

# Predictive Role of Different Dimensions of Burden for Risk of Complicated Grief in Caregivers of Terminally Ill Patients

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## Abstract

The aim of the study was to test whether high levels of caregiver burden, as other confirmed predictors, are associated with the risk of prolonged grief disorder in caregivers of terminally ill patients. A predictive study was carried out in order to test the hypothesis. A demographic schedule, the Prolonged Grief 12 (PG-12), the Toronto Alexithymia Scale, Hamilton Anxiety Rating Scale, Hamilton Depression Rating Scale, and Caregiver Burden Inventory were administered to 60 caregivers of 51 patients who were admitted in Hospice. In the regression analysis, difficulty in recognizing emotions, total burden, depression, and developmental burden dimension were significant predictors of PG-12 levels. Findings showed that feeling of deprivation of existential expectations represents the greater risk factor for the prolonged grief disorder, among the burden dimensions.

## Keywords

prolonged grief disorder, caregiver burden inventory, alexithymia, palliative care, hospice, depression

## Introduction

Acute grief is a normal experience of life. It happens in an individual immediately after the death of a loved one. Grief occurs for a physiological period of 6 to 12 months characterized by deep sadness, distressing moods, turbulence, confusing, feeling lonely, and empty. Some important behavioral signs are continuous thoughts about him or her, sadness, insomnia, dreams about him or her, no appetite, and inattention to daily activities.<sup>1,2</sup> Normally, acute grief evolves into a psychological condition characterized by the acceptance of the loss-defined integrated grief. However, sometimes acute grief does not lead toward a resolution. In such cases, the acute condition tends to prolong for more than a year. When the normal grief adjustment does not occur in 10 to 12 months and some of the symptoms remain as intense intrusive thoughts, pangs of severe emotions, distressing yearnings, excessively avoiding tasks reminiscent of the one who died, unusual sleep disturbances, and maladaptive levels of loss of interest in personal activities,<sup>3</sup> acute grief is defined as prolonged leading to a complicated grief.<sup>4</sup> The onset of complicated grief seems connected with the closeness and the intensity of the relationship that the individual had with the one who died and the circumstance of bereavement such as unexpected, sudden, violent, or premature.<sup>5</sup> The risk of complicated grief is also associated with stress, anxiety, posttraumatic stress disorder, and depression.<sup>6-12</sup>

Complicated grief results when there is a failure of transition from acute grief to integrate grief.<sup>13</sup> It is a debilitating disorder, with significant mental and health consequences,<sup>14-19</sup> and it has been proposed as a new diagnostic category in the forthcoming *Diagnostic and Statistical Manual of Mental Disorder* (Fifth Edition).<sup>13</sup>

Previous studies described the association of complicated grief with alexithymia, female gender, and early age of the loved one who died.<sup>13</sup>

Recent studies started to investigate the role of burden on caregivers of patients with neurodegenerative diseases, dementia, psychoses, and eating disorders.<sup>20-23</sup> As of today, there are no studies (only a recent case study<sup>24</sup>) investigating the possible

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predictive role of caregiver burden dimensions on complicated grief in caregivers of terminally ill patients.

The hypothesis of the present study was to test whether high levels of alexithymia, with high levels of caregiver burden, are associated with the risk of complicated grief in caregivers of terminally ill patients.

## Methods

### Participants

This study examined the data collected from an Italian hospice, investigating complicated grief risk in caregivers of terminally ill patients during the period before death (mean hospitalization time was 21 days). In the period between February and September 2012, a total of 60 caregivers of 51 patients were interviewed face to face using a demographic schedule, the Prolonged Grief Disorder 12 (PG-12), the Toronto Alexithymia Scale 20 (TAS-20), Hamilton Anxiety Rating Scale (HAM-A), Hamilton Depression Rating Scale (HAM-D), and Caregiver Burden Inventory (CBI), during the second day of patient hospitalization.

Caregivers were identified as family member of a patient who provided the maximum care to the patient. Caregivers were recruited from a hospice in central Italy (Rome). The inclusion criteria were family relationship with a patient having terminal illness, living in the Lazio region, Italian speaking, able to give informed consent, and at least 18 years old.

### Procedure

After arrival of the patient to the hospice with his or her caregiver, the patient first undergoes a medical examination where the palliative care physician proposed a psychological interview with the caregiver during the next day. A psychologist, through the interview with the caregiver, performed a sociodemographic interview and a psychological assessment. At the end of the evaluation, the psychologist proposed to the caregiver to participate in the research protocol. After obtaining the informed consent, the caregiver underwent the psychological evaluation that included PG-12, TAS-20, HAM-A, HAM-D, and CBI.

Predeath grief symptoms were measured using the PG-12.<sup>25,26</sup> The PG-12 is a validated measure that consists of 12 items. The predeath grief scale asks to the interviewee how often they experienced distressing grief symptoms related to yearning, interpersonal disengagement, and a sense of meaninglessness. The 11 items are rated using a Likert-type scale, with values ranging from 1 (not at all) to 5 (several times a day). The Italian version of PG-12 is a validated form.<sup>27</sup> In order to assess the risk of prolonged grief disorder, the interviewee had to respond “yes” to question 12 of PG-12 (about a significant difficulty in social, occupational, or other important areas of functioning) and must have a total score of  $\geq 28$ .

The TAS-20 is one of the most commonly used instruments to measure alexithymia.<sup>28-32</sup> This instrument is used with

people who have trouble identifying and describing emotions and who tend to minimize emotional experience and focus attention externally. The TAS-20 has 3 subscales or factors; F1: difficulty describing feelings/emotions, F2: difficulty identifying feelings/emotions, and F3: externally oriented thinking. The F3 subscale is used to measure the tendency of individuals to focus their attention externally. The TAS-20 is a self-report scale that is comprised of 20 items. Items are rated using a 5-point Likert-type scale, whereby 1 = strongly disagree and 5 = strongly agree. There are 5 items that are negatively keyed. The total alexithymia score is the sum of responses of all 20 items, while the score for each subscale is the sum of the responses of that subscale. According to TAS-20, the cutoff score  $\leq 50$  = nonalexithymia,  $\geq 61$  = alexithymia, and scores of 51 to 60 = possible alexithymia.

The CBI is a 24-item multidimensional questionnaire in which 5 subscales explore 5 different dimensions of caregiver burden<sup>33-35</sup>:

1. time-dependence burden: objective burden corresponds to the amount of time devoted to caregiving (items 1-5);
2. developmental burden: the caregiver's sense of being left behind and unable to enjoy the same expectations and opportunities as his or her peers (items 6-10);
3. physical burden: feelings of fatigue and chronic health problems (items 11-14);
4. social burden: resulting from a perceived conflict of roles (items 15-19); and
5. emotional burden: originating from awareness of negative feelings toward the patient, which can be induced by the patient's bizarre and unpredictable behavior (items 20-24).

Scores for each item are evaluated using a 5-point Likert-type scale ranging from 0 to 4.

The HAM-D is a questionnaire that clinicians may use to rate the severity of a patient's major depression.<sup>36-39</sup> The questionnaire, which is designed for adult patients, rates the severity of symptoms observed in depression such as low mood, insomnia, agitation, anxiety, and weight loss. It is composed of 21 items.

The HAM-A is a questionnaire used by the researcher to rate the severity of anxiety. It was originally published by Max Hamilton in 1959.<sup>40</sup> It contains 14 symptom-oriented items. Each symptom is measured from not present (0) to very severe (4).

### Statistical Analyses

Correlation analyses (Pearson  $r$ ) were conducted in order to evaluate the relationship between PG-12 values and the other psychological variables. Analyses of variance (ANOVAs; Fisher  $F$ ) were conducted in order to test the differences between patients with risk of prolonged grief disorder and patients without risk of the psychological variables. A linear regression model was carried out in order to evaluate the effect of possible psychological predictors on the risk of complicated grief.

**Table 1.** Correlations (Pearson *r*) Between Clinical-Dependent Variables (Total TAS 20, F1, F2, F3, HAM-A, HAM-D, total CBI, Time Dependence, Developmental, Physical, Social, Emotional burden) and PG-12.

	PG-12 ( <i>P</i> value)
TOT TAS 20	.29 (.25)
F1	.55 (.000)
F2	.15 (.254)
F3	-.18 (.18)
HAM-A	.54 (.000)
HAM-D	.60 (.000)
Total CBI	.66 (.000)
Time-dependence burden	.47 (.000)
Developmental burden	.51 (.000)
Physical burden	.56 (.000)
Social burden	.37 (.004)
Emotional burden	.32 (.012)

Abbreviations: CBI, Caregiver Burden Inventory; F1, difficulty describing feelings/emotions; F2, difficulty identifying feelings/emotions; F3, externally oriented thinking; HAM-A, Hamilton Anxiety Rating Scale; HAM-D, Hamilton Depression Rating Scale; PG-12, Prolonged Grief Disorder 12; TAS-20, Toronto Alexithymia Scale 20.

## Results

In our sample of caregivers of terminally ill patients, we found 28 caregivers with prolonged grief disorder risk (20 females and 8 males) and 32 with no risk (23 females and 9 males). As shown in the previous study,<sup>13</sup> the present one also had more female caregivers (71%) than male caregivers (29%). Moreover, the female caregivers presented an higher risk level than do male caregivers (males  $24.6 \pm 10.1$  vs females  $31.7 \pm 9.7$ ;  $F_{1,58} = 6.4$ ;  $P = .01441$ ).

As shown in Table 1, the PG-12 risk level was correlated with the total TAS-20 ( $r = .29$ ;  $P = .025$ ), F1 ( $r = .55$ ;  $P = .000$ ), F2 ( $r = .15$ ;  $P = .254$ ), F3 ( $r = -.18$ ;  $P = .18$ ), anxiety ( $r = .54$ ;  $P = .000$ ), depression ( $r = .60$ ;  $P = .000$ ), CBI-Tot ( $r = .66$ ;  $P = .000$ ), time-dependence burden ( $r = .47$ ;  $P = .000$ ), developmental burden ( $r = .51$ ;  $P = .000$ ), physical burden ( $r = .56$ ;  $P = .000$ ), social burden ( $r = .37$ ;  $P = .004$ ), and emotional burden ( $r = .32$ ;  $P = .012$ ).

In Table 2, the caregiver at risk ( $n = 28$ ) versus the caregivers at no risk ( $n = 32$ ) showed higher scores on total TAS-20 (risk:  $43.1 \pm 10.9$  vs no risk:  $39.2 \pm 8.7$ ;  $F_{1,58} = 2.4$ ;  $P = .127$ ); F1-TAS-20 (risk:  $14.0 \pm 6.3$  vs no risk:  $10.3 \pm 3.7$ ;  $F_{1,58} = 7.7$ ;  $P = .007$ ); F2-TAS-20 (risk:  $12.7 \pm 5.8$  vs no risk:  $10.9 \pm 6.0$ ;  $F_{1,58} = 1.4$ ;  $P = .243$ ); F3-TAS-20 (risk:  $16.3 \pm 4.6$  vs no risk:  $17.8 \pm 6.2$ ;  $F_{1,58} = 1.1$ ;  $P = .29$ ); anxiety (risk:  $22.0 \pm 13.1$  vs no risk:  $15.6 \pm 9.3$ ;  $F_{1,58} = 4.7$ ;  $P = .033$ ); depression (risk:  $18.4 \pm 8.6$  vs no risk:  $12.1 \pm 7.3$ ;  $F_{1,58} = 9.2$ ;  $P = .003$ ); CBI-Tot (risk:  $41.3 \pm 15.9$  vs no risk:  $22.3 \pm 13.9$ ;  $F_{1,58} = 24.4$ ;  $P = .000007$ ); time-dependence burden (risk:  $13.9 \pm 6.0$  vs no risk:  $8.6 \pm 7.1$ ;  $F_{1,58} = 9.4$ ;  $P = .003$ ); developmental burden (risk:  $9.9 \pm 5.3$  vs no risk:  $4.9 \pm 3.8$ ;  $F_{1,58} = 18.0$ ;  $P = .00008$ ); physical burden (risk:  $11.2 \pm 6.5$  vs no risk:  $4.9 \pm 5.4$ ;  $F_{1,58} = 16.7$ ;

**Table 2.** Analyses of Variance (Fisher *F*) Caregiver Presence of Prolonged Grief Risk (Risk/No Risk) on the Clinical-Dependent Variables (Total TAS 20, F1, F2, F3, HAM-A, HAM-D, Total CBI, Time-dependence, Developmental, Physical, Social, and Emotional Burden).

	PG-12 SI (28) 20 F, 8 M	PG-12 NO (32) 23 F, 9 M	$F_{1,58}$ ( <i>P</i> value)
TOT TAS 20	$43.1 \pm 10.9$	$39.2 \pm 8.7$	2.4 (.127)
F1	$14.0 \pm 6.3$	$10.3 \pm 3.7$	7.7 (.007)
F2	$12.7 \pm 5.8$	$10.9 \pm 6.0$	1.4 (.243)
F3	$16.3 \pm 4.6$	$17.6 \pm 6.2$	1.1 (.29)
HAM-A	$22.0 \pm 13.1$	$15.6 \pm 9.3$	4.7 (.033)
HAM-D	$18.4 \pm 8.6$	$12.1 \pm 7.3$	9.2 (.003)
Total CBI	$41.3 \pm 15.9$	$22.3 \pm 13.9$	24.4 (.000007)
Time-dependence burden	$13.9 \pm 6.0$	$8.6 \pm 7.1$	9.4 (.003)
Developmental burden	$9.9 \pm 5.3$	$4.9 \pm 3.8$	18.0 (.00008)
Physical burden	$11.2 \pm 6.5$	$4.9 \pm 5.4$	16.7 (.00014)
Social burden	$5.9 \pm 5.0$	$2.9 \pm 3.9$	6.3 (.0145)
Emotional burden	$3 \pm 2.9$	$2 \pm 3.4$	1.5 (.23)

Abbreviations: CBI, Caregiver Burden Inventory; F, female; F1, difficulty describing feelings/emotions; F2, difficulty identifying feelings/emotions; F3, externally oriented thinking; HAM-A, Hamilton Anxiety Rating Scale; HAM-D, Hamilton Depression Rating Scale; M, male; PG-12, Prolonged Grief Disorder 12; TAS-20, Toronto Alexithymia Scale 20; TOT, total.

$P = .00014$ ); social burden (risk:  $5.9 \pm 5.0$  vs no risk:  $2.9 \pm 3.9$ ;  $F_{1,58} = 6.3$ ;  $P = .0145$ ); emotional burden (risk:  $3.0 \pm 2.9$  vs no risk:  $2.0 \pm 3.4$ ;  $F_{1,58} = 1.5$ ;  $P = 0.23$ ).

The clinical variables that were significantly ( $P < .05$ ) correlated with the PG-12 scores were inserted in a mathematical linear regression model as predictors of PG-12 levels. As shown in Table 3, the model was significant ( $R = .79$ ;  $R^2 = .62$ ;  $R^2$  adjusted = .58;  $F_{6,53} = 14.4$ ;  $P = .00000$ ). Moreover, CBI-Tot ( $\beta = .8$ ;  $B = 0.5$ ;  $t_{53} = 3.4$ ;  $P = .001$ ), F1-TAS-20 ( $\beta = .4$ ;  $B = 0.7$ ;  $t_{53} = 4.1$ ;  $P = .0001$ ), depression ( $\beta = .4$ ;  $B = 0.5$ ;  $t_{53} = 3.0$ ;  $P = .004$ ), and developmental burden ( $\beta = -.4$ ;  $B = -0.7$ ;  $t_{53} = -2.1$ ;  $P = .04$ ) were able to predict PG-12 scores. Physical burden ( $\beta = -.1$ ;  $B = -0.1$ ;  $t_{53} = -1.3$ ;  $P = .195$ ) and emotional burden ( $\beta = -.1$ ;  $B = -0.4$ ;  $t_{53} = -1.0$ ;  $P = .31$ ) were entered in the model but were not able to predict the PG-12 risk level. Anxiety, time-dependence burden, and social burden were not entered in the model.

## Discussion

Confirming a previous study,<sup>13</sup> the PG-12 scores were strongly correlated with the ability to describe feelings, anxiety levels, depression levels, and with CBI and its subscales. These findings confirm the central role of depression in the prolonged grief disorder.<sup>41</sup>

The ANOVA confirmed the correlation analysis, showing that the caregiver at risk presented higher levels of impairment to recognize feelings, anxiety, depression, and caregiver burden than those at no risk. Previous studies already suggested considering the difficulty of describing feelings during the initial assessment of the patient and his caregiver.<sup>13</sup>

**Table 3.** Mathematical Linear Regression on the Prolonged Grief Risk Inserting the Significant ( $P < .05$  Correlational Analyses) Dependent Variables (Total TAS-20, FI, HAM-D, total CBI, Developmental, Physical Burden) as Predictors.<sup>a</sup>

	$\beta$	Err St $\beta$	B	Err St B	$t_{53}$	P
Intercept			8.1	2.7	3.0	.004
Total CBI	0.8	0.2	0.5	0.14	3.4	.001
FI	0.4	0.1	0.7	0.2	4.1	.0001
HAM-D	0.4	0.1	0.5	0.2	3.0	.004
Developmental burden	-0.4	0.2	-0.7	0.3	-2.1	.04
Physical burden	-0.2	0.2	-0.4	0.3	-1.4	.18
Emotional burden	-0.1	0.1	-0.4	0.4	-1.0	.31

Abbreviations: CBI, Caregiver Burden Inventory; Err St, error standard; FI, difficulty describing feelings/emotions; HAM-D, Hamilton Depression Rating Scale.  
<sup>a</sup>  $R = .79$ ;  $R^2 = .62$   $R^2_{adj} = .58$ ;  $F_{6,53} = 14.4$ ;  $P < .00000$ .

In a very interesting way, caregiver burden was the best predictor of the prolonged grief risk. This finding suggests important clinical implications, where the level of burden that caregiver brings during terminal illness significantly increases the possibility of affecting a prolonged grief disorder. The subscale that best predicted the prolonged grief risk was developmental burden, showing that the increase in risk of prolonged grief disorder was not due to the time-dependent, physical, social, and emotional burden, but due to the developmental burden. This finding suggests that the caregiver role of a terminally ill patient can impair the psychological health of a caregiver not because of the much time or fatigue involved in caregiving but because of the deprived feeling of doing activities they wanted and expected to be doing at this moment in their lives. This means that the caregiver role may be characterized by perception of disrupted life expectations.<sup>34</sup> An important clinical implication of this finding is that it seems necessary to perform a caregiver burden assessment of the individuals involved in caregiving of terminally ill patients in order to prevent a future prolonged grief disorder.<sup>42</sup>

Limitations of the present study was that, despite previous study<sup>27</sup> suggesting a strong convergence between the risk condition and the clinical diagnosis of prolonged grief disorder, in this study only the risk and not the diagnosed prolonged grief disorder was measured for the sample of the caregivers. A longitudinal study should be performed to confirm the predictive role of the considered dependent variables in the onset of prolonged grief disorder once the patient died.

The finding suggests to improve the comprehension of the clinical symptoms of prolonged grief disorder with reference to the risk and protective factors and the possible effective pre- or postloss treatment.<sup>43,44</sup>

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