Burden, resilience, and happiness in family caregivers of spinal cord injured patients

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Abstract

Background: Although, family members face complex problems in caring for patients who suffer from spinal cord injury (SCI), little attention has been paid to burden and its associated factors among family caregivers of patients with SCI in Iran. Therefore, the present study is aimed to explore the relationship between burden, resilience and happiness among family caregivers of patients with SCI.

Methods: A cross-sectional descriptive design was utilized. The samples consisted of family caregivers of 150 patients diagnosed with SCI in Shiraz, the capital city of Fars Province.

Results: Findings showed a significant negative correlation between burden and resilience (r = -0.361, P = 0.000) and a significant negative association between burden and happiness (r = -0.248, P = 0.02). Educational level, happiness and age were factors that predicted caregivers’ burden.

Conclusion: These findings can be a starting point for further research aimed at understanding the nature and causal underpinnings of burden in Iranian family caregivers of persons with SCI. Findings also can benefit policy makers and health care professionals who are to provide support for family caregivers of patients with SCI to diminish their burden.

Key words: burden, family caregiver, happiness, Iran, resilience

Introduction

Nearly 200,000 people in the United States live each day with a disability from spinal cord injury (SCI), with an estimated 11,000 new injuries occurring each year. (1) Unfortunately, the real annual incidence rate of SCI in Iran is not obvious. But, two things are obvious. Firstly, that the most common cause of SCI is motor vehicle crashes. (1) Secondly, previous studies have shown that Iran has too many road traffic injuries. (2) Considering these two facts together, it could be inferred that the incidence of SCI in Iran is high.

After a spinal cord injury occurs, family members often become the primary sources of assistance for various activities of daily living, such as feeding, dressing, transfers, and bowel and bladder care. (3) Often family caregivers enter into this new role without formal preparation or training (4); therefore, they may experience financial strain, psychological and emotional problems. A study by Dreer et al (2007), for example, demonstrated that 15.7% of the family caregivers of persons with SCI had major depression. (5) In another study conducted among parents and spouses/partners of individuals with SCI, participants expressed that there were times when the two responsibilities of work and caregiving conflicted. (6)

Since the 1980s, caregiver burden has been an implicit assumption associated with family caregiving. (7) According to Zarit et al. (1986), burden reflects “the extent to which caregivers perceive their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative”. (8) Theoreticians have distinguished between subjective and objective burden. Whereas subjective burden focuses on the perceived stress...
associated with providing care, objective burden refers to the disruptions in family life and the tasks and activities associated with providing care. (9)

Researchers have sought answers to questions about different aspects of family caregivers’ adjustment to chronic conditions such as a spinal cord injured patient and the burden related to it.

It seems that one of the middle range theories to explain and predict patient and caregiver reaction to chronic illnesses is the resilience theory. According to the theory of resilience, there is a complex interplay among risk factors, protective factors, adaptive outcomes and resilience. (10) Researchers believed that when risk factors are greater than protective factors, people who have been resilient in the past may be defeated. (11)

Resilience has extensively been studied in the context of chronic diseases such as cancer, mental problems and asthma. (12,13,14) However, little attention appears to have been paid to these issues when family members face complex problems in caring of patients who suffer from SCI.

Considering this, the present study aimed to explore the relationship between burden, resilience and happiness among family caregivers of patients with SCI.

The first hypothesis was derived from the theory of resilience. Theoretically, it seemed reasonable that there may be a negative association between resilience and burden among family caregivers.

Thus, the first hypothesis was stated as follows:

**H1:** Family caregivers who report higher levels of resilience will present lower levels of burden.

On the other hand, happiness was considered as an adaptive outcome and it was assumed that family caregivers of patients with SCI experiencing more burden would report a lower level of happiness. It is supposed that happiness can decrease mental illness and the risk of suicide. (15,16) In view of the above-mentioned considerations, the second hypothesis was proposed:

**H2:** Family caregivers who report higher levels of happiness will present lower levels of burden.

**Material and Methods**

A cross-sectional descriptive design was used for testing the hypotheses in this study. Researchers obtained approval for this study from the Research Committee at the Islamic Azad University, Birjand branch, Birjand, Iran. The samples consisted of family caregivers of 150 patients diagnosed with SCI in Shiraz, the capital city of Fars Province. Participants were selected by convenience sampling. The inclusion criteria for caregivers consisted of being (a) designated by a paraplegic patient as a primary caregiver, (b) 18 years of age or older, and (C) able to speak and understand Persian. Only caregivers were included whose patient lived in the community and had a primary diagnosis of paraplegia for at least 12 months.

The participants were informed about the study both orally and in writing and assured of confidentiality and anonymity. They were notified that participation in the study was voluntary and that they could refuse or terminate participation without penalty. Lastly, completed questionnaires were stored securely. It is noteworthy that all the data were collected within a four-week period in 2011.

**Instruments**

**Demographic data form**

Descriptive demographic data were obtained with a form designed for the study. Age, gender, family size, relationship to patient, caring for others besides the patient, employment status, education level, length of time spent as caregiver role for the SCI patient and work status, were collected with this form.

The short version of the Zarit Burden Interview (ZBI), developed by Bedrad et al. (2001), was used for assessing the level of burden. (17) This version of ZBI consists of twelve items, rated from “never” (0) to “nearly always” (4), where higher scores indicate greater burden. This questionnaire was translated by using the back-translation technique. Two bilingual linguistic experts translated the original structure of the questionnaire independently from English into Persian. The experts met and reviewed the Iranian translation together for inconsistencies with the original English form and minor revisions were suggested in some areas. Another linguistic expert back-translated the Iranian version of the questionnaire into English. The back-translated and original forms of the SWLS were compared and found to be highly similar in meaning. After reviewing both translations, the most appropriate terms were selected. In the current research, the short version of the ZBI demonstrated relatively good consistency with a Cronbach’s alpha of 0.7.

**Resilience**

Resilience was measured using the 10-item Connor-Davidson Resilience Scale (CD-RISC). Responses are based upon a 5-point response scale ranging from 0 (not true at all) to 4 (true nearly all the time), higher values reflecting a higher level of resilience. This scale has been shown to have a good internal consistency (Cronbach’s alpha= .085) and construct validity. (18) This scale, like the ZBI, was translated by using the back-translation technique. Subsequently, the most appropriate terms were selected. The Cronbach’s alpha for resilience scale in this sample was .078, indicating good reliability.

**Happiness**

The Memorial University of Newfoundland Scale of Happiness (MUNSH) was used to measure caregiver happiness. This scale includes 24 positively and negatively valenced questions measuring both short-term (affective) and long-term (dispositional) components. Ten of the questions are affect-oriented,
asking how the respondent has been feeling in the past months. The remaining 14 dispositional items query general life experiences, and require the respondent to reflect back on his or her life. Responses are given as “yes”, “no” or “don’t know”. A “yes” response is scored as a 2, a “don’t know” as a 1, and “no” as a 0. Total scores can range from 0 (lowest happiness) to 48 (highest happiness). Previous studies have shown that the MUNSH has had good internal consistency which routinely exceeds Cronbach alphas of 0.8. (19) Test-retest reliabilities of the scale range from \( r = 0.4 \) to \( r = 0.7 \) over 18-48 month intervals. (20) The MUNSH is reportedly appropriate for adults of all ages, and is minimally impacted by social desirability bias. (21) In Iran, this scale has been used in several studies and demonstrated a good reliability. (22,23) The present study found the overall internal consistency of the MUNSH to be good, with a Cronbach alpha of 0.75.

**Statistical analysis**
Statistical analysis was completed using SPSS, Version 15.0. Descriptive statistics (including means, standard deviations, frequencies, and percentages) were calculated to summarize the sample characteristics. Internal consistency of the scales was tested by Cronbach’s alpha. Associations between demographic characteristics and burden, happiness and resilience scores were analyzed by independent t-test and one-way ANOVA. Correlations among burden, happiness and resilience were analyzed by Pearson’s product-moment correlation. Finally, predictors of burden were analyzed by multiple regression analysis. The level of significance was set at \( p < 0.05 \).

**Results**
As shown in Table 1, (next page) most participating caregivers (70%) were female. The mean age of the caregivers was 34.05 ± 6.85 years, with the age ranging from 20 to 53 years. Sixty nine (46%) caregivers were spouses of the patients. The remaining non-spouse caregivers were mothers (36%), fathers (10%), daughters (3.3%), and others (4.6%). The burden, resilience, and happiness mean scores, in respect to the demographic characteristics, are displayed in Table 1.

In this study, the mean burden score was 26.74 (SD= 11.39). Thus, it could be concluded that participants had a moderate burden. Similarly, the mean resilience score was 23.34 (SD= 7.57). Since total score for CD-RISC ranges from 0 to 40, it was obvious that caregivers’ resilience level was moderate. Caregivers also reported moderate scores on the MUNSH (20.71±5.5).

In relation to caregivers’ age, a one-way ANOVA showed that there was a significant difference on the mean scores of the BZI (\( F= 9.03, \) d.f. = 3, \( P= 0.000 \)). Following up this finding with Tukey’s test revealed that caregivers in the age group 47-57 reported the greatest burden score (M= 32.97), followed by those in the age group 36-46 (M= 26.04). The least burden was evident for caregivers in the age group 25-35 (M= 19.07). Also, caregivers at and above age 57 reported having less burden than those in the age group 45-57 (M= 26.74).

Data analysis showed that married participants scored significantly higher on the burden scale (M = 27.22) than single participants (M = 15) (t= 2.15, \( P= 0.01 \)). A significant difference was also found in levels of burden based on educational level (\( F= 6.99, \) d.f. = 2, \( P= 0.000 \)). Tukey’s test showed that caregivers with those with 1-5 years of education had more burden than those with 6-8 years of education (\( P = 0.000 \)).

When examining the mean scores of burden by the number of children, a significant difference between the caregivers was found (\( F= 4.35, \) d.f. = 2, \( P= 0.015 \)). Further analysis demonstrated that caregivers who had 5 or more children reported greater burden (M= 54) compared to those who had 1 or 2 children (M= 36) (P= 0.014).

In respect to relationship to the patients, there was a significant difference in the mean burden score among caregivers (\( F= 3.79, \) d.f. = 2, \( P= 0.02 \)) and results of the Tukey’s post-hoc test indicated that the spouse caregivers had significantly higher scores for burden (M= 27.34) than the daughter or son caregivers (M= 13.2) (\( P= 0.02 \)).

The first research hypothesis was examined using Pearson’s correlation coefficient. Since there was a significant negative correlation between burden and resilience (\( r = -0.361, \) \( P = 0.000 \)), this hypothesis was supported. Furthermore, the correlation between burden and happiness was negatively significant (\( r = -0.248, \) \( P= 0.02 \)). This finding was consistent with hypothesis 2.

Regarding other demographic characteristics of the caregivers and the main variables in this study (burden, resilience, and happiness), data analysis did not reveal any significant finding.

To examine the significant predictors of burden among caregivers’ characteristics, resilience, and happiness, a stepwise multiple regression was conducted. In the first step, the educational level was entered into the model, explaining 14% of the variance in burden. As depicted in Table 2, the entering of happiness as the next variable increased the explained variance to 44%. Finally, in the third step, age was entered into the model and the explained variance increased to 48%.

**Discussion**
The purpose of this study was to investigate the relationship between burden, resilience, and happiness among Iranian family caregivers of patients with SCI. The findings of this study supported the hypothesized relationships. These findings are in line with the findings in other research conducted on burden among caregivers of individuals with different disorders. Similar to our findings, in a study by Chou et al. (1999), caregiving involvement and emotion-focused coping had direct positive effects on caregiving
<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
<th>Burden Mean (SD)</th>
<th>Resilience Mean (SD)</th>
<th>Happiness Mean (SD)</th>
</tr>
</thead>
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<tr>
<td><strong>Gender</strong></td>
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<td></td>
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</tr>
<tr>
<td>Female</td>
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<td>26.19(12.39)</td>
<td>23.31(8.2)</td>
<td>20.39(5.59)</td>
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<td>Male</td>
<td>45(30)</td>
<td>28.02(8.63)</td>
<td>23.42(5.94)</td>
<td>21.46(5.4)</td>
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<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-35</td>
<td>27(18)</td>
<td>19.07(10.68)</td>
<td>23.29(7.06)</td>
<td>22.11(6.02)</td>
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<tr>
<td>36-46</td>
<td>66(44)</td>
<td>26.04(10.82)</td>
<td>23.78(7.24)</td>
<td>21.00(5.36)</td>
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<td>47-57</td>
<td>35(23.3)</td>
<td>32.97(9.46)</td>
<td>22.11(8.00)</td>
<td>18.94(5.24)</td>
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<td>&gt;57</td>
<td>22(14.7)</td>
<td>26.74(11.33)</td>
<td>24.04(8.69)</td>
<td>20.95(5.78)</td>
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<td><strong>Marital status</strong></td>
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<td>Married</td>
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<td>27.22(11.21)</td>
<td>23.21(6.61)</td>
<td>20.78(5.63)</td>
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<tr>
<td>Unmarried</td>
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<td>15(9.95)</td>
<td>26.5(6.34)</td>
<td>19.00(3.63)</td>
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<tr>
<td><strong>Education level</strong></td>
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<td>1-5</td>
<td>68(45.3)</td>
<td>30.69(10.75)</td>
<td>22.86(8.16)</td>
<td>21.04(6.04)</td>
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<td>6-8</td>
<td>25(16.7)</td>
<td>19.84(7.76)</td>
<td>22.84(7.54)</td>
<td>19.92(5.92)</td>
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<td>9-12</td>
<td>43(28.7)</td>
<td>25.37(11.79)</td>
<td>23.27(5.79)</td>
<td>20.20(4.59)</td>
</tr>
<tr>
<td>&gt;12</td>
<td>14(9.3)</td>
<td>24.07(12.03)</td>
<td>26.85(9.23)</td>
<td>22.07(5.66)</td>
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<tr>
<td><strong>Number of children</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2</td>
<td>36(24)</td>
<td>23.88(10.64)</td>
<td>22.41(7.87)</td>
<td>20.72(6.75)</td>
</tr>
<tr>
<td>3-4</td>
<td>51(34)</td>
<td>26.45(9.2)</td>
<td>24.23(6.23)</td>
<td>20.50(4.99)</td>
</tr>
<tr>
<td>5 or more</td>
<td>54(36)</td>
<td>30.59(12.48)</td>
<td>22.96(8.62)</td>
<td>20.7(5.9)</td>
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<tr>
<td><strong>Employment status</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>21(14)</td>
<td>24.23(12.87)</td>
<td>24.9(6.53)</td>
<td>20.47(6.85)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>129(86)</td>
<td>24.14(11.14)</td>
<td>23.09(7.72)</td>
<td>20.75(5.54)</td>
</tr>
<tr>
<td><strong>Relationship to patient</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>69(46)</td>
<td>27.34(9.06)</td>
<td>23.014(7.1)</td>
<td>20.88(5.48)</td>
</tr>
<tr>
<td>Son or daughter</td>
<td>5(3.3)</td>
<td>13.2(14)</td>
<td>26(7.4)</td>
<td>19.4(4.9)</td>
</tr>
<tr>
<td>other</td>
<td>76(50.7)</td>
<td>27.07(12.66)</td>
<td>23.47(8.08)</td>
<td>20.64(5.7)</td>
</tr>
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<td><strong>Caring for others besides the patient</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>30(20)</td>
<td>26.8(12.23)</td>
<td>23.46(7.93)</td>
<td>20.03(4.97)</td>
</tr>
<tr>
<td>No</td>
<td>120(80)</td>
<td>26.72(11.23)</td>
<td>23.31(7.51)</td>
<td>20.88(5.71)</td>
</tr>
<tr>
<td><strong>Years of being a caregiver</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5</td>
<td>56(37.3)</td>
<td>26.03(12.55)</td>
<td>23.41(8.01)</td>
<td>19.57(5.47)</td>
</tr>
<tr>
<td>6-10</td>
<td>19(12.7)</td>
<td>23.47(9.67)</td>
<td>22.89(6.98)</td>
<td>21.05(6.08)</td>
</tr>
<tr>
<td>&gt;10</td>
<td>75(50)</td>
<td>28.09(10.8)</td>
<td>23.41(7.47)</td>
<td>21.48(5.43)</td>
</tr>
</tbody>
</table>
burden of relatives with dementia. Another study indicated that two indicators of resilience (resourcefulness and sense of coherence) were significantly associated with caregiver burden in family members of individuals with serious mental illness. Furthermore, Nunley (2002) showed that in a sample of 44 elderly spousal caregivers caring for a partner diagnosed with Alzheimer’s disease and related dementias, resilience predicted caregiver burden. However, greater psychological resilience did not predict less caregiver burden or greater life satisfaction in work by Kupferschmidt (2009). It is noteworthy to mention that happiness is frequently studied under the heading of “subjective well-being” (SWB), which is a broader term referring to any positive cognitive or affective state, including “positive emotion, engagement, satisfaction, and meaning”. In view of the positive relationship between happiness and burden among caregivers in the current study, Iranian health care policy makers are required to design community based programs focused on improving the overall happiness of family member caregivers, especially those who are dealing with disabled patients. As expected, married participants had a higher burden than single ones. Researchers believe that role demand overload, role strain, and resource availability are important factors in understanding the impact of caregiving on caregivers. In this study, most of participants were female. Thus, it can be said that the combination of childbearing demands, family responsibilities and caregiving tasks has lead to more burden for married participants in comparison to singles. This finding also was consistent with another finding of the present research where caregivers who had 5 or more children reported greater burden compared to those who had fewer children. In addition, the spouse caregivers had significantly higher scores for burden than the daughter or son caregivers, which is consistent with the findings of past studies regarding the burden experienced by family-member caregivers. For example, a quantitative and qualitative study of family caregivers of older persons in Singapore reported that most of the caregivers who scored high on the Caregiver Stress Scale were spouses (Mehta, 2005). In contrast, Zarit et al. (1980) and Coleman et al. (1994) found that the caregiver’s relationship to the person receiving care did not significantly influence caregivers’ experiences. This contrast may be explained by a difference between selected participants. In fact, most of the participants in our study were wife caregivers. Therefore, the loss of the husband’s income that is usually the major source of family money may be related to the experience of burden among wife caregivers in our study. In the present study, caregivers with 1-5 years of education had more burden than those with 6-8 years of education. There are several plausible explanations for this finding. On one hand, it is speculated that better knowledge gives rise to better capability to cope with their caregiving task. On the other hand, caregivers with less educational level will likely be older than those with greater educational level. Physically unhealthy or sick caregivers face more difficulties, which in turn may cause them to experience more burden. Thus, it

Table 1: Mean scores of burden, resilience, and happiness in respect to the demographic characteristics of the participants

<table>
<thead>
<tr>
<th>Predictor variable</th>
<th>b</th>
<th>β</th>
<th>t-value</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational level</td>
<td>5.18</td>
<td>1.85</td>
<td>2.8</td>
<td>0.06</td>
</tr>
<tr>
<td>Happiness</td>
<td>2.29</td>
<td>0.25</td>
<td>9.18</td>
<td>0.000</td>
</tr>
<tr>
<td>Age</td>
<td>0.21</td>
<td>0.065</td>
<td>3.21</td>
<td>0.02</td>
</tr>
<tr>
<td>R²</td>
<td>0.48</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Adj. R²</td>
<td>0.47</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Table 2: Predictors of burden among the participants (n = 150)

It is noteworthy to mention that
is necessary that when assessing caregivers’ burden, nurses consider the age category of caregivers.

Interestingly, the current study found that although scores on the CD-RISC were moderately correlated with burden when entered into a regression analysis they did not predict caregivers’ burden. This finding was inconsistent with some previous research. (39,30) One possible explanation for this finding is that the relationship between resilience and burden are mediated by other variables. Thus, when resilience was entered along with the other independent variables it could not be a significant predictor of burden. We acknowledge that this suggestion only is tentative and further research is necessary before any conclusions can be drawn.

Finally, several limitations are noted in the current study. Firstly, the cross-sectional design limits the understanding for causal explanations. Secondly, the use of a convenience sample limits the generalizability of the findings. Nevertheless, the findings may be a starting point for further research aimed at understanding the nature and causal underpinnings of burden in family caregivers of persons with SCI.

The results of this study confirm the theoretical conceptual framework using resilience theory on the relationship between burden, resilience and happiness among Iranian family caregivers of SCI patients. In addition, this study contributes to identification of the various factors that are associated with burden of these caregivers. Given our results, if policy makers and health care professionals are to provide support to family caregivers of patients with SCI to diminish their burden, they must pay special attention to factors such as educational level, age category, happiness level, marital status, and relationship of caregivers and patients. To our knowledge, the relationships between main concepts in the present study (burden, happiness, and resilience) have not been studied previously in a group of family caregivers in Iran. Thus, our results provide a foundation for the replication and development of future research in family caregivers’ burden area. We acknowledge that the development of evidence-based interventions aimed at improving resilience and happiness of family caregivers need to identify both latent and obvious factors associated with them. Therefore, future research is completely necessary to reach a more comprehensive understanding of components of these concepts.

Acknowledgement
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