

## Supportive and Palliative Care in Cancer

# Investigating the Mediatory Role of Hope and Shame in the Relationship between Caregiver Burden and Quality of Life of Patients with Cancer

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## Abstract



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### Keywords

- ▶ cancer
- ▶ caregiver burden
- ▶ hope
- ▶ oncology
- ▶ quality of life
- ▶ shame

**Objective** Patients suffering from cancer need to receive care from their family; however, their family caregivers do this without preparation or training, so their involvement in patients' care results in a caregiving burden that may affect patient's hope and quality of life (QOL).

**Materials and Methods** This study examines the effect of caregiving burden on the QOL of cancer patients ( $n = 100$ ) with the mediatory role of hope and shame. To achieve this, Persian versions of Zarit Burden Interview, the World Health Organization QOL, Herth Hope Index, and Guilt and Shame Proneness Scale were used. Meanwhile, path regression analysis was implemented to analyze the relationship between caregiving burden and QOL.

**Results** The results implied a relation among caregiver burden, hope, and QOL of patients diagnosed with cancer. It was found that there is a direct and negative relationship between caregiver burden and hope. In addition, there was an indirect and positive relationship between caregiver burden and QOL. Hope and QOL also had a high correlation. Besides, it was shown that there was a negative relationship between the shame experienced by patients and their hope and QOL.

**Conclusion** caregiver burden was proved to be influential and negatively affected the factor for the QOL. Besides, patients' hope decreases while caregiving burden increases; this will in turn affect patients' recovery and their physical, mental, and cognitive functions. This study provides a foundation for future research in this critical area for oncology.

## Introduction

Cancer is a chronic disease that results in considerable, permanent, and variable needs and problems for patients. Because the unit of care in cancer care is the patient and family,<sup>1</sup> investigation of the mutual effects of patient and caregiver relationship is of great significance in the process of sickness, therapy, and recovery.

Care is something that is neither predictable nor selected by people. When someone is confronted with cancer diagnosis

and therapy, his/her family members feel a high responsibility toward caregiving.<sup>2</sup> Moreover, they are committed to offer infinite care and support.<sup>3</sup> However, family members accept this responsibility with low or no training and limited resources.<sup>4</sup> Caregiver burden is defined as the cognitive evaluation of the multidimensional response to demands and their consequences within the context of the evolving caregiving experience.<sup>5</sup> Regarding cancer, the following variables are shown to be effective in the responsibility of caregiver: caregiver age and sex, relation to care receiver, and duration

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of care preparation.<sup>6</sup> Caregiver burden includes physical burden,<sup>7</sup> psychological burden,<sup>8</sup> social burden,<sup>8</sup> and financial burden.<sup>9</sup> Physical burden such as sleep disturbance, fatigue, and pain are often experienced by caregivers.<sup>7</sup> Providing emotional support to patients and helping cancer patients to deal with their feelings about cancer are considered as psychological commitments.<sup>8</sup> Lack of employment due to caregiving activities and taking care of others besides cancer patients are known as social responsibilities.<sup>10</sup> Financial burden might include high medical expenses, loss of income, and savings.<sup>8</sup> In an extensive review of literature, Schulz et al reviewed 41 studies and reported high physical and psychological distemper of caregivers compared with normal populations or control group.<sup>11</sup> In fact, most of the psychological distress levels reported by caregivers are comparable or even more than those experienced by care receivers.<sup>12</sup>

This study tries to identify whether the caregiver's distress affect the patient? if yes, how? It is assumed that caregiver burden affects patients' hope and QoL. Furthermore, it is predicted that patients can keep and raise their hope to control their environment, be less dependent on the caregiver, and recover faster. Recent studies have also shown that quality of life (QOL) can offer distinct prognostic information as a predictor for the recovery duration of different types of cancers.<sup>13</sup>

As a dynamic and multidimensional structure, hope is affected by various factors, and it is defined as the likelihood of better future than a hard and uncertain present.<sup>14</sup> Identifying factors that influence the hope of newly diagnosed cancer patients is of great importance as hopelessness is a risk factor that may lead to suicide,<sup>15</sup> depression, and tendency to early death<sup>16</sup> in cancer patients. Energy and pain levels are among the physical features effective in hope. Energy is considered one of the features of hope, and it is discovered that low energy has a significant relation to hope.<sup>17</sup> The involvement of pain in the daily life of cancer patients has an inverse relation to their level of hope.<sup>18</sup> It is also found that psychological factors such as depression and anxiety are related to hope.<sup>19</sup> An integrative literature review conducted by Lin and Bauer-Wu<sup>20</sup> identified that living with hope and goal is the main element of psychospiritual well-being in terminal patients. Moreover, with this enhanced sense of psychospiritual well-being, patients can face a terminal disease more effectively.

The life quality of cancer survivors shows their therapy pattern and psychophysical functions that may be used to discover patients' subgroups in need of more surveillance and directive perspectives for patient-based interventions after the completion of cancer therapy.<sup>21</sup> Although most cancer survivors cannot retain their physical, psychological, and social functions as before cancer therapy, some specific subgroups of them are at risk of decreased QOL even after 5 years of early diagnosis.<sup>22</sup>

It also seems that caregivers' negative evaluation, whether real or as perceived by patients, may lead to the feeling of shame in the very same patients. Hence, in individuals suffering from cancer who have low ability to control life events, behavioral compensation is not possible, negative evaluation of caregiver is predictable, and feeling shame is inevitable. Thus, studying the effect of the shame felt by the patient on hope and QOL elements is another goal of this research.

The feeling of shame has been studied in psychological theories and has been implicated in lots of psychopathological conditions. Shame is associated with a general punitive judgment of the self, which results in an intense emotional response and a tendency to withdraw and hide.<sup>23</sup> Shame is also defined as a self-conscious negative emotion about self or personal self-blame.<sup>24</sup>

## Conclusion

This study is a novel and important step to exploring the role of shame and hope as cardinal features in the cancer patients' experiences and presenting a composite picture of their quality of life affected by caregiver burden.

## Methods

This research was conducted with patient-caregiver dyads to identify the different views of cancer patients and their caregivers. The patients and caregivers were allowed to complete the research form in multiple settings as needed and to ask assistance from a friend or an intimate person to answer the questionnaire. The patients' form and caregivers' form needed 15 minute and 5 minutes to be completed, respectively. They included valid survey tools and demographic information. The medical reports of patients were not evaluated. In fact, information reported by the individuals themselves was used. The inclusion criteria for patients were (1) older than 18 years, (2) being diagnosed with cancer, (3) being under therapy or follow-up at present, and (4) being in an appropriate physical and mental state to fill the questionnaire. A caregiver was defined as a family member or a close relative who had the highest responsibility to take care of the cancer patient and spend most of his or her time with the patient. Caregivers younger than 18 years or those with severe cognitive disorder were disregarded from the research.

The following four valid questionnaires were used in this study.

### Zarit Burden Interview

Zarit<sup>25</sup> was the first author who offered an operational definition of caregiver burden. He designed a tool called Zarit Burden Interview (ZBI) for evaluating perceived caregiver burden. It consists of 22 questions that are rated on a scale from 0 to 4 based on the presence or severity of positive response. It measures caregiver health, psychological well-being, social life, financial status, and patient-caregiver relationship. The ZBI is translated into many languages, and its internal consistency is reported between 0.85 and 0.94.<sup>26</sup>

### Guilt and Shame Proneness Scale

The Guilt and Shame Proneness Scale<sup>27</sup> is a 16-item, 7-point scale (1 = very unlikely and 7 = very likely), which measures individuals' variance in the tendency to experience guilt and shame. It consists of four subscales of guilt-negative behavior evaluation, guilt-repair, shame-negative self-evaluation (NSE), and shame-withdraw. The  $\alpha$  coefficients tend to show lower reliability in scenario-based measures because each

item consists of a unique variance for the scenario<sup>28</sup>; thus, the reliability was in the range of 0.61 to 0.69.<sup>27</sup> In this study, shame subscales were only used and guilt subscales were removed as they were not related to the study purpose.

### Quality of Life-C 30

QOL<sup>29</sup> is a questionnaire designed by the European Organization for Research and Treatment of Cancer to measure the physical, mental, and social functions of cancer patients. It consists of five functional domains, three sign scales, a general health domain, and six individual items. The internal reliability of the questionnaire obtained by Cronbach's  $\alpha$  is in the range of 0.56 to 0.85 and 0.84 in Cankurtaran et al's research<sup>30</sup> and Tan et al's research,<sup>31</sup> respectively.

### Herth Hope Index

The Herth Hope Index<sup>32</sup> is a 12-item, 4-point Likert scale (1 = completely disagree and 4 = completely agree) that was designed to evaluate the rate of hope in adults based on clinical cases. It suggests three factors of hope namely (a) temporality and future, (b) positive readiness and expectancy, and (c) interconnectedness. The total rate is in the range of 12 to 84. Higher rates imply higher levels of hope. The  $\alpha$  coefficient was 0.97 with a 2-week test-retest reliability of 0.91.

## Results

Patients and caregivers are considered as a dyad when the two parties are willing to participate in the study and only after they have completed the consent form consciously and separately. Patients and their caregivers were evaluated by a trained interviewer in the hospital. The goal and research process were explained by the interviewer. Of 176 dyads requested to participate, 141 dyads accepted (participation rate: 80.11%). If there was any nonreplied item in the questionnaire, those dyads were omitted from the analysis ( $n = 41$ ). As a result, 100 dyads were included in the final analysis. For this study, patients were selected from Namazi and Shahid Mohammadi Hospital in Shiraz and Bandar Abbas, respectively.

The patient characteristics are summarized in **Table 1**. The current study was conducted on 46 men and 53 women (1 missing), with the diagnosis of cancer. In the "severity" section, much data were not completed that may be due to the low education level of the patients and their lack of awareness of their status. In addition, the percentage of cancer type among participants is summarized in **Table 1**. According to **Table 1**, leukemia and liver cancer had the most and the least plentitude among the study individuals, respectively.

The mean, standard deviation, and correlation of research variables are summarized in **Table 2**. According to **Table 2**, there is a significant correlation among exogenous, endogenous, and mediator variables, which made analysis completion possible. The direct and indirect effects are summarized in **Table 3**. **Fig. 1** shows the relationships between the variables and the coefficients of the fitted model. The fitted indices obtained by route analysis employing maximum likelihood method showed the appropriate fitness of the pattern

**Table 1** Patient characteristics ( $n = 100$ )

Characteristic	Value
Age (y), mean $\pm$ SD (range)	45.1 $\pm$ 16.3 (21–80)
Sex, $n$ (%)	
Male	46 (46)
Female	53 (53)
Marital status, $n$ (%)	
Married/living with partner	66 (66)
Single/separated/divorced/widowed	34 (34)
Education level, $n$ (%)	
Primary education	34 (34)
High school	31 (31)
University	24 (24)
Other/unknown/uneducated	11 (11)
Tumor classification, $n$ (%)	
Leukemia	47 (47)
Prostate	5 (5)
Breast	19 (19)
Liver	1 (1)
All others	28 (28)
Severity, $n$ (%)	
Low	35 (35)
Mediate	26 (26)
High	32 (32)
Unknown	7 (7)
Time since diagnosis, years (range)	1.1 (0.08–11)
Signed informed consent for participation, $n$ (%)	
Yes	89 (89)
No	11 (11)

Abbreviation: SD, standard deviation.

with data (Goodness-of-Fit Index (GFI) = 0.99, Comparative Fit Index (CFI) = 0.99, Adjusted Goodness-of-Fit Index (AGFI) = 0.94, Incremental Fit Index (IFI) = 0.99, Root Mean Squared Error of Approximation (RMSEA) = 0.03, and Normed Chi-Square (CMIN/DF) = 1.07).

Caregiver burden negatively correlated with hope ( $r = -0.28$ ,  $p < 0.01$ ) (**Table 2**). Moreover, in the model, hope ( $\beta = -0.22$ ) and QOL ( $\beta = -0.10$ ) both formed strong relations with caregiver burden (**Table 3** and **Fig. 1**).

Hope and shame-NSE subscale positively correlated with each other ( $r = 0.22$ ,  $p < 0.05$ ) (**Table 2**). Furthermore, hope negatively correlated with shame-withdraw subscale ( $r = -0.20$ ,  $p < 0.05$ ) (**Table 2**). QOL was found to be statistically correlated ( $r = 0.34$ ,  $p < 0.01$ ) (**Table 2**) and strongly related with hope ( $\beta = 0.35$ ) (**Table 3** and **Fig. 1**).

Factors that positively correlated with shame-NSE subscale were QOL ( $r = 0.20$ ,  $p < 0.05$ ) and shame-withdraw subscale ( $r = 0.25$ ,  $p < 0.05$ ) (**Table 2**). The model suggests a positive regression between shame-NSE and shame-withdraw subscales ( $\beta = 0.28$ ) (**Table 3** and **Fig. 1**).

**Table 2** Mean, standard deviation, and correlation matrix

Study Variables	Mean ± SD	1	2	3	4	5
1. Shame–NSE	20.89±5.54	1				
2. Shame–withdraw	14.64 ± 5.17	0.255 <sup>a</sup>	1			
3. Hope	37.72 ± 5.77	0.223 <sup>a</sup>	-0.201 <sup>a</sup>	1		
4. Caregiver burden	33.72 ± 9.60	-0.112	0.177	-0.287 <sup>b</sup>	1	
5. QOL	-45.07 ± 16.13	0.205 <sup>a</sup>	-0.100	0.349 <sup>b</sup>	-0.188	1

Abbreviations: QOL, quality of life; shame–NSE, shame–negative self-evaluation; SD, standard deviation.

<sup>a</sup> $p < 0.05$ .

<sup>b</sup> $p < 0.01$ .

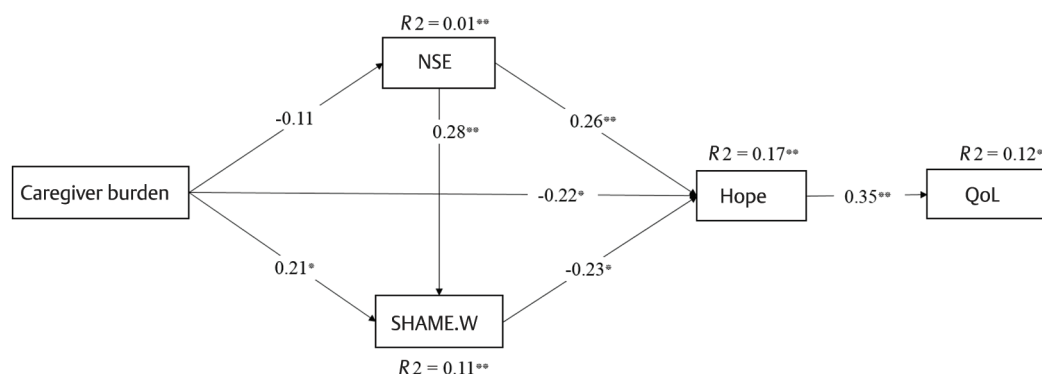
**Table 3** Direct and indirect effects of variables

Path	Direct effect	Indirect effect	Total effect
Caregiver burden			
Shame–NSE	-0.11	-	-0.11
Shame–withdraw	0.21	-0.3	0.18
Hope	-0.22 <sup>a</sup>	-0.07 <sup>a</sup>	-0.29 <sup>b</sup>
QOL	-	-0.10 <sup>b</sup>	-0.10 <sup>b</sup>
NSE			
Shame–withdraw	0.28 <sup>b</sup>	-	0.28 <sup>b</sup>
Hope	0.26 <sup>a</sup>	-0.06 <sup>a</sup>	0.20
QOL	-	0.07	0.07
Shame–withdraw			
Hope	-0.23 <sup>a</sup>	-	-0.23 <sup>a</sup>
QOL	-	-0.08 <sup>a</sup>	-0.08 <sup>a</sup>
Hope			
QOL	0.35 <sup>b</sup>	-	0.35 <sup>b</sup>

Abbreviations: QOL, quality of life; shame–NSE, shame–negative self-evaluation.

<sup>a</sup> $p < 0.05$ .

<sup>b</sup> $p < 0.01$ .



\*\* $p < 0.01$  \* $p < 0.05$

**Fig. 1** Structural equation model to assess the predictive manner of quality of life based on caregiver burden with the mediatory role of hope and shame. The one-headed arrow indicates a directional relationship between two variables. The number next to the arrow represents the relationship ( $\beta$ ). NSE, negative self-evaluation; QoL, quality of life.

Descriptive statistics were implemented to assess demographic information and clinical characteristics. Data analysis was performed by using IBM Corp. Released 2015. IBM SPSS Statistics for Windows, Version 23.0. Armonk, NY, USA: IBM Corp. SPSS Statistics 23.0 for Windows and Amos Graphics Arbuckle, J. L. (2014). Amos (Version 23.0) [Computer program]. Chicago, USA: IBM Corp. 23.0 for Windows. To evaluate the validity of the research tool, Cronbach's  $\alpha$  was used that was estimated to be over 0.70 for all questionnaires.

Before parametric statistical analysis, the data were analyzed with regard to consistency to substructural premises of this type of analysis. These premises are as follows: analyzing missed data, evaluating the normality of variables' data distribution, estimating outlier values' data, and the linearity of variables' relation.<sup>33</sup> For measuring missed values and their probable pattern, missing value analysis algorithm was used. No missing values were found in any of the measures.

For the evaluation of variables' data normality, Kolmogorov-Smirnov and Shapiro-Wilk tests were used besides histogram diagram. According to the results, only the data of QOL and shame-withdraw variables followed normal distribution. For the variables that did not follow a normal distribution, data were transformed by Rankit formula<sup>34</sup> and logarithm.<sup>33</sup> After that, the distribution of hope and caregiver burden grades was normalized by using Box plot.<sup>33</sup> The outlier data recommended by Munro et al<sup>35</sup> were corrected regarding the closest data to the outliers. The last step in data evaluation was investigating the premises of linear relation among the research variables. The presence of a linear relation among the variables was approved by a Scatter plot.

## Discussion

The current study was performed to investigate the predictive model of QOL and hope based on caregiver burden and shame perceived by the patients. The suggested model was approved, and the results showed a negative and direct relationship between caregiver burden and hope. They also showed a positive and direct relationship between hope and QOL. The research hypothesis implied that caregiver burden predicts hope in patients with cancer and hope predicts their QOL. Shame was also significantly related to hope and QOL. Caregivers of cancer patients report that they spend more time in taking care of the patients and pay more efforts during a shorter period of time, besides they have to tolerate a higher financial burden compared with other caregivers. As a result, the more the patient perceives this burden, the less he/she will recover and the patient's hope will diminish faster. Caregiver characteristics that may lead to increase in burden include lower age,<sup>36</sup> female gender,<sup>36</sup> lower level of education,<sup>37</sup> a mixed relation,<sup>38</sup> and higher levels of anxiety and depression.<sup>39</sup> Consequently, it is predicted that patients who are served by such caregivers have lower hope.

Caregiver burden has a negative and indirect effect on QOL with the mediatory role of hope. QOL includes physical, mental, and social elements of patients. Caregiver burden reduces the general health of patients. Recent studies have shown that QOL can bring a distinctive prognostic information to

predict the recovery period of various cancers. Hence, as the caregiver burden increases, recovery is delayed.

It seems that cancer patients' hope depends on some factors, both physical (e.g., pain and energy level) and mental (anxiety and depression). Cancer patients suffer from physical and mental disturbances. They feel loss of goal, pride, and self-glory. In fact, the hope in the case of cancer care is connected to the hope of treatment. As expected, the high level of hope results in better life quality. Our findings support the outcome of van der Biessen et al.<sup>40</sup>

Shame is known as a disturbing feeling toward personal faults. From another perspective, shame is a self-conscious emotion that is aroused through self-assessment and leads to self-regulation. Shame-NSE subscale items describe bad feelings about oneself. Patients with lower degree in NSE are more likely to have personal disturbance and lower self-respect and self-compassion. They are also more likely to ruminate when they are sad. Consequently, they begin to show depressive symptoms such as disappointment and lower mental and physical performance. Shame-withdraw subscale items describe action tendencies focused on hiding or withdrawing from public. This factor has a direct negative effect on hope and an indirect negative effect on QOL. It is likely that loosing social support due to isolation leads to these negative impacts.

This survey has some limitations. First, convenient sampling restricts the generalization of findings. Second, even though caregiver- and cancer patient-related elements were discovered and implemented in the analyses of the relationship between caregiver burden, hope, and QOL, other dimensions of caregiving such as caregiver challenges, caregiver readiness, family function, and social support that might have had a role in the burden were not studied. Seven caregivers of this study were cancer patients. They were included to provide a general overview on caregiver's burden, but it is probable that their burden and QOL are different from that of other caregivers in this study. It is likely that cancer patients are sometimes their own caregivers, so their unique needs require more scrutiny. It is more helpful to perform studies on a larger population and in different centers to get better insights that support our findings.

Our study showed that cancer patients' hope has a significant relation to their QOL. In addition, we found a negative relationship between caregiver burden, hope, and QOL. This finding should be included in the interventions to offer support and notification. In addition, based on the results, interventions must also be caregiver based so as to help a faster recovery by considering caregiver's needs.

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Nil.

### Conflicts of Interest

There are no conflicts of interest.

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