

# The Relationship between Caring Burden and Quality of Life in Caregivers of Type 2 **Diabetes**

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#### Abstract

Background: Taking care of patients with chronic diseases such as diabetes exerts great tiredness and stress on the caregivers. The aim of this study was to determine the extent of the caring burden and its relationship with the quality of life of caregivers of diabetic patients. Methods: In this cross-sectional study, 154 caregivers of patients with type 2 diabetes referred to Imam Hossein hospital in Shahroud city were evaluated. The data collection tools included a demographic questionnaire, SF-36 standard quality of life questionnaire, and Novak & Guest care burden questionnaire. The accessible sampling was used and the data were collected by self-reporting. The data was analyzed using descriptive and inferential statistics (Pearson correlation coefficient and regression analysis). Significant level was set at 0.05. **Results:** The mean age of caregivers was  $41.86 \pm 12.78$  years old. The mean scores of care burden and quality of life of the participants were  $53.21 \pm 49.61$  and  $61.02 \pm 20.71$  respectively. There was a significant inverse correlation between the mean score of care burden and caregivers' quality of life.

Conclusions: According to the results of this study, providing social and informational support for caregivers is recommended to reduce the care burden and subsequently improve the quality of life.

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# ntroduction

Diabetes Mellitus (DM) describes a group of metabolic disorders characterized by high blood glucose levels. This disease is a major public health problem and its prevalence has increased significantly in human societies in recent decades. DM is growing faster in the low- and middle-income countries than high-income countries.<sup>1-4</sup> In 2017, the prevalence of diabetes has been estimated at 8.4% in people between 18 and 99 years old and is predicted to be increased to 9.9% in 2045.5 According to the results of a review and meta-analysis study, the prevalence of diabetes in Iran was 3.41% with the highest and lowest incidences of 18.6% and 1.3% respectively.6 Patients with diabetes are at high risk of life-threatening events increasing the costs of medical care and mortality while lowering quality of life.<sup>2</sup> The chronic nature of diabetes is associated with long-term problems such as diabetic foot, blindness, renal failure, cardiovascular disease, as well as lesions in the peripheral

nervous system, eyes, kidneys, and vascular system. 7 Individuals with type 2 diabetes experience different mental and personality traits compared with people without type 2 diabetes. 8 In addition to the lives of the patients themselves, chronic diseases such as diabetes also affect the caregiver's life. In fact, a direct relationship has been described between the high demand for care and the clinical problems of patients with chronic diseases. On the other hand, over-care by caregivers can negatively impact their health. Chronic illnesses are associated with mental health problems (especially anxiety and depression) as well as physical complaints (such as back pain, headache and muscle aches). The chronic nature of such diseases also leads to social isolation, lack of leisure time, family conflicts and poor economic conditions which have been called the care syndrome by some authors. These conditions have a negative impact on caregivers' quality of life necessitating a comprehensive approach for watching patients and those caring for them. <sup>9</sup> Caring burden modulates the caregivers' quality of life. In caregivers with high working burden, both the patients' characteristics (such as being unemployed) and the caregivers' characteristics (such as poor health, low income, and marital status) have negatively affected caregivers' quality of life. In caregivers with low work burden, the characteristics of both patients (such as long-term hospitalization) and caregivers (such as poor health conditions) are considered as negative predictors of caregivers' quality of life.10 In previous studies, caregivers of chronic physical and psychological illnesses such as neurological diseases experience high caring burden, 11 while caretakers of elderly under hemodialysis had moderate to severe caring burden.<sup>12</sup> In caretakers of patients with lung cancer, the care burden has been associated with emotional distress and quality of life of caregivers.<sup>13</sup> Bammari et al.<sup>14</sup> evaluated the caring care burden in caregivers of diabetic patients describing a moderate care burden in this population. Caring burden alone can predict 30% of the variance in caregivers' quality of life. 15 Family caregivers are prone to many illnesses. 16 Because of the negative impacts of illnesses on caregivers' quality of life, these individuals are more susceptible to physical and mental disorders. Therefore, considering the important role of caregivers in supporting the patients in coping with the diseases, <sup>17</sup> and the lack of a similar study on this issue in diabetic patients, it is important to assess the relationship between care burden and the quality of life of caregivers. So, this research aimed to investigate the care burden and its relationship with quality of life in caregivers of diabetic patients.

# **Materials and Methods**

This cross-sectional study was carried out to determine the relationship between quality of life and caring burden in caregivers of patients with type 2 diabetes in 2018. The study population consisted of 154 caregivers of patients with type 2 DM in Imam Hossein hospital of Shahroud city. The inclusion criteria of diabetic patients and caregivers were as following: A definitive diagnosis of type 2 diabetes in the patients by a physician, the caregiver should have been a first-degree relative or the main caregiver of the patient, the caregiver should not be a health care worker, not afflicted with physical or mental illnesses, and not being treated with drugs affecting psychological condition (self-reported or diagnosed by a physician), the caregiver should have been able to answer the questions of the questionnaire.

The eligible caregivers were selected by accessible sampling method. After obtaining the necessary permissions, they were asked to complete the data collection tools including a demographic form, the SF-36 questionnaire, and Novak & Guest care burden questionnaire to assess quality of life and caring burden respectively. The demographic data included age, gender, educational level, marital status, economic status, occupation, relative to the patient, duration of illness in the patient, the duration of care needed for the patient overnight, any specific illness in the caregiver and the caregiver's monthly income. These data were obtained by self-reporting. The SF-36 questionnaire is used to assess the quality of life. The questionnaire has 36 phrases and evaluates 8 domains of physical function, social function, physical role, emotional role, mental health, vitality, physical pain, and general health. In addition, the 36-SF also evaluates two general areas of an individuals' physical and mental functions. Higher scores mean better quality of life. 18,19 The reliability of the questionnaire has been evaluated by using statistical analysis of internal consistency. The questionnaire validity has also been determined using the comparison of known groups method as well as convergence validity. The internal consistency analysis has shown that the Persian version of the 36-SF questionnaire has the minimum standardized reliability coefficient in the range of 77% to 90%. 20 The care burden questionnaire of Novak & Guest includes 24 questions. The questionnaire consists of five subscales (i.e. time-dependent, evolutionary, physical, social, and emotional). The caregivers' responses to each question fitted into a 5-option Likert scale (completely incorrect to completely correct). The minimum and maximum attainable scores are 24 and 120 respectively. The scores of 24 to 47, 48 to 71, 72 to 95, and 96 to 120 indicated mild, moderate, intensive, and very intensive care burden respectively. This questionnaire has acceptable reliability with the Cronbach's alpha coefficient of 0.80 for the whole questionnaire and 0.69 to 0.87 for the subscales.<sup>21</sup> The Persian version of this questionnaire has been validated by Abbasi et al with the Cronbach's alpha coefficient of 0.90 for the whole scale and the coefficients of 0.76 to 0.82 for the subscales.22

The data were analyzed by descriptive and inferential statistics (Pearson correlation coefficient and regression analysis). The significant level was set at 0.05. This study was approved by the research administration of Shahroud university of medical sciences, Shahroud, Iran (ethical approval code: IR.SHMU.REC.1396.100).

#### **Results**

The mean age of caregivers of diabetic patients was  $41.86 \pm 12.78$  years old. Most of the participants were women (76.6%) and married (81.2%) (table 1).

Table 1. The demographic characteristics of caregivers of type 2 diabetic patients

patients	
Variables	Number (%)
Sex	
-Male	36 (23.4)
-Female	118 (76.6)
Marital status. Caring burden rating	
-Single	29 (18.8)
-Married	124 (80.5)
Duration of illness in the patient	
-<1 year	19 (12.3)
-1-3 year	28 (18.2)
->3 years	105 (68.2)
The relative of caregiver with the patient	
-Child	92 (59.7)
-Spouse	23 (14.9)
-Parent	16 (10.4)
-Other	23 (14.9)
The ability of caregiver to do personal duties alone	
-Low	21 (13.6)
- Moderate	83 (53.9)
-High	50 (32.5)
The daily care requirement	, ,
-Very extensive	22 (14.3)
-Extensive	42 (27.3)
-Low	47 (30.5)
-Very low	22 (14.3)
–Few	21 (13.6)
Severity of caring burden	
-Mild	72 (46.8)
-Moderate	50 (32.5)
-Severe	22 (14.3)
-Very severe	8 (5.2)
Age (mean ± SD, years)	41.86 ± 12.78

N: Number; %: Percent; SD: Standard Deviation

According to the results, the mean scores of caring burden and quality of life of the participants were  $53.49 \pm 21.61$  and  $61.02 \pm 20.71$ , respectively. Also, most of the participants had the moderate caring burden (table 2).

The multivariate regression model with stepwise method showed that quality of life in caregivers of diabetic patients was associated with the care burden, the need for care, and age. The Pearson correlation coefficient for the quality of life and caring burden (Pvalue < 0.001, r = -0.542) were calculated, and it was significant at (Pvalue < 0.001). Care burden and age explaining 45% of the variance in quality of life of diabetic patients. The remained variance is therefore explained by variables outside the scope of this research. The regression model showed that one-unit increase in care burden upgraded the quality of life of family caregivers by 0.419 unit. On the other hand, one-unit increment in care requirement decreased the quality of life of the caregivers by 5.88 units. Furthermore, for each year increase in the age of caregivers, their quality of life increased by 0.311 unit (table 3).

Table 2. The mean and standard deviation of care burden and its subscales in caregivers of patients with type 2 diabetes

Variables	Mean ± standard deviation		
Care burden	53.49 ± 21.61		
Time dependent care burden	14.55 ± 5.73		
Evolutionary care burden	11.13 ± 5.59		

Physical care burden	8.93 ± 4.83
Social care burden	10.47 ± 5.13
Emotional care burden	8.52 ± 4.27

0 10 000	64.02 + 20.74
Quality of life	61.02 ± 20.71
SD: Standard deviation	

Table 3. The role of independent variables on quality of life of caregivers of patients with diabetes in multiple regression model

Variable	В	SE	β	t	Pvalue
Constant value	82.195	7.162		11.477	<0.001
Care burden	-0.419	0.066	-0.415	-6.344	<0.001
Care requirement	-5.887	1.083	-0.345	-5.437	<0.001
Age	0.311	0.105	0.189	2.959	0.004

SE: Standard error; P: Pvalue

### **Discussion**

This study aimed to investigate the relationship between care burden and quality of life in caregivers of diabetic patients. Nowadays, quality of life as an important factor in evaluating the health of patients has been especially addressed by organizations and decision-making centers.<sup>23</sup> Most studies in this area have been conducted exclusively on patients with chronic illnesses, and the family caregivers who are also prone to many illnesses and are considered as hidden patients are often overlooked.<sup>24</sup>

Our results showed that more than half of the caregivers in this study had moderate to moderate-high levels of caring burden. In the study of Salmani et al in 2014 on cancer caregivers, all the participants experienced high levels of care burden.<sup>25</sup> Abbasi et al. (2011) also reported severe care burden in the majority of caregivers of hemodialysis patients<sup>26</sup> which is not consistent with the results of the present study. Health care burden is influenced by a combination of factors such as the chronic course of the disease, the type of disease, care requirement, the frequency of hospitalization and finally socioeconomic factors. In the present study, the mean and standard deviation of the overall quality of life score in our participants was lower than those reported in various studies on healthy Iranians.<sup>27,28</sup> In other words, companions of diabetic patients had a lower than normal quality of life. We found no similar study addressing the quality of life of the caregivers of diabetic patients. Nevertheless, the results of other studies on the quality of life of caregivers of patients with chronic diseases such as cancer, <sup>29</sup> hemodialysis <sup>23</sup> and patients hospitalized in the intensive care unit<sup>30</sup> were consistent with our results.

According to the results of this study, the quality of life of caregivers of diabetic patients significantly increased with age. We found no study on caregivers of diabetic patients; however, Sharifi et al. (2015) who examined the quality of life and its related factors in the families of psychiatric patients showed that older family caregivers had a better quality of life which is similar to our findings.<sup>31,32</sup> In line with the results of this study, Coco and Maldonada (2006) stated that age affected people's perceptions of their quality of life, so that older individuals experienced more satisfaction with their life resulting in a better quality of life. 33 Nevertheless, Kayghobadi et al. (2013) noted no significant relationship between age and quality of life among family caregivers of psychiatric patients<sup>34</sup> which contradicts the results of present study. The differences in the statistical populations and the tools utilized to measure the quality of life can be the probable causes for this difference.

In the present study, there was a significant association between caring burden and quality of life of caregivers of diabetic patients as the quality of life decreased by increasing care burden. This is consistent with the Edili (2018), Bartolo (2010) and Tang (2011) studies. 17,35,36 Rha et al (2015) also declared that care burden alone can explain 30% of the variance in caregivers' quality of life. 15 Considering that a reduction in care burden can improve the quality of life, attitudes, and interaction with patients, it is important to pay attention to the psychological problems of caregivers.

In this study, there was an inverse and significant relationship between quality of life and patients' care requirements in caregivers of diabetic patients. With increasing patients' needs for care, caregivers of patients must spend more time daily and therefore they experience higher care burden <sup>26</sup> lower quality of life. <sup>17</sup>

The findings of this study showed the caring burden had a negative impact on the quality of life of caregivers of diabetic patients. Given the negative impact of the disease on caregivers' quality of life and the importance of caregivers in the health of patients, it is recommended to expand social care and support for these individuals. Accordingly, it is suggested to strengthen the social support network of caregivers including the development of self-help associations.

Among the limitations of the study was its small sample size which limits the generalizability of its findings.

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# **Conflict of Interest**

The authors declare that they have no conflict of interest.

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