

Veronica Zavagli¹, Silvia Varani², Adir Robert Samolsky-Dekel², Gianni Brighetti¹, Franco Pannuti²

Worry as a risk factor for mental and somatic diseases. A research on home-cared cancer patients family caregivers*

¹ Dipartimento di Psicologia, Università di Bologna, Bologna, Italy

² Fondazione ANT Italia, Bologna, Italy

ABSTRACT. Objective: Cancer patients family caregivers are exposed to several physical and emotional distress. Many recent reviews have provided strong evidence linking negative affective states and dispositions to disease. Moreover, several recent studies suggested that perseverative cognition, as manifested in worry, plays a role in nearly all anxiety disorders and is a crucial factor in somatic health as well. In this study, we tested a group of family caregivers since we wanted to find out whether worry might act directly on psychological and somatic diseases. Methods: The sample consists of 107 family caregivers. Participants completed a battery of self-report questionnaires including the Caregiver Burden Inventory, the Penn State Worry Questionnaire, the Psychophysiological Questionnaire and the Beck Depression Inventory. They underwent tests at the moment of oncological home-care request.

Results: The study has revealed that there is a significant positive correlation between worry measures and mental and physical health of the participants. In fact, the tendency to perseverative cognition resulted as a powerful and solid predictor of physical symptomatology ($R=0.5$, $\beta=0.67$, $p<0.001$) and depression level ($R=0.46$, $\beta=0.52$, $p<0.000001$).

Conclusions: Worry plays an important role in psychological and physical health and it is a counterproductive attempt at constructive mental problem solving. These results have great practical and operative value. Interventions improving caregiver's ability to cope with stress situations are likely to result in more positive benefits for cancer patients: in fact, if we promote the caregiver's physical and emotional well-being, he or she can provide the best care possible to the patient.

Key words: family caregiver, cancer, oncology, worry, perseverative cognition, oncological home-care.

RIASSUNTO. IL RIMUGINIO COME ATTIVATORE POTENZIALE DI MALATTIA. UNA RICERCA SUI FAMILIARI CAREGIVER DI PAZIENTI ONCOLOGICI IN ASSISTENZA DOMICILIARE. **Obiettivo:** L'assistenza ai pazienti oncologici comporta nei caregiver lo sviluppo di elevati livelli di stress. Numerosi studi hanno evidenziato come stati affettivi negativi possano influire sullo sviluppo e sul mantenimento di disturbi somatici invalidanti. Inoltre, è stato dimostrato che il pensiero perseverativo, come si manifesta nel rimuginio, gioca un ruolo determinante in quasi tutti i disturbi d'ansia ed è un fattore cruciale nei disturbi somatici. Il lavoro si prefigge di valutare in quale misura il rimuginio, in quanto attivatore potenziale di malattia, possa influire negativamente sulla salute psicofisica dei familiari caregiver. **Metodo:** Il campione sperimentale è costituito da 107 familiari caregiver. A ogni caregiver sono stati somministrati i seguenti questionari self-report: il Caregiver Burden Inventory, il Penn State Worry Questionnaire, il questionario psico-fisiologico e il Beck Depression Inventory.

Risultati: Sono emersi risultati significativi in merito alla relazione tra il disagio psicologico e i sintomi somatici.

Il grado di rimuginio risulta infatti un predittore potente e solido di sintomatologia fisica ($R=0.5$, $\beta=0.67$, $p<0.001$) e depressione ($R=0.46$, $\beta=0.52$, $p<0.000001$).

Conclusioni: La tendenza a rimuginare risulta una variabile determinante rispetto alla salute delle persone che si trovano ad affrontare il difficile compito di assistere un familiare malato di tumore. Questi risultati hanno un grande valore pratico e operativo. Infatti, un aiuto specialistico per i cosiddetti "rimuginatori" assume tanta più importanza se si considera che è ormai riconosciuto che caregiver e paziente costituiscono una diade inscindibile e che il "ben-essere" del primo è premessa per la salute del secondo.

Parole chiave: familiari caregiver, cancro, oncologia, rimuginio, pensiero perseverativo, assistenza domiciliare oncologica.

Introduction

In our country, as well as abroad, assistance to cancer patients in most cases lies with the responsibility of the family and in particular with those in charge of administering the treatment: the caregivers (1). This is revealed also by a recent study on the Italian population, which found that, on a sample of 2000 cases of people dying from cancer, 92% were assisted by an informal caregiver in the last months of illness (2).

Informal caregivers meet the patient's requirements mainly on two levels: medical nursing care and emotional well-being. For this reason, caregivers are requested not only to dedicate time, energy and emotions to the betterment of the patient's remaining life, but also to maintain a high level of their own health (2-6).

Burden and distress on family caregivers has been studied since the early 1980s. Long research studies have documented the effects cancer can have on emotional, social and physical well-being of family caregivers. In short, most of them seem to report that caregivers are exposed to

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a variety of stressors, defined "burden", which favors the onset of psycho-physical symptoms (such as sleep disturbances, weakness/fatigue and, less frequently, gastric problems, loss of appetite, headache and dizziness) and psychological disorders (especially anxiety, sadness, irritability and depression) (7-18). These effects can last for a long time after the caregiving role has ended (19, 20).

Previous studies on caregiving as a risk mainly laid emphasis on caregivers reacting with a series of distress sometimes leading to vulnerability. Consequently, according to data in the literature, caregivers are a population at risk, although not everyone experiences negative consequences (21-23). Their reactions, in fact, are largely influenced by the coping strategies used and the sense given to their experience and, therefore, the position taken on illness. However, to the best of our knowledge, very little information is available on the mental processes moderating the health consequences of stressors (24).

Several recent studies (25, 26) suggested that perseverative cognition, as manifested in worry, is a common response to stress and moderates the health consequences of stressors because it can prolong stress-related affective and physiological activation, both before and after stressors.

Worry is a chain of thoughts and images, negatively affect-laden, and relatively uncontrollable. The most concrete function attributed to worry is an attempt at constructive mental problem solving, although it may represent an unproductive and, perhaps, even a counterproductive attempt. In fact, 'worriers' people do not plan complex responses to overwhelming events. Instead, they tend to repeat to themselves that things will get worse. In this way, worry or related manifestations of perseverative cognition theoretically leave the individual in a prolonged state of psychophysiological "action preparation," and this prolonged state may have important long-term health consequences. As a result, perseverative cognition, can be thought of as a mediator, or a final pathway, by which the stressor exercises its effects on the body's systems: it does so by virtue of its propensity to prolong the stressor itself in a representational form continuing to activate the organism via the cardiovascular, immune, endocrine and neurovisceral systems (27). Thus, without perseverative cognition or a comparable mechanism maintaining a cognitive representation, which may operate to prolong the activation, a stressor cannot have an impact on the development of a chronic disease in a direct manner. Moreover, perseverative cognition is caused by perceived uncontrollability of a stressor and, at the same time, it prolongs the experience of uncontrollability. Briefly, extensive research has proposed that perseverative cognition prolongs stressor effects by maintaining its cognitive representation, together with its degree of uncontrollability. This, in turn, sustains the physiological response to the stressor, which, over time, will lead to disease. Several findings support the latter notion that prolonged physiological activity is a risk factor for organic diseases, but biopsychological models of stress and health have largely ignored it.

Starting from literature data briefly described, this study aims to assess whether prolonged intense worry would have measurable pathogenic somatic effects on itself and thus would become a direct threat to caregivers' physical health.

In our opinion this theme is of great interest: in fact, if caregivers fall ill, rather than being a resource, may end up representing a further aggravating factor in a context which is already very difficult. So it's important to protect the informal caregivers and support them because it is difficult to think you can help the cancer patient without helping those who care about him.

Materials and methods

Study sample

The sample consisted of 107 family caregivers (77 female and 30 male) of oncological patients assisted at home by the ANT Italia Foundation. A summary of the characteristics of the subjects who took part in the study is presented in Table I. The characteristics of the sample are uniform to the profile of the caregiver that emerges in the literature. In fact, the work shows how this role is played mostly by women (70-80%) with an average age of 50-55 years (1).

Participants were enrolled in Bologna during the medical home-care request at ANT Institute.

The ANT Italia Foundation provides since 1985 free medical, nursing, psychological and social home care and support for cancer patients through its 20 oncological hospitals at home in Italy (28).

Caregivers included in this study (I) were regularly providing volunteer care to their adult cancer patient at home (by managing the symptoms/pain of the patient at home, giving personal care, supporting the patient in the house and hospital/bureaucratic settings and providing emotional support); (II) were not receiving any financial support for their caregiving work; and (III) were 18 or older and played a key role in daily contact with physicians.

Procedure

Participants completed a battery of self-report questionnaires focusing on overall stress and burden (i), worry (ii), somatic symptoms (iii) and depressive symptoms (iv). They underwent tests at the moment of oncological home-care request at the ANT Institute.

Table I. Study population

	Caregivers
N	107
Age [yrs]	50.8 ± 12.8
Gender (male/female)	30/77
Caregiver role:	
- husband/wife [%]	4.67/16.82
- son/daughter [%]	17.76/47.66
- other relatives [%]	13.08
Years of Education:	
- 5 yrs [%]	6.54
- 8 yrs [%]	24.30
- 13 yrs [%]	47.66
- ≥ 16 yrs [%]	21.50
Italian law 104:	
- beneficiaries [%]	7.47

burden subscales. Furthermore, the tendency to perseverative cognition was significantly correlated with the total score on the Caregiver Burden Inventory and the developmental and the physical burdens.

On the basis of theoretical assumptions described above (see Introduction), a one-way ANOVA was conducted to investigate the effects of worry on caregivers' mental and physical health. It showed a significant effect of worry on caregivers' physical health and so revealed that who has higher scores of worry show also higher levels of physical symptoms ($F(1, 105)=23.737, p=0.00000, \eta^2=0.18$; Figure 1).

Subsequently, based on the results of the analyses of variance and the theoretical assumptions, some simple linear regression were carried out. Worry resulted as a powerful and solid predictor of physical symptomatology ($R=0.5, \beta=0.67, p<0.001$). Furthermore, another simple linear regression assessed the capacity of worry measures to predict the level of depression ($R=0.46, \beta=0.52, p<0.000001$). Finally it was found that worry predicts the CBI total score ($R=0.5, \beta=0.65, p<0.01$) and the developmental ($R=0.47, \beta=0.54, p<0.05$) and physical burden ($R=0.49, \beta=0.56, p<0.0001$).

Then further analysis were performed to assess which somatic symptoms were much more significantly associated with the perseverative cognition. A T-test for independent variables assessed the differences between high and low scores on the Penn State Worry Questionnaire and the symptom categories identified from the Psychophysiological Questionnaire (gastric symptoms, cardiovascular symptoms and migraine/headache symptoms). Analyses revealed statistically significant differences between worrying caregivers and not worrying caregivers: in fact, the first show significantly more physical symptoms than the latter ($F(3,234)=3.4861; p=0.01653$; Figure 2). However, the most marked difference was found for the gastric symptoms.

Discussion

Perseverative cognition, as manifested in worry, is a common response to stress. The purpose of this study was to ex-

perimentally examine whether prolonged intense worry would have measurable pathogenic somatic effects on itself and thus would become a direct threat to caregivers' physical health.

From this point of view, research is particularly innovative and differs from previous studies conducted on the same theme. In fact, there are no works in the literature concerning the construct of worry in caregivers or in persons who are facing dramatic life events.

Consistent with our hypothesis, participants' scores on the Penn State Worry Questionnaire were positively and significantly correlated with the scores on the Psychophysiological Questionnaire. We also found positive association between the worry measures and the level of depression.

Furthermore, the tendency to perseverative cognition was significantly correlated with the total score on the

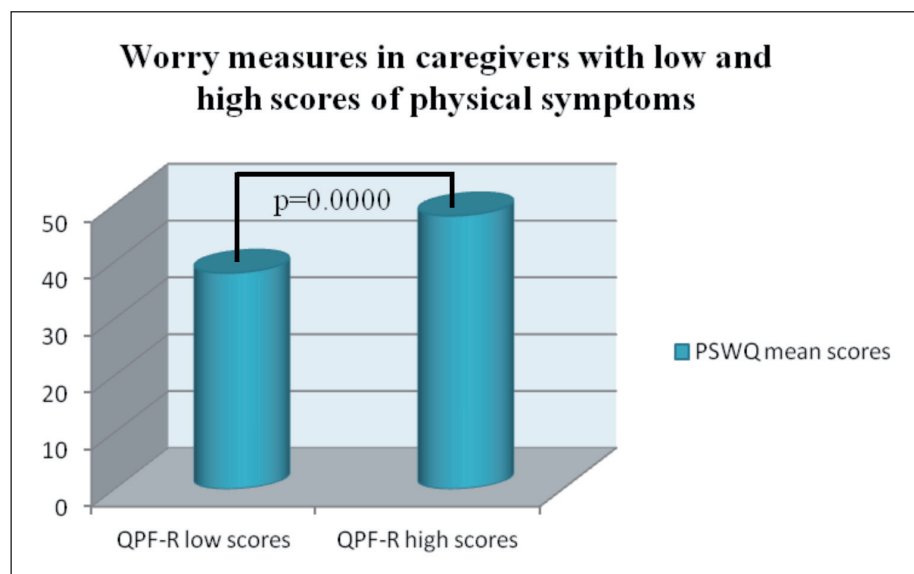


Figure 1.

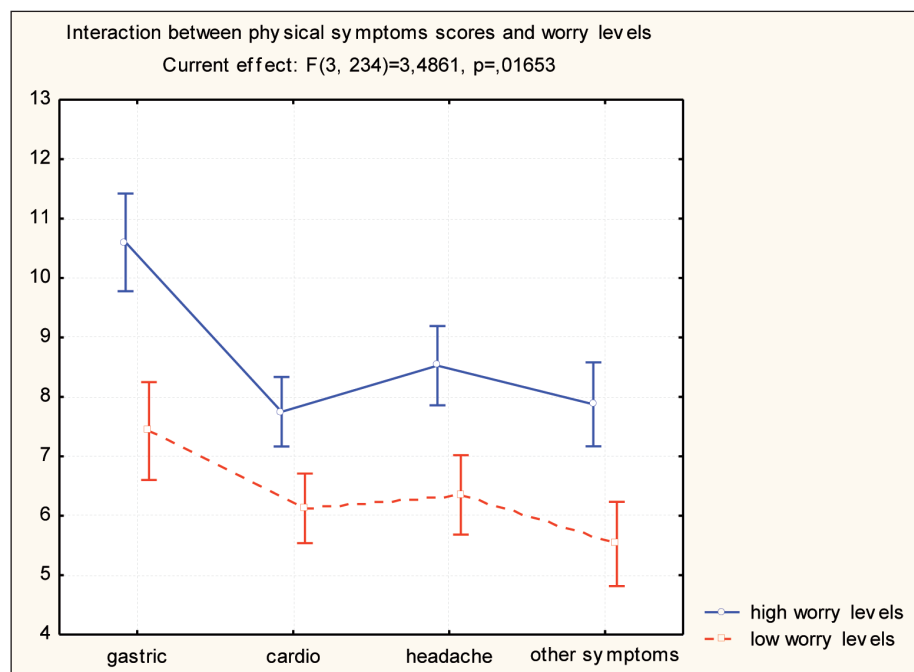


Figure 2.

Caregiver Burden Inventory and the developmental, physical, social and emotional burdens. All these data are certainly innovative and relevant because they connect worry with a greater vulnerability to unpleasant physical symptoms.

A simple linear regression has demonstrated the capacity of perseverative cognition to predict psychophysiological symptoms. This result is of particular importance because the studied subjects, i.e. the caregivers, are exposed to a systematic concern for the plight of their relatives. In detail, worry seems to be a powerful and robust predictor of health-related outcomes and somatic symptoms. These experimental findings are consistent with previous research (25-27) documenting that perseverative cognition might act directly on somatic disease via enhanced activation of the cardiovascular, immune, endocrine and neurovisceral systems. In fact, perseverative cognition may contribute to ill health by expanding the temporal duration of a stressor beyond the traditional reactivity period to include anticipation and recovery, thereby being the source of prolonged physiological activation.

Furthermore, another simple linear regression has demonstrated the capacity of perseverative cognition to predict the level of depression. Therefore, the depressive symptoms are produced not only by the observation of the relative's suffering, but also by negative thoughts and uncertainty about the future. In fact, recent evidence (26) indicates that worry leads to amplification of depressed affect and is also frequently associated with depressive rumination, which is consistent with our findings.

In conclusion, this study enriches previous findings by demonstrating that the decision to support a seriously ill family member can lead to prolonged and intense worry that produce physical symptoms, depression and discomfort.

Obviously, this is a preliminary observational study and thus there is a need for further future investigations. However, these findings have high practical and operative value. In fact, family caregivers have a legitimate and crucial role in the cancer home-care team. That is why their well-being must be our concern. The 'worriers' family caregivers must be identified early and treated properly, so that they can maintain their own health and provide the best care possible to the patient. In this regard, considerable progress has been made recently in the design and scientific evaluation of effective treatments for worry (39). Although these techniques are mostly based on cognitive-behavioral therapy, basic research is taking into consideration other factors to be included in treatment (for example, mindfulness techniques and elements of interpersonal therapy).

In conclusion, it is important to remember that if we promote the caregiver's physical and emotional well-being, he or she can more effectively attend to the physical and emotional needs of the cancer patient.

References

1) Corli O, Pizzuto M, Marini MG, Natri A. La famiglia e il malato terminale. Milano: GPAnet Ed, 2005.

2) Giorgi Rossi P, Beccaro M, Miccinesi G, Borgia P, Costantini M, Chini F, Baiocchi D, De Giacomo G, Grimaldi M, Montella M; ISDOC Working Group. Dying of cancer in Italy: impact on family and caregiver. The Italian Survey of Dying of Cancer. *J Epidemiol Community Health* 2007; 61: 547-54.

3) Given BA, Given CW, Kozachik S. Family support in advanced cancer. *CA Cancer J Clin* 2001; 51: 213-31.

4) Bolis T, Masneri S, Punzi S. Il caregiver in oncologia: tra ruolo e bisogno. [The caregiver in oncology: duties and needs]. *G Ital Med Lav Ergon*. 2008 Jul-Sep; 30(3 Suppl B):B32-6.

5) Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *J Clin Nurs* 2009; 18: 1379-93.

6) Tsigaropoulos T, Mazaris E, Chatzidarellis E, Skolarikos A, Varkarakis I, Deliveliotis C. Problems faced by relatives caring for cancer patients at home. *Int J Nurs Pract* 2009; 15: 1-6.

7) Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with Family Caregivers of Cancer Patients: Meta-Analysis of Randomized Trials. *CA Cancer J Clin* 2010; 60: 317-39.

8) Gaugler JE, Hanna N, Linder J, Given CW, Tolbert V, Kataria R, Regine WF. Cancer caregiving and subjective stress: a multi-site, multi-dimensional analysis. *Psychooncology* 2005; 14: 771-85.

9) Kitrungroter L, Cohen MZ. Quality of life of family caregivers of patients with cancer: a literature review. *Oncol Nurs Forum* 2006; 33: 625-32.

10) Grov EK, Dahl AA, Moum T, Fosså SD. Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Ann Oncol* 2005; 16: 1185-91.

11) Grov EK, Dahl AA, Fosså SD, Wahl AK, Moum T. Global quality of life in primary caregivers of patients with cancer in palliative phase staying at home. *Support Care Cancer* 2006; 14: 943-51.

12) Swore Fletcher BA, Dodd MJ, Schumacher KL, Miaskowski C. Symptom experience of family caregivers of patients with cancer. *Oncol Nurs Forum* 2008; 35: E23-44.

13) Berger AM, Parker KP, Young-McCaughan S, Mallory GA, Barsevick AM, Beck SL, Carpenter JS, Carter PA, Farr LA, Hinds PS, Lee KA, Miaskowski C, Mock V, Payne JK, Hall M. Sleep wake disturbances in people with cancer and their caregivers: state of the science. *Oncol Nurs Forum* 2005; 32: E98-126.

14) Francis LE, Worthington J, Kypriotakis G, Rose JH. Relationship quality and burden among caregivers for late-stage cancer patients. *Support Care Cancer* 2010; 18: 1429-36.

15) Doorenbos AZ, Given B, Given CW et al. The influence of end-of-life cancer care on caregivers. *Res Nurs Health* 2007; 30: 270-81.

16) Grov EK, Fosså SD, Sørebo O, Dahl AA. Primary caregivers of cancer patients in the palliative phase: a path analysis of variables influencing their burden. *Soc Sci Med* 2006; 63: 2429-39.

17) Youngmee K, Spillers RL. Quality of life of family caregivers at 2 years after a relative's cancer diagnosis. *Psychooncology* 2010; 19: 431-40.

18) Robison J, Fortinsky R, Kleppinger A, Shugrue N, Porter M. A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. *J Gerontol B Psychol Sci Soc Sci* 2009; 64: 788-98.

19) Ratnakar S, Banupriya C, Doureradjou P, Vivekanandam S, Srivastava MK, Koner BC. Evaluation of anxiety, depression and urinary protein excretion among the family caregivers of advanced cancer patients. *Biol Psychol* 2008; 79: 234-8.

20) Weitzner MA, Haley WE, Chen H. The family caregiver of the older cancer patient. *Hematol Oncol Clin North Am* 2000; 14: 269-81.

21) Blum K, Sherman DW. Understanding the experience of caregivers: a focus on transitions. *Semin Oncol Nurs* 2010; 26: 243-58.

22) van Ryn M, Sanders S, Kahn K, van Houtven C, Griffin JM, Martin M, Atienza AA, Phelan S, Finstad D, Rowland J. Objective burden, resources, and other stressors among informal cancer caregivers: a hidden quality issue? *Psychooncology* 2011; 20: 44-52.

23) Lucini D, Cannone V, Malacarne M, Bruno D, Beltrami S, Pizzinelli P, Piazza E, Di Fede G, Pagani M. Evidence of autonomic dysregulation in otherwise healthy cancer caregivers: a possible link with health hazard. *Eur J Cancer* 2008; 44: 2437-43.

- 24) Sherwood PR, Given BA, Donovan H, Baum A, Given CW, Bender CM, Schulz R. Guiding research in family care: a new approach to oncology caregiving. *Psychooncology* 2008; 17: 986-96.
- 25) Thayer JF, Brosschot JF. Psychosomatics and psychopathology: looking up and down from the brain. *Psychoneuroendocrinology* 2005; 30: 1050-8.
- 26) Brosschot JF, Gerin W, Thayer JF. The perseverative cognition hypothesis: a review of worry, prolonged stress-related physiological activation and health. *J Psychos Res* 2006; 60: 113-24.
- 27) Thayer JF, Friedman BH, Borkovec TD. Autonomic characteristics of generalized anxiety disorder and worry. *Biol Psychiatry* 1996; 39: 255-66.
- 28) Casadio M, Biasco G, Abernethy A, Bonazzi V, Pannuti R, Pannuti F. The National Tumor Association Foundation (ANT): A 30 year old model of home palliative care. *BMC Palliat Care* 2010; 9: 12.
- 29) Novak M, Guest C. Application of a multidimensional Caregiver Burden Inventory. *Gerontologist* 1989; 29: 798-803.
- 30) Caserta MS, Lund DA, Wright SD. Exploring the Caregiver Burden Inventory (CBI): further evidence for a multidimensional view of burden. *Int J Aging Hum Dev* 1996; 43: 21-34.
- 31) Zanetti O, Geroldi C, Frisoni GB, Bianchetti A, Trabucchi M. Contrasting results between caregiver's report and direct assessment of activities of daily living in patients affected by mild and very mild dementia: the contribution of the caregiver's personal characteristics. *J Am Geriatr Soc* 1999; 47: 196-202.
- 32) Meyer TJ, Miller ML, Metzger RL, Borkovec TD. Development and validation of the Penn State Worry Questionnaire. *Behav Res Ther* 1990; 28: 487-95.
- 33) Morani S, Pricci D, Sanavio S. Penn State Worry Questionnaire e Worry Domains Questionnaire: presentazione delle versioni italiane e analisi della fedeltà. In: Carraresi C, Melli G. (a cura di). *Assessment in psicologia clinica. Strumenti di valutazione psicometrica*. Trento: Erickson, 2012: 13-34.
- 34) Pancheri P, Chiari G, Michielin P. *Questionario Psicofisiologico forma ridotta*. Firenze: Organizzazioni Speciali, 1986.
- 35) Beck AT, Steer RA, Brown GK. *Manual for the Beck Depression Inventory II*. San Antonio, TX: Psychological Corporation, 1996.
- 36) Beck AT, Ward C, Mendelson M. Beck Depression Inventory (BDI). *Arch Gen Psychiatry* 1961; 4: 561-71.
- 37) Beck AT, Steer RA, Ball R, Ranieri W. Comparison of Beck Depression Inventories -IA and -II in psychiatric outpatients. *J Pers Assess* 1996; 67: 588-97.
- 38) Sanavio E. *I test di personalità*. Bologna: ed. Il Mulino, 1999.
- 39) Borkovec TD, Ruscio A. Psychotherapy for generalized anxiety disorder. *J Clin Psychiatry* 2001; 62: 37-45.

Reprint request: Veronica Zavagli, Dipartimento di Psicologia, Università di Bologna, Viale Berti Pichat, 5 40127 Bologna, Italy - Tel.: +39 339 7757945; fax: +39 051 243086 - E-mail: veronica.zavagli@studio.unibo.it