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Brief Report

Pre-loss symptoms related to risk of complicated grief in caregivers of terminally ill cancer patients

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ABSTRACT

Purpose: A number of studies have underlined a 10–20% prevalence of complicated grief (CG) among caregivers of cancer patients. The study aimed at examining the relationship between pre-loss criteria for CG and post-loss diagnosis of CG and at evaluating the validity and factor structure of a predictive tool, the Inventory of Complicated Grief (ICG), in order to identify the risk of developing CG in a sample of Italian caregivers.

Methods: Sixty family members of terminally ill patients admitted to hospice and receiving a Palliative Prognostic Score (PaP) predictive 30 day survival time $<30\%$ completed the Pre-Death ICG (ICG-PL) (T0). Family members were met again 6 months after the death of their loved one (T1) and submitted to the interview for Complicated Grief (Post-loss interview-PLI).

Results: Caseness for CG was shown in 18.3% of caregivers at T1. ICG-PL score (T0) were higher among those who developed CG at T1 than non-cases. A cut off score ≥ 49 on the ICG-PL (AUC=0.98) maximized sensitivity (92%) and specificity (98%) on caseness at T1. Pre-loss criteria related to traumatic distress, separation distress and emotional symptoms in general were significantly related to a post-loss diagnosis of CG, while no effect was shown on duration of pre-loss distress.

Conclusions: The use of short screening tools, like the ICG-PL, may help health care professionals to identify subjects at risk for CG.

1. Introduction

Over last 20 years, several studies have concentrated attention to complications of grief and bereavement (Zhang et al., 2006; Hudson et al., 2012). A syndrome characterized by emotional, behavioral and cognitive symptoms (e.g. yearning, searching, detachment, numbness, bitterness, emptiness, and lost sense of trust and control) has been identified and initially named as complicated grief (CG), then traumatic grief (TG), and, more recently, prolonged grief (PG) (Prigerson et al., 2009).[1] A bulk of data is now available on CG as a distinct entity from other psychiatric disorders, such as anxiety, depression, post-traumatic stress disorder and adult separation anxiety (Prigerson et al., 1995a; Boelen and van den Bout, 2005; Bonanno et al., 2007; Golden and Dalgleish, 2010; Boelen et al., 2010; Boelen, 2013). CG has also been shown to predict long-term functioning impairments, reduction of quality of life, risk for mental disorders and suicidality, and physical health problems (e.g. hypertension, hearth disorders) (Prigerson et al., 1997; Ott, 2003; Latham and Prigerson, 2004; Boelen and Prigerson, 2007).

In order to study the prevalence, possible risk factors, outcomes, and prevention and treatment of CG (Prigerson et al., 1999; Jacobs et al., 2000; Forstmeier and Maercker, 2007), diagnostic criteria were developed and a diagnosis of PG disorder has been proposed for the DSM-5 (Prigerson et al., 2008; Kaplow et al., 2012).[2] Furthermore, several instruments have been developed to assess CG, including the Inventory of Complicated Grief (ICG). This, as a measure of a single underlying construct, has proved to have high internal consistency and test-retest reliability in many studies (Prigerson et al., 1995b, 1996; Chiu et al., 2010; Guildin et al., 2011; Guldin et al., 2012). Prigerson et al. (1999) have suggested that a diagnosis of CG is made if certain criteria are met, specifically criterion A (i.e. symptoms of "separation distress"), criterion B ("traumatic distress"), criterion C (duration of symptoms) and criterion D (presence of dysfunctioning).

Less data are available on the relationship between pre-loss CG and post-loss CG. With regard to this, a pre-loss version of the ICG, the Pre-Death Inventory of Complicated Grief (ICG-PL), was

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[1] Since in the study we used the Italian version of a tool defined as Inventory for Complicated Grief we maintained the term "complicated grief" (CG) throughout the paper.

[2] In DSM-5 Persistent Complex Bereavement Disorder has been introduced as a Condition for Further Study.

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developed as a possible screening tool for those at risk for CG after loss. Tomarken et al. (2008) administered the ICG-PL to 248 caregivers of terminally ill cancer patients, showing that a younger age, a pessimistic thinking and stressful life events, were risk factors for pre-loss CG, but without providing data on the prevalence of post-loss CG. A more recent Australian prospective study found that, among 301 caregivers of terminally ill patients, CG symptoms on entry to palliative care were a strong predictor of both CG symptoms and CG disorder at 6 and 12 months. Greater bereavement dependency, a spousal relationship to the patient, greater impact of caring on schedule, poor family functioning, and low levels of optimism also were risk factors for CG symptoms (Thomas et al., 2013).

A very few data are available in Italy with regard to this area of research and, specifically, on the use of the ICG to predict CG in family caregivers in palliative care. The ICG was used by Pini et al. (2012) in a general retrospective study of adult psychiatric outpatients with a diagnosis of DSM-IV mood or anxiety disorders. They found that CG (23% rate) was associated with adult separation anxiety disorder (ASAD). In a different retrospective study of 116 bereaved patients, Dell'osso et al. (2012), also by using the ICG, showed that adult anxiety separation was higher only in those with CG and PTSD, but not in those with CG alone. None of the two studies were carried out, however, in palliative care settings. In the only Italian study carried out in this setting, Lai et al. (2013) found that female gender and difficulty in describing feelings were associated with CG among caregivers of terminally ill patients.

Given the substantial lack of prospective data on pre-loss conditions as possible predictive factors of post-loss CG and the repeatedly underlined need to explore CG and its risk factors (Shear et al., 2013), the aims of the present study were (i) to prospectively evaluate the role of pre-death CG in predicting CG after loss in caregivers of terminally ill cancer patients, (ii) and to evaluate the applicability and the validity of the Italian version of the ICG in a Italian population, in order to confirm its factor structure.

2. Methods

The study was carried out, during a period of one year, in the only hospice available in Ferrara, Northern-East Italy. This is a 12-bed unit linked to the NHS Local Health Agency that, in agreement with the palliative care philosophy, provides personalized interventions aimed at improving the quality of life for the terminally ill patients and their families. Most patients admitted are affected by cancer and the mission of the unit is to relieve physical, emotional and spiritual suffering, and to promote the dignity of the terminally ill persons. The study was introduced as part of the assessment routinely done in the unit and was approved by the Ethics Committee of the local institutions.

Prediction of survival time (in weeks) of the patients was evaluated by using the Palliative Prognostic Score (PaP score) (Pirovano et al., 1999). This is a valid predictive tool (Maltoni et al., 1999; Glare et al., 2004; Tarumi et al., 2011), consisting of an algorithm based on the Karnofsky Performance Scale and five other criteria (i.e., dyspnea, anorexia, clinical prediction of survival in weeks, total white blood cells, lymphocyte percentage) which creates three risk groups for survival: group A, with a predictive 30 day survival time $>70\%$; group B, with a predictive 30 day survival time 30–70%; group C, with a predictive 30 day survival time $<30\%$. Caregivers of patients included in group C were screened for inclusion in the study. Each caregiver was individually met in the hospice by one of the authors who explained the aims of the study and obtained a written informed consent. Sociodemographic data with information including the degree of relationship with the patient and if caregiver lives alone or with other members were also collected.

2.1. Assessment

2.1.1. Pre-loss assessment

The ICG-PL (Prigerson, personal communication) was administered to each caregiver. The ICG-PL is a 13-item questionnaire derived from a longer version of the ICG(Prigerson et al., 1995b), investigating caregivers' mood and feelings during the terminally ill of their loved one in the last month (e.g., I feel like I have become numb since _____ became so seriously ill; I feel that life would be empty or meaningless without _____ being healthy). Each item is rated on 1–5 Likert scale, while a further item (item 14) investigates the length of caregiver's distress. A possible syndromal level of CG is given if at least 3 of 4 items (items 1, 2, 3, and 11) have a score ≥ 4 (criterion 1; separation distress); at least 4 out of 8 items (items 4, 5, 6, 7, 8, 9, 10, and 12) have a score ≥ 4 (criterion 2; traumatic distress); duration of distress is >2 months (criterion 3); and item 13 has a score ≥ 4 (criterion 4; social, occupational or other

Table 1
Criteria for Complicated Grief (from Prigerson et al.).

Criterion A 1: Event Criterion
Death of a significant other, the respondent should be bereaved
Criterion A2: Separation Distress
A2.1: Experienced intrusive preoccupations about the death
A2.2: Felt intense longing and yearning for the deceased
A2.3: Felt intensely drawn to places and things associated with the deceased
A2.4: Felt intensely lonely
Criterion B: Traumatic Distress
B1. Tried to avoid reminders that the person is gone (e.g., avoid thoughts, feelings, activities, people, places)
B2. Felt like the future holds no meaning or purpose without the deceased
B3. Felt numb, detached from others, and an absence of emotional responsiveness
B4. Felt stunned, dazed, or shocked over _____'s death
B5. Felt disbelief over _____'s death
B6. Felt that life is empty or meaningless without _____?
B7. Felt unable to imagine life being fulfilling without _____?
B8. Felt that a part of yourself died along with _____?
B9. Felt that the death has changed your view of the world (eg., lost sense of security, trust, or control)?
B10. Felt pain in the same area of your body, some of the same symptoms, or assumed any of the behaviors or characteristics of the deceased
B11. Felt excessive anger, irritability or bitterness about _____'s death
Criterion C: Impairment
Disturbance causes marked and persistent dysfunction in social, occupational, or other important domains