

Empathy and burden in caregivers of patients with schizophrenia spectrum disorders

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Abstract

Background

The caregiver of patients loads different kind of burdens, including emotional distress. Aims of this study were to evaluate the burden and empathy of caregivers of patients with schizophrenic spectrum disorders and to evaluate if these dimensions are correlate between them and/or with selected variables of caregivers and assisted patients.

Methods

We selected a sample of 60 caregivers (34 women and 26 men), who assisted patients with schizophrenia spectrum disorders treated in our local Community Mental Health Center for a 1-year minimum period. We administered to our sample two scales, Zarit Burden Interview (ZBI) and Balanced Emotional Empathy Scale (BEES) and collected data of caregivers and their assisted patients in a 3-month period.

Results

We reported a mean ZBI score of 49.68 (± 15.03 SD) and a mean BEES score of 14.35 (± 9.05 SD), indicating the perception of moderate-severe burden and a low level of empathy, respectively. The analysis of internal consistency confirmed the good reliability of both ZBI (Cronbach's alpha = 0.90) and BEES (Cronbach's alpha = 0.77). The correlation between the two scales was not statistically significantly at Spearman test. Only a few variables, the living environment ("do not live with the patient") indirectly, and the Clinical Global Impression-Severity (CGI-S) score of assisted patients, in a direct way, were statistically significantly correlated with ZBI score. We highlighted only a positive statistically significant correlation between the fifth dimension score of BEES ("Tendency to avoid emotional involvement with fragile people") and CGI-S and GAF (Global Assessment of Functioning) scores of assisted patients.

Conclusions

Our study highlights that the burden of caregivers of patients with severe psychiatric disorders is similarly high to that of organic or neurologic disorders and is associated with low emotional empathy experienced by caregivers, probably due to a defensive psychological mechanism.

Background

Relatives or close friends who provide unpaid practical daily or weekly assistance to patients are defined caregivers [1, 2]. In psychiatric practice, this role includes different tasks and responsibilities in comparison with the most well-known caregiver role of geriatric or oncological patients. Schizophrenia

onset commonly occurs in early adulthood and disrupts live of patients, who can present many social and relational disabilities, requiring caregiving for many years [3]. The caregiver of a patient with psychotic disorders has to support patient's self-care and psycho-physical well-being [4, 5, 6], often to provide him/her extensive support in terms of finance and housing and, in the same time, to manage complex issues such as social and professional re-integration of assisted patient. In addition, caregiver has an important role in administering pharmacological treatment due to poor adherence to therapy shown by patients with psychotic disorders [7, 8, 9]. Some studies showed that family caregivers of individuals with schizophrenia complain of heavier burden compared those caregiving for an individual with a chronic medical illness [1, 10], reporting worse Health-Related Quality of Life (HRQoL). Other studies reported that that emotions experienced by caregivers of patients with schizophrenia are frequently "guilt, fear and anger" due to ambivalent feelings closely related to chronic mental illness. The relationship between caregiver and patient is often so close to be defined a dyad, which can condition the outcome of treatment. In fact, when this relationship is correct and caregiver is well aware of his/her role, assisted patients become more adherent to treatments [11]. In accordance with some authors, family interventions were effective among people with psychiatric illness in reducing relapse risk and re-hospitalization rates [12]. On the other hand, due to the close relationship between caregiver and patient, if caregiver experiences psychological or physical distress in caring, this condition can often lead to a worsening in the health of the assisted patient. Caregiver burden is the state resulting from necessary care tasks or restrictions that cause discomfort to the caregiver [13] due to multiple kind of stressors linked with the caregiving activity [14]. In fact, the onerous task of the caregiver, in general, often leads to high levels of psychological pain [15, 16], such as anxiety and depression, which are the most common manifestations reported by caregivers [17, 18]. Caregivers, who are overwhelmed by these problems, tend to experience less satisfaction in their life and take less care of their health, both conditions which represent significant indicators of depression [19]. Other symptoms that can afflict caregivers are lack of sleep [20], perennial tiredness, sense of abandonment, terror and despair at the thought of facing another day of caregiving [21, 22]. Caregivers usually have limited time to maintain their social relationships, such as friendships and interpersonal activities, therefore loneliness associated with social isolation is considered a critical issue for caregivers of patients with schizophrenia and other mental health problems [23, 24]. It is also reported that uneasiness, disappointment, suffering and fear of care responsibilities are common among caregivers during the care process [23, 24]. In the last few years, an increasing number of studies have analysed the characteristics of caregivers, assisted patients in order to discover the cause of the perceived "caregiver burden", with mixed results. Although some studies are not able to highlight any correlation between caregiver burden and patient characteristics [25, 26, 27], some research shows that some variables of patients affected by schizophrenia could worsen caregiver burden: male gender, young age, impaired functional skills, severe mental illness for a long time, multiple psychiatric hospitalizations [28, 29, 30]. Regarding disorder characteristics, suicidal ideation, behavioural disorders and/or negative symptoms have the highest impact on the increase of perceived burden [31]. Regarding caregiver characteristics, some studies point out that being female, being old, having a low socio-economic status and assisting more than one patient could increase caregiver burden [29, 30, 32]. The level of caregiver empathy could affect the perceived burden. Empathy may be defined as a complex bio-psychosocial

concept which includes cognitive and emotional components, both leading to identify with others [33]. Recent research, especially in the field of dementia, focuses on informal caregiver empathy to reduce in caregivers depressive and anxious symptoms as well as their emotional burden, increasing the caregiver and patient well-being. A study suggests that interventions for reducing caregiver depression and anxiety symptoms could be aimed at heightening cognitive empathy and lowering affective empathy [34]. Only a few studies face this issue for caregivers of patients diagnosed with schizophrenia spectrum disorders. During the last decades, in many countries, the so-called “deinstitutionalization” has changed the primary location of health care from hospital to community-based outpatient services [35]. Nonetheless, the financial resources for community-based interventions are limited [6, 36, 37], although most severe mental disorders compromise many areas of an individual’s life, such as interpersonal relationship, work and/or self-care [38, 39]. This change in health care organization has permitted new rehabilitative programs for the patient at the cost of an increase in responsibilities for families of patients affected by severe psychiatric disorders such as schizophrenia [40]. In fact, community health care frequently involves family members as informal caregivers who play a fundamental role in the lives of individuals with schizophrenia and other serious mental illnesses [41].

The aim of the present study is to evaluate the caring burden and empathic abilities of caregivers of patients affected by schizophrenia spectrum disorders treated in a community outpatient service. We hypothesize, based on literature data, that a caregiver’s workload is inversely proportional to his empathic abilities and that there is an increased burden concomitant with lower levels of empathy in case of a serious, chronic and greatly disabling psychiatric condition. In case of severe and long-lasting psychiatric pathology, a reduction in the BEES values and an increase in the ZBI are expected, with an inverse correlation between the two scales administered.

Patients And Methods

Sample

Our sample is composed of the caregivers of patients treated in a Community Mental Health Center (CMHC), during the three-month period of study, in accordance at our inclusion and exclusion criteria.

We selected caregivers in accordance with the definition of Martinez-Martin [42]: person who is not a professional caregiver, who lives with or close to the assisted patient and is directly involved in the treatment and caring of the patient’s health problem.

Inclusion criteria:

Caregivers of patients diagnosed with schizophrenia spectrum disorders treated in local CMHC for at least 1 year.

Caregivers and their assisted patients who provide valid informed consent to participate in the study.

Exclusion criteria:

Caregivers of patients diagnosed with other disorders or not treated in local CMHC or treated for period less than 1 year.

Assisted patients not able to provide valid study consent due cognitive decline previously diagnosed by CMHC psychiatrists.

Caregivers and/or their assisted patients who refused valid study consent.

Caregivers involved in this study did not receive any payment for their assistance; professional caregivers, such as community mental health nurses or workers who receive a salary for giving patient assistance, were excluded.

Design and period of the study

This observational study is aimed at evaluating the caring burden and empathy in caregivers by administering two scales: Zarit Burden Interview (ZBI) [13] and Balanced Emotional Empathy Scale (BEES) [43].

The study period of data collection and analysis lasted three months from 21 July to 11 October 2019. The data collection period was dedicated to identification of suitable caregivers who accepted to participate in the study, and to whom the two scales were subsequently administered.

Scales

1) Zarit Burden Interview (ZBI) [13] is a scale which can be autonomously completed, initially consisting of 29 items and currently reduced to 22 items. Each part of the scale is composed of statements which correspond to 5 preferences, ranging from 0 (never) to 4 (almost always), depending on the level of distress. Scores ranging from zero to one are evaluated as negative, while scores from two to four are regarded as positive. The ZBI has a score ranged between 0 and 88.

The ZBI 22-item version is one of the most used scale for measuring caregiver burden, which includes physical, mental, social, and economic aspects of caregiving. Originally developed to evaluate the burden of dementia patient caregivers, the ZBI has been widely applied in measuring caregiver burden of patients affected by mental illnesses. ZBI has shown good reliability and validity [44,45].

Authors who performed factor analysis of ZBI highlighted the two-factor model, which addresses “personal” and “role” tension. With this model, the most certain information is provided regarding the reliability and validity of the questionnaire, with a Cronbach’s alpha coefficient of 0.92 [46]. The two-factor model provided results that were not related to age, gender, language, marital status, life situation or employment status and, therefore, ZBI can be used in various populations.

The ZBI score obtained determines four different conditions based on the severity of the emotional load:

<21 not present or mild burden

22-40 mild to moderate burden

41-60 moderate to severe burden

> 60 severe burden.

The Italian version of ZBI was validated in 273 caregivers of patients with dementia [47]. We used the Italian version of ZBI which is not under license as reported by the authors who had previously used it [45,47].

2) Balanced Emotional Empathy Scale (BEES) is a scale used to quantify the level of emotional empathy, i.e. the degree of involvement in others' emotions, the ability to emotionally understand the other in his uniqueness and originality. The BEES, is a unidimensional measure of affective or emotional empathy.

The BEES is a scale, which can be autonomously completed. It is a self-reported measure of one's ability to experience another individual's emotions or to feel what someone else feels. The BEES was developed from the Emotional Empathic Tendency Scale and, as reported by Mehrabian (1996), who constructed the scale, the data pertaining to the process of validation relative to the BEES largely refer to the process of validation in the Emotional Empathic Tendency Scale [43]. It is composed of 30 items, of which 15 items expressed by affirmations with positive orientation and the other 15 with negative orientation. The participants must express their degree of agreement/disagreement in a scale of 7-point Likert, with a score ranged between 0 (completely disagree) and 6 (completely agree). The BEES has been validated in the Italian version [48]. We obtained the BEES use license after purchasing the scale from the Giunti Psychometrics S.r.l. Publisher.

BEES investigates the following five dimensions:

- I. "Impermeability to the emotional feelings of others", where high scores in this dimension denote a difficulty in empathizing, higher scores of two standard deviations than the average are characteristic of subjects who are described as cold, distant or insensitive;
- II. "Susceptibility to the emotional feelings of others", this dimension is opposite to the previous one; in fact high scores indicate very empathic subjects, who lack the distinction between themselves and the other, while very low scores denote people with characteristics hardness and insensitivity;
- III. "Emotional spread responsiveness", is composed of items that are negatively oriented with respect to the construct measured. Therefore, very high scores indicate closure towards experiences potentially capable of arousing emotions that are difficult to manage and the tendency to avoid moving situations, while low scores indicate individuals with a strong imagination and propensity to fantasize and get excited;
- IV. "Susceptibility to emotional involvement with people nearby", in which the items describe emotional situations denoted by the actual presence of the other; high scores indicate the presence of characteristics closer to emotional contagion, on the contrary, low scores denote coldness, detachment or cruelty;

V. "Tendency to avoid emotional involvement with fragile people", measures the specific difficulty of empathizing with the emotional experiences of the elderly and children; high scores indicate emotionally immature, self-centred individuals, while low scores indicate individuals suitable for caring for children and the elderly, even if they are handicapped or disabled.

Cronbach's alpha of the total BEES varies between 0.83 and 0.87 [43,48].

The total score of BEES indicates, if above average (M: 32.0; SD: 18.0 in a range between 7 and 56.5 in general population), individuals with high emotional empathy, who are able to respond empathically to the emotions and behaviour of others, while, if below average, it indicates individuals who have difficulty empathizing.

BEES has been used to evaluate empathy level in different kinds of populations [49,50,51]. In particular, BEES has been used to score the level of empathy in caregivers of patients affected by cancer [52], showing that patient's physical pain can be correlated with caregiver's distress. To date, there are no known studies that have used the BEES scale to assess the level of empathy in caregivers of patients diagnosed with schizophrenia.

Modality of data collection

The questionnaires were administered by the same researcher, who was not involved in the patient's care and treatment. Over the three months of data collection, the same researcher asked to each caregiver who went to CMHC during opening hours from Monday to Saturday to take part in the study, providing adequate information. The decision of caregivers to voluntarily participate in the study was respected.

If caregiver decided to participate in the study, he/she was asked to sign the informed consent and the privacy form and, subsequently, ZBI and BEES were administered. Caregivers autonomously completed the two scales. Those who were not independently able to fill them out were helped to compile the scales by the researcher.

Subsequently, the same researcher filled in the form with the demographic and clinical data of the caregiver and the relative assisted patient, after having obtained the assisted patient's consent.

Selected variables

The following socio-demographic variables of caregivers were collected: age, gender, relationship with assisted patient (son, father, mother, etc.), schooling, work, daily time spent in caregiving.

The following clinical variables of patients assisted by our caregivers were collected: age, gender, psychiatric diagnoses in accordance with ICD-9-CM [53], organic comorbidity, substance use, period of treatment in CMHC, number of psychiatric hospitalizations, Global Assessment of Functioning (GAF) and Clinical Global Impression-Severity (CGI-S) scores, therapeutic adherence. For each patient, the variables were collected retrospectively from the medical charts and informatics system of the CMHC.

Statistical analysis

We performed descriptive statistical variable analysis: mean and Standard Deviation (SD) for continuous variables; percentages for categorical variables. Cronbach's alpha coefficient was used to highlight the internal consistency of both ZBI and BEES. We correlated the two scale scores through the Spearman correlation test. The ZBI score and total and 5 dimensions BEES scores were correlated with the selected variables by means of multiple linear regression. We used the backward stepwise selection, considering variables to be removed from the model if their p-value was ≥ 0.2 , considering for re-entry the variables previously deleted with a p-value was < 0.1 . We adopted the probability statistic level of significance ranging between $p < 0.05$ and two-sided alpha level of 0.05. The statistical analysis was conducted with the STATA 12 software program version (2011).

Results

Sample

The sample is represented by all the caregivers who agreed to participate in this study. The researcher had asked 95 caregivers but, although initially most of them had shown interest in the research, only 60 caregivers, of which 34 were women and 26 men, provided their informed consent and correctly completed the scales (response rate of 63%).

Demographic variables of caregivers

The analysis of demographic variables (Table 1) shows that our caregivers have an average age of 56.5 years, without a statistically significant difference between the two genders. Most of them graduated high school (42%), are employed (67%) and live with the assisted subject and other people (45%), like children or their spouse. More than half of them are parents of their assisted subject (53%), without a statistically significant difference between the two genders. The caregiving time spent by our sample is 7.58 hours per day, without a statistically significant difference between the two genders (Table 1).

Demographic and clinical variables of patients

As shown in Table 2, the patients assisted by our caregivers are 43.13 years old on average, without a statistical significant difference between the two genders; most of them have been suffering from a schizophrenia spectrum disorder for a long time and 90% of them have been in care at our CMHC for more than 1 year. The psychiatric disorders suffered by the patients assisted by our sample are distributed as follows: 20% of patients are affected by schizoaffective disorder, 18% by delusional disorder, 14% by paranoid schizophrenia, 10% by disorganized schizophrenia, 7% by brief psychotic episodes, 5% by residual schizophrenia and 17% by other types of schizophrenia. Substance abuse is reported in 22% of cases, without substantial differences between the two genders. On the contrary, regarding the presence of comorbidities, there is a statistically significant difference between the two genders (Pearson chi²=5.21, p=0.022; Table 2). From the onset of schizophrenia spectrum disorder, the

totality of our sample has been hospitalized in a psychiatric ward an average of 1.8 times. Our patients present an average score of 56.25 at GAF and an average score of 4.36 at CGI-S. Regarding their adherence to therapy, we noticed that in most cases (90%) there weren't significant interruptions in psychiatric therapy (Table 2).

Analysis of ZBI and BEES Scales

On the ZBI scale, we obtained an average score of 49.68 (± 15.03 SD), which is within the moderate-to-severe score range, without any statistically significant difference between the two genders of caregivers (Table 3). The alpha coefficient of Cronbach (0.90) reflects the good reliability and the internal consistency of the scale (Item-test correlation:0.28). The BEES scale score was calculated using the correction grid provided by the authors who validated the scale in Italian [48]. On the BEES scale, we obtained an average score of 14.35 with a standard deviation of ± 9.05 (median=15), indicating a low level of empathy, since, across the general population, the range of the scale varies between 7 and 56.5 [48]. Cronbach's alpha (0.77) indicates the good reliability of this scale (Item-test correlation:0.10). We did not report any statistically significant difference between the scores of two genders of caregivers (Table 3).

We have extrapolated the score of the 5 dimensions that make up the BEES (Figure 1):

1. "Impermeability to the emotional feelings of others": 5.5 ± 4.33 (m \pm SD)
2. "Susceptibility to the emotional feelings of others": 3.65 ± 4.81 (m \pm SD)
3. "Emotional spread responsiveness": 3.93 ± 3.54 (m \pm SD)
4. "Susceptibility to emotional involvement with people nearby": 5.75 ± 3.52 (m \pm SD)
5. "Tendency to avoid emotional involvement with fragile people": -0.35 ± 3.53 (m \pm SD).

High scores at the first, third and fifth dimensions indicate a scarce capacity to empathize; on the contrary, low scores at the second and fourth dimensions indicate good empathic tendency.

The correlations between ZBI score and both the total BEES score and each of the five dimension scores were not statistically significant (total Bees score: Spearman's rho=0.02; p=0.88; I Dimension: Spearman's rho=-0.22; p=0.085; II Dimension: Spearman's rho=0.16; p=0.21; III Dimension: Spearman's rho=-0.08; p=0.53; IV Dimension: Spearman's rho=0.04; p=0.75; V Dimension: Spearman's rho=-0.1; p=0.45).

Variables related to ZBI and BEES scores

As shown in Table 4, among the selected variables, only a few show a statistically significant correlation with the final score of ZBI at multiple linear regression, stepwise model. In particular, the home environment, especially "not living with the assisted patient" is inversely related to the ZBI score; on the contrary, there is a direct correlation with severity of schizophrenia spectrum disorders as highlighted by the positive correlation with the score of CGI-S. At our stepwise model of multiple linear regression between the total and five dimensions BEES scores (dependent variables) and selected variables

(independent variables), we have highlighted a direct, statistically significant correlation between the V dimension BEES score "Tendency to avoid emotional involvement with fragile people" and CGI-S and GAF scores.

Discussion

This observational study was aimed at evaluating the emotional burden and empathy among caregivers of patients affected by schizophrenia spectrum disorders, evaluated by means of two scale, ZBI and BEES, respectively.

The overall response rate was 60% since just over half of caregivers asked to participate in the study agreed to answer the scales after having given their informed consent. The relatively low rate of response suggests a partial interest in this study but it could have been conditioned by the modality of data collecting. The researcher who collected the data was not directly involved in patient care in order to avoid a collection bias and was completely unfamiliar to caregivers. For this reason, most of the caregivers probably did not accept to participate in the study. Some caregivers declared that the scales were too generic and not very specific in identifying subjective aspects of their daily life, showing feelings of shame in manifesting intimate information of their own life and, indirectly, of their assisted relatives. Among caregivers, the parents of assisted patients showed highest interest in the scales, probably because they felt valued and wished, at the same time, to improve their caregiving. In any case, all caregivers who participated in the study manifested great emotional involvement in caring for their assisted patients and, concomitantly, complained of overwhelming "emotional burden", thus describing two distinctive features of their activity.

In our sample, homogeneous for sex and age, 53% of caregivers were parents of assisted patients; 67%, despite the caring burden, were employed and 45% lived with their assisted relative in the same house, often with other relatives. Similarly, the group of assisted patients was homogeneous for demographic and clinical variables, which did not statistically significantly differ between the two genders, with the exception of organic comorbidity, more frequent in females. All patients assisted by our caregivers have been suffering from severe but stabilized schizophrenia disorders, as highlighted by CGI-S scores and low number of hospitalizations during the illness period ($m = 1.8 \pm 1.6$ SD), respectively. Among assisted patients, therapeutic adherence was good although the global functioning was precarious, as confirmed by low scores at GAF scale. Substance abuse was reported in less than a quarter of cases.

The response of our caregivers at the two scales highlights a moderate-severe emotional burden associated with low emotional empathy. The two scales administered, already validated in Italian healthcare context, have been extensively used in psychiatric settings.

The ZBI was validated in many countries across the world [54] and has recently been used in psychiatric clinical practice to assess the emotional burden in caregivers of patients affected by schizophrenia spectrum disorders [30, 55]. A study, using ZBI, reported high level of burden associated with some caregiver variables (age, gender, educational level) and, at the same time, with the duration of both

caregiving and schizophrenia [54]. In particular, it was reported that caregivers who were married, less educated, living in rural areas and with low economic income normally provided longer period of support to their assisted individuals than others, often assuming an avoidant coping behaviour towards their assisted patients, which resulted in higher caregiver burden [30, 55, 56].

Regarding the time dedicated to caregiving, our study highlights that caregivers spent 7.58 ± 3.16 hours on average a day in assisting relatives; in contrast to these results, the study of Liu and colleagues [20] indicated that the management of a chronically ill patient requires only 2.8 ± 2.1 hours per day. Our different result can be explained by the great number of parents among our caregivers, who dedicated most of their time to caregiving their assisted offspring due to strong affective relationship with them.

Our sample reported a mean ZBI score of 49.68 ± 15.03 , indicating that caring burden in assisting relative patients suffering from a severe and chronic psychiatric disorder is huge. Moreover, this result suggests that our caregivers were at risk for both depression and anxiety, according to a recent study [57], which highlighted that a cut-off score of 48 in ZBI was a significant predictor for identifying caregivers vulnerable to depressive and anxiety disorders. We highlight that the final score of ZBI is positively correlated with psychiatric disorder severity and cohabitation. The more serious the disorder, measured by CGI-S and GAF, the more the caring burden increases proportionally; on the contrary, if caregivers do not live with their assisted patients, the caring burden is perceived to be less. This finding is in line with other studies [10, 58, 59], which put in evidence that severe and chronic disorders as well as disability conditions require complex and extensive caring, which can strongly increase the emotional load of caregivers. These results confirm others findings in the literature. Bennett and Beaudin [60] demonstrated that the caring burden statistically significantly increased in accordance with the severity of many chronic and disabling disorders: schizophrenic disorders, dementia [61, 62], stroke [63] and/or palliative care in terminally ill patients [64]. These observations indicate that different but severe health conditions can cause a huge caregiver burden, that increases as the illness persists for a long time. The correlation between the caring burden and the living environment is also highlighted in another recent investigation [65]: the caregivers who do not live with their assisted patients feel lower caring burden than those who live with their assisted individuals. Our result indicates that sharing the space and time of daily life with assisted patients is an important determinant of caregiving burden. Differently from the research of Sinha and colleagues [66], we did not find any correlation between the caring burden and demographic variables like age and gender but, as in that study, we highlight a close association with severity and long duration of illness.

Higher quality of care in people affected by dementia is often correlated with the good quality of empathic capacities [67]. Supportive assistance for informal caregivers is focused on caregiver empathy, which is believed to improve well-being in the caregiver and, consequently, in the recipient [34, 68, 69]. Caregivers with higher empathy levels are considered more positive and flexible with a better relationship with their assisted individuals, being able to experience their caregiving as a meaningful event. Caregivers who show less empathy have a less positive attitude towards caregiving [70]. On the contrary, our study highlights low level of emotional empathy in our sample, suggesting a different attitude among

caregivers who assisted patients with chronic and severe schizophrenia spectrum disorders. In fact, at BEES, our sample reported low values both at total (14.35 ± 9.05) and V dimension score ("Tendency not to get involved by conditions of fragile subjects"). The former of these findings indicates low empathy whereas the second one could differently indicate good ability to empathize and to take care of suffering people, as already highlighted by the authors of the Italian validation of the scale [48]. The statistically significant correlation between the V dimension BEES score and both of the clinical scale scores, CGI-S and GAF, suggests that empathy capacity is reduced by the exposure to an emotional burden induced by severe and chronically ill patients, which activates an avoidance coping behaviour as psychological defense mechanism. This result overlaps the finding of other studies, that put in evidence the risk of a reduced empathy in caregivers who have to take care of disabled patients for a long time [55, 71].

In our research, empathic ability and caring burden are not influenced by any other socio-demographic variables of either caregivers or patients, such as age or gender, or even by any patients' clinical variable, as evidenced by other studies [71, 72].

Finally, we can confirm our initial hypothesis that reduced level of emotional empathy is concomitant with high emotional burden, but we did not confirm that the two dimensions are negatively statistically significantly correlated to each other. In light of our results, we suggest that empathy and emotional burden represent two different but parallel aspects of caregiving, depending on both caregiver and assisted patient characteristics.

Limitations And Strengths Of The Study

The principal limitations of the study consist of the partial representativeness of caregivers' sample, due to the response rate of 60%, and the small size of our sample. Moreover, other variables, such as economic income and/or anxiety and depression symptoms of caregivers could have been evaluated and correlate with the scale scores. A comparison with caregivers who assisted patients affected by other psychiatric disorders could have been evaluated to deepen this topic.

Strengths of the study are represented by the homogeneity of the caregiver sample and assisted patients and in its design, which allowed us to better understand the caring burden and the empathic ability of caregivers regarding their assisted patients in a community mental health center.

Conclusions

Our study highlights that the caregiver burden of patients with severe psychiatric disorders is similarly high to that of patients affected by organic or neurologic disorders and is associated with low emotional empathy experienced by caregivers, probably due to a psychological defense mechanism. The emotional burden was reduced when caregiver did not cohabit with the assisted patient and worsened with the increase of severity of assisted patient disorder. In our sample, the V dimension of BEES, "Tendency to avoid emotional involvement with fragile people", obtained a very low score and was directly correlated

with the severity of patient disorders, indicating that empathy capacities are strongly conditioned by the illness severity of patients assisted. The perceived burden and empathy did not show any statistically significant correlation, suggesting that they could represent two separate emotional dimensions of caregiving, conditioned by different factors. In the future, exploring this issue would allow us to implement interventions to safeguard the health of both the caregiver and, consequently, of the patient.

Abbreviations

HRQoL

Health-Related Quality of Life

CMHC

Community Mental Health Center

ZBI

Zarit Burden Interview

BEES

Balanced Emotional Empathy Scale

ICD-9-CM

International Classification of Diseases-9th revision-Clinical modification

GAF

Global Assessment of Functioning

CGI-S

Clinical Global Impression-Severity

Declarations

Ethics approval and consent to participate

This research was carried out in accordance with the principles of the Helsinki Declaration (World Medical Association Declaration of Helsinki, 1964) and good clinical practice. The study was approved by the Ethics Committee of the Vast Emilia Nord Area (Prot. AOU 0012430/19 of 22-05-2019) and was authorized by the local Department of Mental Health and Drug Abuse (decision No. 1139 of 28-05-2019).

Consent for publication

Informed consent was requested from each caregiver and their assisted patients before their participation in this research.

Availability of data and materials

The data generated and analysed in the current study are not publicly available, in order to protect the confidentiality of the study site and participants; however, further data to support the current findings can

be provided by the corresponding author upon reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

RD and PF conceived the study and conducted analysis, interpretation and manuscript preparation. NP contributed to the study design. AG contributed to the study design and conducted data collection, interpretation, and manuscript preparation. GF, GV, MP and FM conducted the manuscript preparation and revision process. All authors read and approved the final manuscript.

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Tables

Table 1. Caregiver socio-demographic variables of our sample

Variables	Male	Female	Total
	N= 26 (43%)	N= 34 (57%)	N= 60 (100%)
Age, (m±SD)			
Years	56.69±9.81	56.35±15.75	56.5±13.4
Schooling, n (%)			
Elementary school	2 (8%)	0 (0%)	2 (3%)
Middle school	4 (15%)	5 (15%)	9 (15%)
High school	12 (46%)	13 (38%)	25 (42%)
University degree	9 (34%)	15 (44%)	24 (40%)
Work, n (%)			
Employed	17 (65%)	23 (68%)	40 (67%)
Unemployed	2 (8%)	1 (3%)	3 (5 %)
Retired for age	7 (27%)	10 (29 %)	17 (28%)
Student	0 (0%)	0 (0%)	0 (0%)
Caregivers relationship, n (%)			
Parent	11 (42%)	21 (61%)	32 (53%)
Son/Daughter	1 (2%)	3 (9%)	4 (7%)
Husband/Wife	3 (12%)	1 (2%)	4 (7%)
Other degree of relationship	10 (38%)	10 (29%)	20 (33%)
Home environment, n (%)			
Living with the assisted patient	5 (19%)	10 (29%)	15 (25%)
Living with the assisted patient and others	13 (50%)	14 (41%)	27 (45%)
Not living with the assisted patient	8 (31%)	10 (29%)	18 (30%)
Time dedicated to caregiving, (m±SD)			
Hours per day	7.11±3.05	7.94±3.25	7.58±3.16

Table 2. Clinical variables of patients assisted by caregivers of our sample

Variables	Male N=26 (43%)	Female N=34 (57%)	Total N=60 (100%)
Age (m±SD)			
Years	39.83±16.43	48.08±16.32	43.13±16.75
Psychiatric diagnoses (ICD-9-CM), n (%)			
Schizophrenia	21 (58%)	14 (58%)	35 (58%)
Delusional disorder	8 (22%)	3 (13%)	11 (18%)
Brief psychotic episodes	1 (3%)	3 (13%)	4 (7%)
Other types of schizophrenia	6 (17%)	4 (17%)	10 (17%)
Organic comorbidity, n (%)			
Absent	35 (97%)	19 (79%)	54 (90%)
Present	1 (3%)	5 (21%)	6 (10%)
Substance use			
Absent	26 (72%)	21 (58%)	47 (78%)
Present	10 (28%)	3 (12%)	13 (22%)
Period of treatment in CMHC, n (%)			
< 1 year	3 (8%)	3 (13%)	6 (10%)
> 1 year	33 (92%)	21 (87%)	54 (90%)
Psychiatric hospitalizations from schizophrenia spectrum disorder onset, (m±SD)			
Number	1.61±1.71	2.08±1.50	1.8±1.6
GAF (m±SD)			
Total score	58.05±17.24	53.29±11.39	56.25±15.25
CGI-S (m±SD)			
Total score	4.16±0.94	4.66±0.48	4.36±0.82
Therapeutic adherence, n (%)			
No therapeutic interruption	33 (92%)	21 (88%)	54 (90%)
> 1 month interruption	3 (8%)	3 (12%)	6 (10%)

Table 3. ZBI and BEES scores divided by the two genders

Scales	Male	Female	Total	Statistical test
	N=26 (43%)	N=34 (57%)	N=60 (100%)	Probability
ZBI, (m±SD)				
Total score	47.54±14.47	51.32±15.46	49.68±15.03	t=0.97 p=0.34
BEES, (m±SD)				
Total score	13.58±7.10	14.94±10.37	14.35±9.05	t=0.57 p=0.57
I Dimension	5.54±3.25	5.47±5.05	5.5±4.33	t=0.06 p=0.95
II Dimension		4.47±4.51	3.65±4.81	t=1.53
	2.58±5.06			p=0.13
III Dimension	4.04±4.13	3.85 ±3.08	3.93±3.54	t=0.20 p=0.84
IV Dimension	5.85±3.02	5.68 ±3.91	5.75±3.52	t=0.18 p=0.85
V Dimension	-0.35±3.21	-0.35±3.80	-0.35±3.53	t = 0.01 p=0.99

Table 4. Statistically significant variables related to ZBI and BEES scores

at linear multiple regression

Variable	Coeff.	Standard error	Probability	Confidence interval 95%
ZBI scale total score				
Home environment: "Living alone with the assisted patient" (reference variable)				
"No living with the assisted patient"	-15.08	4.95	p=0.004	-25.01 -5.16
CGI-S score	5.24	2.18	p=0.020	0.85 9.62
V dimension BEES scale score "Tendency to avoid emotional involvement with fragile people"	1.8	2.09	p=0.042	0.07 3.54
CGI-S score	0.11	2.55	p=0.014	0.02 0.19
GAF score				

Figures

BEES: five dimension scores

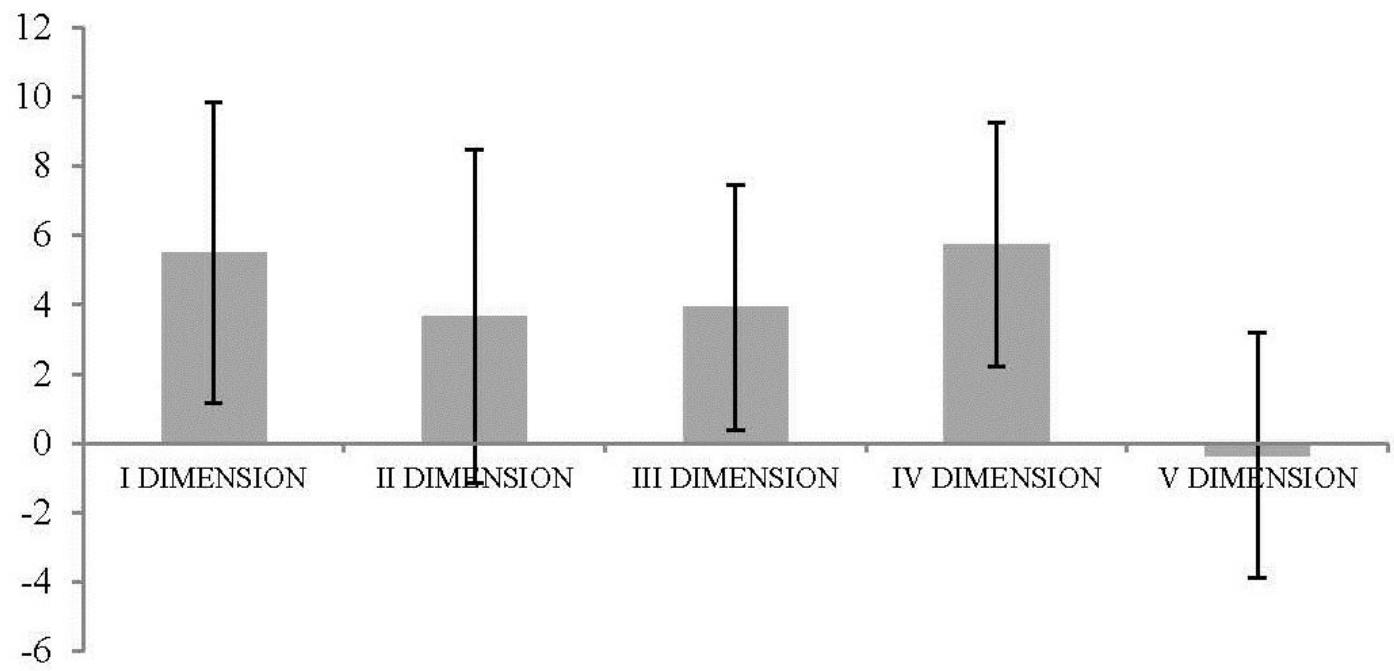


Figure 1

BEES: five dimension scores