

Health-related quality of life and caregiver's burden in patients with chronic diseases: a cross-sectional study

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A – Study Design, B – Data Collection, C – Statistical Analysis, D – Data Interpretation, E – Manuscript Preparation, F – Literature Search, G – Funds Collection

Summary Background. Cancer and type 2 diabetes (T2D), as two groups of prevalent chronic diseases, are associated with different social, economic and emotional consequences, and they can change the quality of life (QoL) of their caregivers.

Objectives. The aim of the present study was to determine the relationship between QoL and the burden on caregivers of patients with cancer and T2D.

Material and methods. This comparative cross-sectional study was conducted on 308 caregivers of patients with cancer and T2D. Data collection tools included a demographic characteristics form, SF-36 quality of life form and care burden inventory (Novak and Guest). Data was collected using the convenience sampling method. Data analysis was then carried out using descriptive and inferential statistics (linear backward stepwise regression method).

Results. The mean age of the caregivers of patients with cancer and T2D was 41.30 ± 13.12 and 41.86 ± 12.78 years, respectively. There was no significant difference between the mean score of care burden and QoL in the two groups of caregivers. There was a significant direct relationship between caregivers' QoL and caregivers' disease and a significant inverse relationship between caregivers' education and caring burden.

Conclusions. Caregivers of patients with chronic diseases suffer from care burden, which negatively affects their QoL; thus, it is recommended to reduce the care burden, increasing their QoL by providing appropriate mental, psychological, and social support. Due to the negative impact of caring burden on caregivers' QoL, care services for chronic patients in developing countries should be strengthened.

Key words: quality of life, caregivers, chronic disease.

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Background

The rapid development of community dynamics, changes in lifestyle and environment and aging of the population have caused chronic non-communicable diseases (NCDs), such as stroke, coronary heart disease, cancer, diabetes mellitus, hypertension, dyslipidemia, obesity and chronic lung disease, to become the main cause of death worldwide [1]. The term 'chronic disease' here covers a wide range of professional communities (i.e. medical, public health, academic and political). For example, the Center for Disease Control (CDC) classifies heart disease, stroke, cancer, type 2 diabetes (T2D), obesity and arthritis as chronic diseases [2]. Three-fifths of deaths are attributable to four major non-communicable cardiovascular diseases, i.e. cancer, chronic lung diseases and diabetes [3]. The World Health Organization (WHO) estimates that 60% of all deaths can be attributed to chronic diseases, of which 70% occur in low and middle-income countries [4].

NCDs killed 287 thousand people in Iran in 2016. The rising trend of the number of disability-adjusted life years (DALYs) over the past decades poses a serious threat to Iran. Not only do NCDs lead to premature death, but they also cause significant dis-

abilities [5, 6]. Among chronic diseases are diabetes and cancer, which have been on the rise in recent years [7, 8]. Chronic diseases, including chronic physical and mental illness, while altering certain aspects of a patient's life, while altering certain aspects of a patient's life impose different diseases, responsibilities and difficulties on their families and caregivers at home or in hospital [9, 10]. Caring burden is one of these difficulties, which is defined as a type of distress that caregivers experience while providing care for their patients [11]. Caring burden affects caregivers' quality of life (QoL) and may reduce care services or deteriorate conditions for patients with chronic illnesses. The deterioration of the patient's condition can increase the caring burden and cause a vicious cycle, and if timely intervention is not made, it may drive caregivers to a gradual burnout [12].

QoL is a multidimensional concept that is dependent on many aspects, such as cultural, social, economic and environmental factors. The perennial burden of the disease and patient care exerts negative effects on caregivers' QoL. As the need for family caregivers is on the increase, more studies must be carried out on the QoL of these caregivers [13]. Many factors affect caregivers' QoL, including caregivers' age, level of education, religious beliefs, emotional distress, insurance coverage, as



well as patient's age (where they are younger than caregivers) [14]. Some other factors which are of similar importance are the caregiver's mental status, patient's poor mental health, like depression and anxiety, social support, marital status, personal and social functions and performance and the severity of the patient's symptoms [15–20].

Previous studies have investigated the caring burden and QoL in caregivers of chronic patients with diseases such as T2D and cancer. Bamari et al., for example, reported a moderate level of caring burden in caregivers of diabetic patients [21]. Ogunmodede et al. also indicated that many caregivers of patients with T2D experienced a caring burden and psychological distress [22]. Moreover, Parizad et al., in a study in Iran, showed that diabetes and its complications imposed a heavy economic burden on patients and their families and decreased their QoL [23]. According to the results of Costa et al.'s study, family caregivers of patients with T2D were prone to dysphoria and a sense of aloofness, thus experiencing poorer QoL [24]. In a study on the caring burden and its related factors on QoL in caregivers of patients with lung cancer, Li et al. referred to the caring burden as a factor negatively affecting caregivers' QoL [16]. Safaeian et al., in their study on the relationship between caring burden and depression, anxiety and stress in family caregivers of cancer patients in Iran, showed that more than half of the caregivers experienced a high caring burden, and there was a positive and significant relationship between caring burden and caregivers' depression, stress and anxiety [25]. Families play a key role in supporting their patients and providing them with care during chronic diseases. The emergence of new care needs, including physical and mental needs in the patient and their family, the experience of long-term stress and lack of similar research in this area were the major reasons why we conducted the present study.

Objectives

The present study aims at determining and comparing the relationship between caring burden and the QoL of caregivers of patients with cancer and diabetes.

Material and methods

Design

The present study used a descriptive, correlational study and was carried out to investigate the relationship between QoL and the caring burden of caregivers of patients with cancer and diabetes in 2018.

Participants

The study population consisted of 308 caregivers of patients with chronic diseases, including caregivers of patients with cancer and T2D who referred to the Imam Hossein Hospital (the only regional referral center). Inclusion criteria include a definitive diagnosis of cancer or diabetes made by the physician and the caregivers of first degree relatives or those in charge of the patient's care. Exclusion criteria included psychiatric disorders and psychiatric medication use in caregivers.

The sample size was calculated at 25 individuals in each group according to the studies of Li et al., who obtained a mean caring burden of 21.98 ± 1.35 and 21.08 ± 0.52 [26] in each group with $\alpha = 5\%$ and power of 85%. Awadalla et al. also calculated a sample size of 140 individuals with a mean QoL score of 7.3 ± 1.8 and 7.9 ± 1.5 in each group [27] considering the 15% probable samples loss, the total sample size was calculated at 330 individuals in the present study ($n = 165$ individuals per group). A total of 330 patients were included in the present study after examining their hospital records and being diagnosed with cancer or T2D by a physician. The closest caregiver was identified

for each patient during patient interviews. Thirteen caregivers were not evaluated during the study due to their inaccessibility, five caregivers were excluded due to their unwillingness to participate in the study, and four caregivers due to submitting incomplete questionnaires.

Study instruments

After obtaining the needed permissions from participants, QoL, demographic characteristics and caring burden were assessed using a demographic data form, short-form 36 (SF-36) questionnaires and the care burden inventory [28]. The demographic form including age, gender, education, marital status, economic status, caregiver's occupational status, caregiver's relationship with the patient, duration of disease, duration of daycare needed, presence of chronic diseases (chronic respiratory, cardiovascular or metabolic disease) in the caregiver and the monthly income of the caregiver.

The SF-36 questionnaire, which was used to assess QoL, consists of three items and assesses eight domains of physical functioning, social functioning, role limitations due to physical health, role limitations due to emotional problems, emotional well-being, pain, energy/fatigue and general health. The SF-36 questionnaire also provides two general measures of one's physical and mental dimensions of functioning. The possible score range is 0 to 100, with the higher scores indicating better QoL [29]. The reliability of the quality of life questionnaire has been evaluated in Iran by using internal consistency and reliability by means of known group comparisons and convergent validity. Internal consistency analysis showed that the Persian version of the SF-36 questionnaire had a minimum standard reliability coefficient of 77–90% [30, 31].

The caring burden inventory [28] consists of 24 items. The questionnaire consists of five subscales (including Time Dependence Burden, Developmental Burden, Physical Burden, Social Burden, and Emotional Burden). The caregiver's answer to each question is scored based on a 5-point Likert scale (ranging from completely wrong to completely true). The possible score range is 24 and 120, with scores of 24–47, 48–71, 72–95, 96–120 showing mild, moderate, severe and very severe caring burden, respectively. This questionnaire has acceptable reliability, and Cronbach's alpha values for the total questionnaire were reported at 0.80, and four subscales ranged from 0.69 to 0.87 [32]. The Persian version of this caring burden questionnaire has been validated by Abbasi et al., and the Cronbach's alpha coefficient of the total scale has been reported to be 0.90, and the alpha coefficients of the subscales ranged from 0.76–0.82 [33].

Data analysis

Data was analyzed using descriptive and inferential statistics (linear backward stepwise regression method). A p -value < 0.05 was considered as the significance level in all tests.

Ethical consideration

The present study was approved by the Research Council of Shahroud University of Medical Sciences (96105) and the Ethics Council of Shahroud University of Medical Sciences (Ir.SHMU.REC.1396.100).

Results

The majority of caregivers (68.5%) were female (Table 1). The mean age of the caregivers of patients with cancer and T2D was 41.30 ± 13.12 and 41.86 ± 12.78 years, respectively. The results showed a significant difference between the two groups in terms of duration of disease ($p < 0.001$) and chronic disease in caregivers ($p = 0.010$). Additional information is shown in Table 1.

Variable		Caregivers of patients with type 2 diabetes <i>n</i> (%)	Caregivers of patients with cancer <i>n</i> (%)	<i>p</i>
Gender	male	36 (23.4)	46 (29.9)	0.197
	female	118 (76.6)	108 (70.1)	
Marital status	single	29 (18.8)	30 (19.5)	0.907
	married	124 (80.5)	124 (80.5)	
Level of education	illiterate	30 (19.5)	24 (15.6)	0.243
	high school	49 (31.8)	42 (27.3)	
	diploma	43 (27.9)	41 (26.6)	
	college education	31 (20.1)	46 (29.9)	
Employment status	employed	53 (34.4)	44 (28.6)	0.674
	unemployed	92 (59.7)	94 (61.0)	
	student	9 (5.8)	10 (6.5)	
Duration of diagnosis in patient	less than 1 year	19 (12.3)	87 (56.5)	< 0.001
	1 to 3 years	28 (18.2)	41 (26.6)	
	more than 3 years	105 (68.2)	21 (13.6)	
Relationship with patient	child	92 (59.7)	82 (53.2)	0.553
	spouse	23 (14.9)	32 (20.8)	
	parents	16 (10.4)	17 (11.0)	
	other	23 (14.9)	22 (14.3)	
Chronic disease in the caregiver	yes	49 (31.8)	29 (18.8)	0.010
	no	105 (68.2)	124 (80.5)	
Income	low	60 (39.0)	58 (37.7)	0.586
	medium	92 (59.7)	88 (57.1)	
	high	1 (0.6)	3 (1.9)	
Caregiver's ability to do personal things	low	21 (13.6)	23 (14.9)	0.516
	medium	83 (53.9)	73 (47.4)	
	high	50 (32.5)	58 (37.7)	
Daily care	very much	22 (14.3)	22 (14.3)	0.465
	much	42 (27.3)	52 (33.8)	
	low	47 (30.5)	48 (31.2)	
	very little	22 (14.3)	17 (11.0)	
	rarely	21 (13.6)	13 (8.4)	
Caregiver's burden	mild	72 (46.8)	55 (35.7)	0.190
	moderate	50 (32.5)	67 (43.5)	
	severe	22 (14.3)	23 (14.9)	
	very severe	8 (5.2)	8 (5.2)	
		Mean (\pm SD)	Mean (\pm SD)	
Age		41.86 \pm 12.78 Min = 17; Max = 72	41.30 \pm 13.12 Min = 16; Max = 84	0.710

n – number, % – percent, SD – standard deviation.

Developmental burden ($p = 0.027$) and the social functioning subscale of QoL ($p = 0.020$) were significantly different in caregivers of T2D and cancer patients, but there was no significant difference between the two groups in terms of the total score of caregiving' caring burden and QoL and other subscales (Table 2).

The linear backward stepwise regression method showed that 38.6% of the variance of QoL can be explained by the variables within the model (Table 3). It should be noted that caring burden alone accounts for 28.1% of the variance of QoL. Additional information is shown in Table 3.

Variables	Caregivers of patients with type 2 diabetes	Caregivers of patients with cancer	<i>p</i>
	Mean (SD)	Mean (SD)	
Caring burden	53.49 (21.61)	55.85 (20.33)	0.326
time dependence burden	14.55 (5.73)	15.49 (5.74)	0.153
developmental burden	11.13 (5.59)	12.53 (5.44)	0.027
physical burden	8.93 (4.83)	9.24 (4.39)	0.554
social burden	10.47 (5.13)	10.20 (5.04)	0.643
emotional burden	8.52 (4.27)	8.34 (4.11)	0.704

Variables	Caregivers of patients with type 2 diabetes	Caregivers of patients with cancer	p
	Mean (SD)	Mean (SD)	
Quality of life	61.02 (20.71)	59.79 (19.65)	0.593
physical health	61.14 (22.70)	61.39 (22.42)	0.923
mental health	60.75 (21.46)	58.18 (20.87)	0.288
physical function	66.14 (27.90)	66.75 (29.60)	0.853
Role limitations due to physical health	62.17 (36.63)	65.74 (33.81)	0.375
Role limitations due to emotional problems	57.29 ± 41.26	57.57 (40.56)	0.953
Energy/fatigue	57.35 (20.09)	54.93 (22.19)	0.318
Emotional well-being	61.15 (19.58)	59.27 (22.99)	0.418
Social functioning	67.35 (24.20)	60.95 (23.45)	0.020
Pain	61.57 (29.03)	60.42 (31.05)	0.737
General health	54.22 (17.06)	52.66 (18.03)	0.437

SD – standard deviation.

Variable		β	SE	T	p
Constant value		157.72	18.30	8.61	< 0.001
Gender	female (ref)				
	male	-3.589	2.603	-1.483	0.139
Chronic disease in the caregiver	no (ref)				
	yes	4.976	2.275	2.188	0.030
Employment status	unemployed (ref)				
	employed	1.103	2.569	0.429	0.261
	student	10.671	4.126	2.586	0.010
Income	low (ref)				
	medium	4.935	2.095	2.356	0.019
	high	9.663	8.581	1.126	0.261
Caregiver's burden	mild (ref)				
	moderate	-11.168	2.184	-5.113	< 0.001
	severe	-23.538	2.914	-8.077	< 0.001
	very severe	-32.180	4.653	-6.916	< 0.001

SE – standard error, p – p-value.

Discussion

Descriptive data of this study showed that the majority of caregivers were women (73.4%), which confirmed similar data in previous studies [34]. Female caregivers [35] seem to experience significantly less stress than male caregivers, so they can play an effective caring role [36].

According to the results of the present study, the disease duration in cancer patients was significantly shorter than those with T2D, which may be due to differences in the severity of mortality of cancer and T2D. In this regard, Saadat et al. found in their cohort study in Iran that cancer and diabetes were among the third and eighth leading causes of mortality in Iran, respectively [37]. Another possible reason for this result may be late cancer diagnosis, especially as poor public awareness of cancer symptoms is considered to be the main cause of a late diagnosis [38].

The results of the current study also demonstrated that the risk of chronic diseases in caregivers of patients with T2D was significantly higher than caregivers of patients with cancer. Alves Costa et al. found that chronic diseases affected different life aspects of caregivers of patients with T2D, including their QOL, and further reported that those who were not sufferers from chronic diseases were better QoL predictors [39]. The findings of this study revealed a significant difference between the two groups of caregivers in terms of the developmental car-

ing burden subscale, where caregivers of cancer patient had a higher subscale. A developmental caring burden reflects the caregiver's departure from the peer group and conveys a feeling of being left behind, which is a corollary of their patient care. Spending more time on patient care means that caregivers are pressed for time to socialize and participation in leisure activities. Consequently, reduced leisure time and a lack of social activities may have a negative impact on their own lives, which may lead to a greater caring burden [40]. The QoL subscale was also significantly lower in caregivers of cancer patients in the social functioning dimension. Social functioning is a type of mental state in which individuals can understand the social activities of others and can ensure that they participate in social activities normally and effectively [41]. Consistent with these results, it can be stated that non-socio-physical stressors can also cause significant changes in social functioning [42, 43].

These results highlight the importance of social support and the role that social support plays in improving the social performance of caregivers, and according to Dębska's findings, the level of burden determines the need for support. It has been observed that as the level of the caregiver's burden increases, the need for support also increases [44].

Since cancer patients need more care time compared to patients with T2D, cancer-patient caregivers also need to spend more time on caring for their patients and accompanying them, and therefore they will have less time to devote to themselves

or to spend with others, which will ultimately lead to a decrease in social activities and a more severe decline in QoL. In other words, caregivers of cancer patients experience poorer QoL than caregivers of T2D in regard to the social functioning dimension. Evidence suggests that caring for a cancer patients has a negative impact on caregivers' health and well-being and leads to a decrease in their QoL [45].

The results of this study showed a significant and direct relationship between chronic diseases and caregiver's QoL. Contrary to the findings of the present study, the results of a study aimed at examining the QoL of family caregivers of cancer patients in Turkey demonstrated that caregivers with chronic diseases reported lower QoL [46]. The results of Alves Costa et al.'s study, which aimed to determine the QoL predictors and modulators in caregivers of diabetic patients with amputated legs, showed that the absence of a disease in a caregiver predicts a better QoL for them. The possible reason for the difference between the results of the present study and those mentioned earlier in this study may be due to the cultural differences in the studied communities, as well as a better understanding of patients and their problems by caregivers. In addition, caregivers who suffer from diseases themselves would better understand their patients' tough situations compared to other caregivers without diseases [39].

The findings of the present study also revealed that educated and employed caregivers had a significantly better QoL than those who were uneducated and unemployed. The results of a study in Iran showed that the QoL of caregivers of cancer patients was significantly related to their job status [47].

Another finding of this study was that middle-income caregivers had better QoL than low-income caregivers. Hacialioglu et al. found that caregivers of cancer patients who had higher incomes experienced better QoL [46]. In a study aimed at assessing the QoL of caregivers of cancer patients hospitalized at home, Cubukcu et al. also found a direct relationship between higher income and better QoL [48].

The results of the present study also demonstrated that increasing caring burden predicted a decrease in QoL, and an increase in caring burden would lead to a decrease in a caregiver's QoL, which is consistent with studies by Adili et al. [49], Farzi et al. [50], Bartoszek et al. [51] and Young et al. [52].

The importance of this study lies in the social and cultural differences between Iran and many other countries. The multi-

axial model suggests that the social and cultural context of coping plays an important role in an individual's relationship with their families, religious institutions, employment organizations, charitable institutions, neighborhoods and ethnic groups [53, 54]. Therefore, relationships between care recipients and caregivers may vary depending on cultural values and the societal context [55]. Family caregiving (informal and home care) for patients with chronic diseases has become an increasingly important issue in all parts of the world, including North African and the Middle Eastern countries like Iran [56]. Preserving a heritage of oriental origin, Iranians tend to respect their parents and abide by familial rules, which maintain family honor and dignity. An emotional closeness and tight networks still exist, and family support is often normative and ordinary in Iranian culture.

Limitations of the study

The present study has some limitations, including being cross-sectional, using a low sample size for generalization to larger populations and investigating just two chronic diseases (cancer and T2D). Chronic diseases need to be thoroughly and concurrently investigated to capture more extensive data and to do a more accurate assessment. Moreover, the present study only investigated caregivers' monthly income; thus, it is recommended that secondary sources of income, such as financial support by rare-disease associations, etc., be studied in future research. Further details of patients, such as the stage of cancer in cancer patients and the presence of diabetic ulcers and amputated feet in patients with T2D, were not controlled. However, the results of the current study yielded important findings for further investigation.

Conclusions

This study showed that caring burden has a negative impact on the QoL of caregivers of patients with cancer and T2D. Considering the negative impact of the caring burden on caregivers' QoL and the important role of caregivers in the health care of patients, it is recommended that social care not be focused solely on patients but that caregivers also receive optimal social support.

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