of the war veterans' caregivers in the present study. The caregivers who were employed scored higher in the scales of mental health than did the caregivers who were housewives. The employment of the caregiver might have resulted in the lower dependence of the amputee for dealing with his daily tasks, eventually decreasing the burden on the caregiver. On the other hand, employment can be regarded as a means of increased socializing and income. Accompanying physical ailments either in the caregiver or in the amputee did not influence the QOL of the caregivers significantly. The results of a similar study also pointed out that accompanying physical ailments did not influence the QOL of the caregivers.<sup>34</sup> On the other hand, coexisting mental health problems in the amputees resulted in a lower QOL among the caregivers. Some investigations have proved a correlation between stress of the patients and the stress level of the caregivers, resulting in a lower QOL.<sup>19</sup>

Many caregivers of amputee patients are distressed, and their emotional and functional impairments can influence the functioning of their patients.<sup>35</sup> Thus, health providers should focus on more attempts to develop intervention strategies directed toward both amputees and their families. Preparing families for potential psychosocial problems or situations and teaching them coping skills may increase QOL in both patient and caregiver. Social support can exert a buffering effect on caregiver burden. One study found that caregivers who obtained

more social support reported less burden.<sup>7</sup> Chiming in with our results, most caregivers are usually the unpaid family members who suffer from the burden of caregiving.<sup>34</sup> Individuals with chronic conditions usually suffer from multiple comorbidities, which might lead to complicated management and require considerable efforts from their caregivers over long periods. This population of caregivers is usually neglected by the health system due to the major disabilities of their patients and as a result might suffer from emotional and functional impairment,<sup>35</sup> depression,<sup>34</sup> and distress.<sup>19</sup>

History of hospitalization ranks among the most important factors influencing QOL among caregivers.<sup>17</sup> Our results also revealed that a history of hospital admission among the amputees during the most recent year before the study had a negative influence on the QOL of the caregivers. As the predictive factors for QOL were analyzed through a regression model, a history of hospital admission and the presence of mental health problems proved to exert the most negative influence on QOL. The results of other studies confirm such an influence.<sup>17,19</sup>

The current study was limited in that it failed to gather all bilateral lower-limb amputees and their caregivers in Shiraz; some of them were not able to participate in this study due to the long distance. Another drawback of note was the lack of proper communication with some participants who spoke the local dialect.

## Conclusion

The results of the present study highlight the unfulfilled health and well-being needs of the caregivers of bilateral lower-limb amputees and their poor HRQOL. The most important factors that should be considered in the efforts aimed at enhancing caregivers' QOL include comprehensive medical management for amputees and training amputees and their caregivers regarding the social, emotional, and psychological aspects of amputees' life. This might lead to lower hospitalization rates, better adjustment to day-to-day life, and improved overall QOL in both amputee and caregiver.

Additionally, since the most important factors in the caregivers' QOL were found to be a positive history of hospitalization and mental health problems in the amputees, it is important to support and provide more facilities for the amputees and their caregivers with multiple comorbidities. The caregivers of amputees with advanced age and high dependency needs face increased demands for care provision, predisposing the care recipients themselves to

more adverse outcomes. This may be reduced by caregiver training, promoting amputees' coping methods, offering rehabilitation programs, and applying appropriate intervention for long life support. Simultaneous care and service to maintain physical and mental health should be provided to amputees and their caregivers in order to promote the QOL of caregivers, a status which will eventually confer a higher QOL among amputees. We recommend that further studies assess and compare QOL among the family caregivers of war survivors suffering from different types of injuries.

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