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Research article

Vulnerability and physical well-being of caregivers: what relationship?

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Abstract

Objectives. To assess relationships among burden, compassion, and well-being and health among an active group of caregivers.

Methods. 301 caregivers with female prevalence (F = 61.1%, M = 38.9%) and ages between 18 and 84 years old (average = 38.72; SD 13.36) participated. Evaluation was carried using standardized instruments to assess: Burdens (CBI), dimensions related to Compassion and Burnout (ProQOL-5), State of Well-being (Who-5) and particular health-related domains (Emotional State, Physical Health, Depressive Polarity, Dysphoric Polarity-SF-36). Correlational analyses and multivariate linear regressions were performed.

Results. Positive correlations emerged between Burdens and Compassion Fatigue, Well-being and Satisfaction; inverse correlations emerged among Well-being and Burnout, Compassion Satisfaction and Emotional State, with the exception of Time Dependence. Multivariate linear regression indicated relations among Compassion Fatigue with Depression and Social Burden, Compassion Satisfaction with Depressive Polarity and Dysphoria and Burnout with Social Burden.

Conclusions. Caregivers’ work presents various risks, with negative outcomes that need to be addressed for this group of professionals. These risks present a professional and human development opportunity.

Keywords: caregivers, burden, compassion fatigue, well-being, emotions

Highlights
- The experience of contact with pathologies can produce different existential outcomes in caregivers, manifested through different phenomenologies. The research proposes an analysis of the relationships existing among the different components involved.
- The knowledge about links among dimensions such as fatigue and burnout with mood, the conflict of role, the burdens and the emotional state, could be useful for the necessary interventions aimed to reduce possible suffering of caregivers.
- The fatigue and the burnout, would represent one of the possibilities due to the continuous contact with different pathologies, but not the only one.


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Introduction

The caregiver in the management of other’s pathological states is subject to prolonged distress, physical demands related to care, and biological vulnerability that can compromise his/her health and psychological well-being, all factors related to increased mortality (1). Burdens that are physical, social, and emotional and that involve significant time commitment affect the quality of life of caregivers, independent of whether the recipient’s needs are physical or psychological (2, 3). Common negative consequences of providing such assistance for the caregiver include emotional problems, decreased in performance, and discomfort regarding contact with other adults and with family members (4, 5). Studies not only show decreased quality of life for both caregivers and patients compared to the control group of healthy subjects (6, 7), but also that the burden experienced by caregivers is related to patients’ living conditions (8). Ongoing care of and contact with patients with various pathologies can produce different existential outcomes in caregivers, manifested through different experiences.

In this study we investigated the burden and effects of caregiving. The “Burnout” (9), defined as a negative state of physical, emotional and mental damage, is caused by long-term involvement in emotionally difficult situations, manifests as the final result of exposure to high levels of stress at work, and may lead to actual abandonment of work (10). This condition (burnout) has been described as the result of the combination of three factors (11): emotional friction, depersonalization, and reduced personal sense of fulfillment. Emotional friction is based on a sense of void linked to work; depersonalization manifests itself as an attitude of estrangement and rejection of those who require professional service; and the sense of a reduced personal fulfillment is related to diminished self-esteem and the feeling of failure related to work.

Regarding the causes of burnout, an important role is attributed to the characteristics of the work, in this case in health services, where relevant factors include the complex conditions related to the quality of the relationships between patient and workers, the expectations of healing, and the frustrations that accompany the path of care. Burnout is present in 85% of health workers, in 48.8% of physicians, and up to 40% in practicing psychologists (12).

Dealing with other’s traumatic experiences can result in severe stress, and can eventually lead to transition from a stage of secondary traumatic stress (13) to “Compassion Fatigue” (14-18). Compassion fatigue is sudden (19), acute, and may emerge as the result of a single exposure to a traumatic representation. In contrast, Burnout syndrome is associated with a gradual and progressive strain on the professional, who feels overwhelmed by his work and thus unable to promote positive change. As suggested by Labra et al. (20), caregiving also has positive aspects, first evidenced by the studies of Lawton et al. (21). “Compassion Satisfaction” refers to the pleasure derived from being adequate in work activities, for example the pleasure related to helping/service work, feeling positive about colleagues, or about the ability to contribute support. High scores on this dimension represent greater satisfaction from being an effective caregiver (22).

Given the above, we hypothesize: (1) significant correlations among the different Burdens and Compassion Satisfaction, Compassion Fatigue, Burnout, Emotional State; (2) significant correlations among Well-being and Compassion Satisfaction, Compassion Fatigue, Burnout; and (3) relationships among such predictor covariates as Age, Sex, Emotional State, Dysphoria, Depressive Polarity, Time Dependence Burden, Developmental Burden, Physical Burden, Social Burden, Emotional Burden, Physical Health and outcomes such as Compassion Satisfaction, Burnout and Compassion Fatigue, as indicated through regression analysis.

Materials and Methods

Participants

The sample consisted of caregivers working in the southern Italian territories of Calabria and Sicily, a total of 301 subjects, 117 males (38.9%) and 184 females (61.1%). The average age was 38.72 years (SD = 13.36, range 18 to 84).

Research Method

The following research instruments were used:

- The Short Form Health Survey (SF-36) (23, 24) was used to study specific health dimensions: Emotional state (Items scale 5); Physical health (Items drops 3); Depressive polarity (Items 9 c, f, g, i); and Dysphoria (Items 9 a, b, e, h);
- The Italian version of the Caregiver Burden Inventory CBI (2), a 24-items multi-dimensional questionnaire that measures the caregiver’s burdens along 5 dimensions: Time Dependence, Developmental, Physical, Social, Emotional, with each evaluated using a 5-point Likert scale from 0 (not at all disruptive) to 4 (very disruptive);
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- Professional Quality of Life Scale (ProQOL-5) (25). The ProQOL-5 (Italian adaptation) (26) measures aspects related to the quality of life of care professionals. It consists of three sub-scales: Compassion Satisfaction, Burnout, and Compassion Fatigue.
- WHO (Five) Well-Being Index (WHO-5, 1998), composed of 5 items assessing well-being, evaluated using a 6-point Likert scale from 5 (always) to 0 (never).

Statistical Analysis

Descriptive data were expressed as mean, median, and standard deviation. A non-parametric approach was used since the numerical variables were not normally distributed, such as verified by Kolmogorov Smirnov test. Spearman correlations were used to assess associations among burdens and (1) compassion satisfaction, (2) compassion fatigue, (3) burnout, and (4) emotional state, as well as relationships among well-being and (1) compassion satisfaction, (2) compassion fatigue, and (3) burnout.

Multivariate linear regression was used to assess the dependence of each outcome (Compassion Satisfaction, Compassion Fatigue, Burnout) on a set of independent predictors, as Age, Gender, Emotional State, Depression, Dysphoria, TD-burden, D-burden, P-burden, S-burden, E-burden and Physical Wellness.

Statistical analyses were performed using SPSS 17.0 for Window package, with two-tailed tests (p<0.05) of significance used throughout.

Results

Table 1. Descriptive statistics for study variables

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Median</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time dependence</td>
<td>8.7</td>
<td>8.0</td>
<td>5.8</td>
</tr>
<tr>
<td>Developmental</td>
<td>5.3</td>
<td>4.0</td>
<td>5.2</td>
</tr>
<tr>
<td>Physical</td>
<td>4.7</td>
<td>4.0</td>
<td>4.0</td>
</tr>
<tr>
<td>Social</td>
<td>3.9</td>
<td>3.0</td>
<td>4.3</td>
</tr>
<tr>
<td>Emotional</td>
<td>2.2</td>
<td>0.0</td>
<td>3.7</td>
</tr>
<tr>
<td>Compassion satisfaction</td>
<td>38.4</td>
<td>40.0</td>
<td>7.0</td>
</tr>
<tr>
<td>Burnout</td>
<td>29.9</td>
<td>29.0</td>
<td>4.1</td>
</tr>
<tr>
<td>Compassion fatigue</td>
<td>21.9</td>
<td>21.0</td>
<td>7.2</td>
</tr>
<tr>
<td>Emotional state</td>
<td>5.1</td>
<td>6.0</td>
<td>1.2</td>
</tr>
<tr>
<td>Depressive polarity</td>
<td>17.8</td>
<td>18.0</td>
<td>3.9</td>
</tr>
<tr>
<td>Dysphoria</td>
<td>13.9</td>
<td>14.0</td>
<td>3.1</td>
</tr>
<tr>
<td>Physical health</td>
<td>24.4</td>
<td>26.0</td>
<td>4.0</td>
</tr>
</tbody>
</table>

Table 2. Correlation coefficients among study variables

<table>
<thead>
<tr>
<th></th>
<th>Compassion Satisfaction</th>
<th>Compassion Fatigue</th>
<th>Burnout</th>
<th>Emotional state</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time dependence</td>
<td>-.115*</td>
<td>.140*</td>
<td>.025</td>
<td>-.074</td>
</tr>
<tr>
<td>Developmental</td>
<td>-.331**</td>
<td>.429**</td>
<td>.113</td>
<td>-.285**</td>
</tr>
<tr>
<td>Physical</td>
<td>-.285**</td>
<td>.395**</td>
<td>.136*</td>
<td>-.271**</td>
</tr>
<tr>
<td>Social</td>
<td>-.289**</td>
<td>.479**</td>
<td>.218**</td>
<td>-.284**</td>
</tr>
<tr>
<td>Emotional</td>
<td>-.212**</td>
<td>.369**</td>
<td>.134*</td>
<td>-.245**</td>
</tr>
</tbody>
</table>

* p < .05 (2-tailed)        ** p < .01 (2-tailed)

Hypothesis 1. The study demonstrates significant inverse correlations among all the Burden domains and Compassion Satisfaction, suggesting that decreasing level of burden corresponds to increasing compassion satisfaction level.

Significant and positive correlations were found among the five Burdens and Compassion Fatigue. Thus, when the caregivers’ burdens increase, their sensitivity to compassion fatigue also increases.

Significant positive correlations were also found among Burnout and each of the three covariates, Physical, Social, and Emotional Burdens. Thus, chronic and somatic fatigue (Physical Burden), the perception of a role conflict (Social Burden), and the experience related to the patients’ behavioral sphere (Emotional Burden) were associated with increased Burnout.

Significant inverse correlations were evident between burdens and emotional state, with the exception of temporal burden. Thus, as these burdens increase, emotional state decreases.

Table 3. Correlations among Wellness, Compassion Satisfaction, Compassion Fatigue, and Burnout

<table>
<thead>
<tr>
<th></th>
<th>Wellness State</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compassion Satisfaction</td>
<td>.550**</td>
</tr>
<tr>
<td>Compassion Fatigue</td>
<td>-.029</td>
</tr>
<tr>
<td>Burnout</td>
<td>-.462**</td>
</tr>
</tbody>
</table>

* p < .01 (2-tailed) ** p < .05 (2-tailed)
Table 3 shows the correlations between Wellness State, Compassion Satisfaction, Compassion Fatigue and Burnout (Hp. 2).

The correlation between Well-being and Compassion Satisfaction was positive and significant, demonstrating that improvement of well-being increases with compassionate experiences in assistance work. The correlation between wellness and burnout was instead inverse.

To determine associations among Age, Sex, Emotional State, Depressive Polarity, Dysphoria, Physical Health, Time Dependence Burden, Developmental Burden, Physical Burden, Social Burden, Emotional Burden and outcome variables such as Compassion fatigue, Compassion Satisfaction and Burnout (Hp. 3), Spearman correlations are reported in Table 4.

Multivariate regression with Compassion Fatigue as dependent variable suggests two statistically significant dynamics, Depressive Polarity and Social Burden.

For Compassion Satisfaction as dependent variable, Depressive Polarity (positive), the Dysphoric Polarity, and the Developmental Burden (both negative) showed significant association. For Burnout as the dependent variable, Social Burden (positive dependence) showed significant association.

**Discussions**

The results of this study provide greater understanding of the experiences of being a caregiver. The demands of a competitive life and the relationships among these...
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demands can turn competition into burdens (27). In a substantial literature review Sinclair et al. (28) suggest that in the relationship between work satisfaction and its pathological outcome, it is important to clarify that negative aspects are produced by an interference represented by a moral suffering (29, 30). Our research highlights the inverse relationship between the negative impact of burdens and the possibility of experiencing benefits through work. It also suggests a strong link between burdens and the psychopathological outcome provided by suffering. As suggested by Roeser and collab (31), it would be interesting to understand how compassion develops during life and how it's related to dynamics such as inter-personal relations, well-being, society and health, considering the increasing attention given to the theme (32). The authors reported studies where the topic of the creation of models to improve such dynamics is central (33).

Consistent with the above research, this study demonstrates an inverse relationship between caregivers’ burdens and the impact of emotions related to work activities (34, 35). The general well-being of caregivers was positively related to compassion satisfaction. Roeser and collab. (31) suggest a similar relationship resulting from receiving and extending compassion. Such relations should be considered when trying to promote better health conditions for children, adolescents, and also adult caregivers.

The value of compassionate experience can really make the difference in improving personal well-being, as known in literature (36, 37, 28). With reference to dependence links, our research demonstrates the relationship between the compassion fatigue and independent variables such as depressive polarity and social burden.

The presence of depressive symptoms among caregivers, as reported by Fazio et al. (34), is known in the literature (35, 38, 39). Lown, (40) defines as a mission critical, the link between the person in need of care and the caregiver. This difficulty can be seen in the decreasing satisfaction and emotional difficulties in those who heal others. This should be considered in order to prevent the negative outcomes (41) of pathological maladjustment due to the exposition to extreme states (34). As a strategy there are some studies that suggest paying more attention to introspection, empathy (42, 43) and consideration of inner dynamics and the positive outcomes of a higher self-compassion (44).

Based on the experience of this study, and in line with the reported literature, it is clear that introspection and the greater propensity to notice the negative could indirectly affect the manifestation of compassion fatigue. We understand that this fact has a direct link with the role conflict represented by the social burden. In our research, it is also linked to the burnout, which suggests the need to improve the quality of inter-personal relationships.

Consequently a trend in line with compassion satisfaction is placed in diametrically opposed terms to suffering. So suffering shows a causal and positive relationship with the depressive state and clearly an inverse polarity with adaptive mood. Training based on mindfulness, meditation and introspective practices for health workers provides higher levels of compassion, kindness and humanity as qualities desired and deserved by patients (42).

As suggested by Adelman et al. (45) in citing previous studies (46, 47), the risk that the caregiver may become the "invisible patient" is real. It means that the possibility that the caregiver receives less consideration from other health-care workers, along with the role conflict, could lead to the condition of “silent suffering”. So the caregiver would accumulate their maladjustment and it could therefore be possible to deduce that the role conflict is a causal factor in burnout dynamics.

Our experience in this field and this research suggest the need to reflect on the role and on the issue of the health service, especially when confronted with illness and disability.

The personal space that the caregivers should reserve for themselves could be used for the recovery of their physical and emotional health. The implementation of their resilience passes through activities and practices that are in close relation to the meaning of satisfaction.

For this reason, the existence of those models that directly refer to this issue have been taken into account in this research. The meaning of everyone’s experience, work, practice and contact with illness needs to be supported by professionals of medical and psychological science. In this sense, we must consider not only the development of a rational way to elaborate experiences, but also an irrational way of building everyone's experience, beliefs and modalities to reach an adjustment. Clinicians can provide proof of this practice to take care of others, especially when action speak louder than words.

Conclusions

The intention of this study was to highlight the impact of stressful work on the psychological and health status of caregivers who play a role in the management of the pathology of others. The conditions to which
caregivers expose themselves are not easy to deal with, especially in terms of health, and the effects are not mitigated by the caregiver’s motivation or propensity for the other’s suffering. The fact that two possible dimensions are related to compassion, both satisfaction and fatigue, opens the possibility to the caregivers’ experience sublimation. Fatigue and burnout—outcomes reported in this study—represent one possibility, but understanding the links between such outcomes and mood, the conflict of role, the burdens, and the emotional state could be useful for interventions that reduce possible suffering and pathologies. Such knowledge might assist caregivers in re-establishing health and well-being so they can meet their personal and professional goals as a caregiver.

**Conflict of interest disclosure**

There are no known conflicts of interest in the publication of this article. The manuscript was read and approved by all authors.

**Compliance with ethical standards**

Any aspect of the work covered in this manuscript has been conducted with the ethical approval of all relevant bodies and that such approvals are acknowledged within the manuscript.

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