

# Adaptation and validation of the Caregiver Burden Inventory in Eating Disorders

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## Research article

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# Abstract

## Background

Living with people diagnosed with a mental disorder is known to increase the risk of developing high levels of so-called “caregiver burden” in informal caregivers. In-depth analysis of this phenomenon and specific assessment tools for caregivers of patients diagnosed with Eating Disorders are lacking. In this study, we aimed to evaluate the psychometric properties of the Caregiver Burden Inventory scale in a sample of caregivers of Eating Disorder patients (CBI-ED).

## Methods

A cross-sectional study was conducted in the Eating Disorders outpatient unit of an Italian University hospital. Face and content validity were investigated by calculating standard Content Validity Indices (CVI-I and CVI-S) after administering the Inventory to 5 expert nurses with a minimum 5 years' experience in mental health services assisting people diagnosed with Eating Disorders. Reliability was evaluated with Cronbach's alpha coefficient for the overall scale and subscales. An exploratory factor analysis was also performed to assess construct validity.

## Results

CBI-ED was administered to 62 informal caregivers from May 1st to July 31st, 2019. The exploratory factor analysis yielded a 5-factor structure. The CVI-S was 97.2%; the Cronbach  $\alpha$  coefficient was 0,90 (> 0.74 in each subscale). The mean overall burden level in the experimental population was 40 [21;54], in a theoretical range from 0 (no burden) to 96 (highest level of burden).

## Conclusion

The Caregiver Burden Inventory appears to be a valid and reliable instrument to assess caregiver burden in individuals diagnosed with Eating Disorders. Further research is needed to evaluate this tool's efficiency in improving individually tailored interventions on families.

## Plain English Summary

Eating disorders (EDs) are characterized by the development of abnormal eating habits, dysregulation of body weight and/or body image distortion. The pervasiveness of EDs may significantly affect the life of patients' caregivers and lead to a condition of psycho-physical distress and psychological discomfort, defined as burden. This may impact the quality of life of the entire family and promote conflicts which may in turn exacerbate ED behaviours. Several different assessment tools that aim to measure Caregiver Burden (CB) are available internationally, among which the Caregiver Burden Inventory (CBI) is probably

the most widely employed. However, this tool has never been tested for the evaluation of this phenomenon in ED patients. We created a modified Caregiver Burden Inventory (CBI) in this category of caregivers (CBI-ED), which seems to adequately measure burden in caregivers of patients with EDs. The systematic use of this instrument can support physicians and nurses in assessing the carer's discomfort, and promote a focused monitoring of subjects with increased risk, in order to adequately plan targeted intervention programs.

## Introduction

Eating Disorders (EDs) are complex mental disorders defined by disturbed eating behaviours, distorted beliefs, and extreme concerns about food, eating and body image, shape or weight. The prevalence of these conditions is rising in many countries and recent studies suggest that EDs are not rare in the general population [1, 2]. Their association with decreased quality of life, increased risk of depression and substance abuse has been shown in several studies [1]. Moreover, the frequency, severity of clinical manifestations, considerable psychiatric comorbidities and somatic disease associated with these disorders [3, 4] lead to high levels of disability and increased mortality rates [5]. Treatment approaches of EDs include behavioral interventions, psychological and pharmacological treatments and often require a multidisciplinary team composed of psychiatrists, physicians, psychologists, nurses, dietitians, and social workers.

Moreover, research and clinical developments progressively built a response to the growing request for help, supporting the social rehabilitation of psychiatric patients; in this context, family involvement and informal caregiver support are considered necessary for therapeutic alliance and medical adherence [6, 7].

However, prolonged caregiving activity, albeit necessary to support the person affected with mental illness as well as healthcare professionals, can significantly affect the caregiver's life [8, 9]. The combination of physical emotional and social pressures can lead to a condition of psycho-physical stress and psychological discomfort, defined as burden, which can severely impact the quality of life of the entire family [10]. Furthermore, burden can contribute to a difficult and problematic relationship between ED patients and family caregivers which may in turn exacerbate ED behaviours, as proposed by the Cognitive-Interpersonal Maintenance Model of Anorexia Nervosa (AN), originally described in 2006 and recently revised [11, 12]. Specifically, this model suggest that caregivers' emotional reactions characterised by high levels of anxiety and depression, psychological distress and dysfunctional responses to the illness, can cause divisions amongst family members, develop divergent forms of reactive expressed emotion and act as maintaining factors of an ED.

Despite the existence of broad evidence on the burden experienced by informal caregivers of ED patients, specific instruments are lacking [13]. Several different assessment tools that aim to measure CB are available internationally, among which the Caregiver Burden Inventory (CBI) is perhaps the most widely employed. A large literature describes the use of CBI to identify burden in caregivers of people affected by

Alzheimer's disease and related dementias or with cancer, but this tool has never been tested for the evaluation of this phenomenon in ED patients; the aim of this study was to evaluate the psychometric properties of the Caregiver Burden Inventory (CBI) in this category of caregivers.

## Methods

### Scale Adaptation

In its original version composed by 24 items, the CBI was administered to 6 expert nurses (with at least 5 years of previous assistance to people diagnosed with Eating Disorders) who work in the Department of Mental Health and Addiction of the San Paolo University Hospital in Milan, Italy. The aim was to evaluate the scale's face and construct validity. Each nurse received a document with the definition of informal caregiver burden, information on the study purpose and the CBI scale; for all 24 items, participants were asked to evaluate their relevance by rating a score from 1 ("not at all relevant") to 4 ("very relevant"); this allowed to calculate the Content Validity Index of each single item (CVI-I) and the Content Validity Index of the scale in its complex (CVI-S); at the end of the questionnaire, two additional questions allowed the participant to communicate other relevant aspects that were not in the questionnaire and to report an overall opinion about clarity and exhaustiveness of the scale. Two items were modified according to these observations: Item 4 "I have to help my care receiver with many basic functions (dressing, washing, use of toilet)" was changed to "I have to help my care receiver with many basic functions (dressing, washing, use of toilet, meal assistance)"; item 5 "I don't have a minute's break from my caregiving chores" was changed to "I can't get enough free time from my caring chores". A second administration of the modified assessment tool (CBI-ED) was used to obtain a final judgment by the panel of experts.

### Sampling and data collection

A cross-sectional, observational study was conducted; a non-probabilistic sample of informal caregivers was recruited among ED patients who consecutively accessed the Eating Disorders Clinic of the San Paolo University Hospital from May 1st to July 31st, 2019. This unit serves a population of approximately 350,000 inhabitants in the South of Milan. The caregiver could be any relative, partner or friend, excluding professional caretakers.

Inclusion criteria were (i) patient's confirmed diagnosis according to Diagnostic and Statistical Manual of Mental Disorders, 5th edition [14] criteria by the treating clinician (SB) and (ii) at least one year of experience as caregiver for the recruited subject.

Each recruited caregiver received a file including study information, consent form, CBI-ED scale and a questionnaire for the collection of socio-demographic data; all documents, independently filled out by each participant in a restricted area of the clinic, were then placed inside a sealed ballot box to guarantee full anonymity.

## Statistical analysis

CBI-I and CBI-S were used to calculate the content validity of the scale; alpha Cronbach coefficient was calculated to evaluate the internal consistency. The explorative factorial analysis (EFA) was carried out to investigate the construction validity; factors were extracted with the main component method, according to Kaiser criteria and rotated with Varimax algorithm. Factor loading was assessed according to Stevens criteria.

Prior to the analysis, Kaiser-Meyer-Olkin test and Bartlett's correlation matrix were employed to test the variables' sampling adequacy. Factor loadings were compared to Stevens' cut-off.

The median, first and third quartile scores and ranges of scores for each domain as well as the scale as a whole were verified.

All analyses were conducted with SAS University edition software for MacOS-X

## Results

Sixty-two participants were enrolled in the study (100% response rate); forty-two were married, 17 separated and 3 lived alone. Forty carers had at least one other dependent child in addition to the one diagnosed with an ED. Thirty-eight caregivers were mothers, 23 were fathers and only one was a sister. The median time of caregiving was 4 years [3;5].

Patients diagnosed with an ED were 62 (58 females and 4 males); 40 were diagnosed with Anorexia Nervosa (AN), 16 Bulimia Nervosa, 4 with Unspecified Eating Disorder and 2 with Binge-Eating Disorder.

### Construct validity

The Kaiser-Mayer-Olkin test (0.74) and the Bartlett test correlation matrix ( $p < 0.01$ ) confirmed adequacy of the data and sample size to carry out a factor analysis that confirmed the 5-factor structure of the original version (Table 1).

Table 1  
CBI-ED factor loadings

Item	Objective Burden	Developmental Burden	Physical Burden	Social Burden	Emotional Burden
1.My care receiver needs my help to perform many daily tasks	0.68				
2.My care receiver is dependent on me	0.77				
3.I have to maintain a high level of attention	0.74				
4.I have to help my care receiver with many basic functions (dressing it, washing it, use of toilets, meal assistance)	0.61				
5.I do not have enough breaks my caregiving chores	0.74				
6.I feel I am missing out on life		0.71			
7.I wish I could escape from this situation		0.65			
8.My social life has suffered		0.58			
9.I feel emotionally drained due to caring for my care receiver		0.60			
10.I expected that things would be different at this point in my life		0.75			
11.I am not getting enough sleep			0.57		
12My health has suffered			0.72		
13.Caregiving has made me physically sick			0.65		
14.I am physically tired			0.70		
15 I do not get along with other family members as well as I used to				0.66	
16.My caregiving efforts are not appreciated by others in my family				0.49	
17.I have had problems with my marriage				0.56	

Item	Objective Burden	Developmental Burden	Physical Burden	Social Burden	Emotional Burden
18.I do not do as good a job at work as I used to				0.68	
19.I feel resentful of other relatives who could but do not help					0.51
20.I feel embarrassed about my care receiver's condition					0.82
21.I feel ashamed of my care receiver					0.56
22.I resent my care receiver					0.61
23.I feel uncomfortable when I have friends over or when we go out					0.72
24.I feel angry about my interactions with my care receiver					0.50

### Reliability

The alpha Cronbach coefficient was equal to 0.90; alpha coefficients were then calculated for each single subscale of CBI with values ranging from 0.74 and 0.91.

### Content Validity

The content validity index of the instrument (CVI-S) was equal to 97.2% (CVI-I always  $\geq$  0.80)

### Clinical results

The sample's total burden score was equal to 40 [21;54], in a theoretical range from 0 (no burden level) to 96 (maximum burden level); the burden level in each single subscale was then investigated, in order to frame the most critical areas weighing on the overall burden level (Table 2).

Table 2  
Median CB scores in the subscales

Subscales	Me [21;54]	Theoretical range
objective burden	9[3;11]	0–20
psychological burden	12[6;17]	0–20
physical burden	6[4;10]	0–16
social burden	7[5;11]	0–20
emotional burden	6[2;8]	0–20

## Discussion

The modified CBI for the Caregiver Burden evaluation of patients affected by ED demonstrated good psychometric properties. The CVI-S score obtained by interviewing the expert nurses panel confirmed the scale's content validity which also resulted simple, clear and understandable. Moreover, the explorative factor analysis confirmed the original 5-factor structure that was also recently observed in other clinical settings [15]. The high values of Cronbach's  $\alpha$  – for the scale and also each domain – confirmed the internal consistency of CBI-ED.

Previous research on CB in ED employed the Depression Anxiety Stress Scales (DASS) or questionnaires based on the related construct of Expressed Emotion within the patient's family [13]. However, these instruments do not specifically address the construct of CB and are likely to measure related, albeit different characteristics of caregivers' distress. Disentanglement of these constructs is likely to clarify the mechanisms that lead caregiver distress to maintain the illness [12]. Indeed, novel approaches to the treatment of EDs centralize psychoeducational interventions on caregivers to moderate emotionally driven responses such as criticism, overprotection, accommodating and/or enabling behaviours that have been shown to maintain the illness [16].

## Limitations

This study aimed to offer a preliminary overview of the CB phenomenon in a specialized outpatient unit. However, the reduced sample size should certainly be considered the main limitation and a larger, possibly multicentric study is necessary to confirm our findings. Nonetheless, the significant levels of CB detected in a median 4 years of activity, suggest the relevance of the phenomenon and the need to address it. Another limitation was the lack of a standardized interview to exclude psychiatric diagnoses in caregivers. Future studies are needed to clarify the relationship between CB and the socio-demographic and psychological characteristics of patients' caregivers. A more thorough understanding of this aspect is fundamental to the implementation of a preventive intervention path.

## Conclusions

The study results support the usefulness of CBI-ED for the assessment of Caregiver burden in patients diagnosed with EDs. The systematic use of this instrument can support physicians and nurses in assessing the carer's discomfort and a focused monitoring of subjects with increased risk to adequately plan targeted intervention programs.

Future research should assess whether early identification of burden and distress leading to focussed interventions might interfere with psychopathological mechanisms underlying EDs.

## **Abbreviations**

ED Eating disorders

CB Caregiver Burden

CBI Caregiver Burden Inventory

## **Declarations**

### **Ethics approval and consent to participate**

The study was approved by Milan's Area 1 Ethical Committee; study participation was voluntary and data treatment guaranteed the anonymity, in line with available legislation in Italy and the Helsinki declaration principles. All patients gave informed consent for study participation.

### **Consent for publication**

Not applicable

### **Availability of data and materials**

The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

### **Competing interests**

The authors declare that they have no competing interests

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### **Authors' contributions**

PF and SB conceived and drafted the study design. EB, SB and SD actively enrolled patients. ST conducted statistical analyses. EB, PF and SD prepared the initial draft of the manuscript. OG, AD'A and

AD provided supervision, commented on, and revised subsequent drafts of the manuscript. All authors read and agreed to the content of this article.

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