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# Burden and support needs of carers of persons with borderline personality disorder: a systematic review

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# Burden and support needs of carers of persons with borderline personality disorder: a systematic review

## **Abstract**

**Background:** A major feature of personality disorders is significant impairment in interpersonal functioning, which may create challenges in close relationships. This article aims to systematically review the experience of carers of persons with personality disorders. **Method:** The PRISMA systematic review method was followed, and empirical studies written in English, published between 1996 and 2011, and cited in major electronic databases were searched. Studies meeting the following selection criteria were included: (1) carers or families of persons with personality disorders; (2) intervention involving the carers or families; (3) burden or related construct used. Studies were required to meet either criteria 1 and 3 or criteria 2 and 3. Reference lists were scanned, and experts were consulted for further studies. **Results:** Six studies met inclusion criteria, representing data on 465 carers. Five of the six studies focused on carers of persons with borderline personality disorder. The findings indicated that carers experience elevated objective and subjective burden, grief, impaired empowerment, and mental health problems, including depression and anxiety. Scores on objective and subjective burden were half a standard deviation above the mean compared to carers of inpatients with other serious mental illnesses. **Conclusions:** This study is the first to report data on a large, aggregated sample of carers of persons with personality disorders. Significant gaps in the literature remain, and it is recommended that future research focus on the burden and support needs of carers of persons across different personality disorders, that attention be paid to the gender balance of patients, and that data be reported in a way to allow meta-analysis.

## **Keywords**

Borderline personality disorder, burden, carer, intervention, personality disorder, support

## **Disciplines**

Medicine and Health Sciences

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## **ABSTRACT**

**Background:** A major feature of personality disorders is significant impairment in interpersonal functioning, which may create challenges in close relationships. This review aimed to systematically review the experience of carers of persons with personality disorders.

**Method:** The PRISMA systematic review method was followed and empirical studies written in English, published between 1996 and 2011, and cited in major electronic databases were searched. Studies meeting the following selection criteria were included: (1) carers or families of persons with personality disorders; (2) intervention involving the carers or families; (3) burden or related construct used. Studies were required to meet either criteria 1 and 3 or criteria 2 and 3. Reference lists were scanned, and experts were consulted for further studies.

**Results:** Six studies met inclusion criteria, representing data on 465 carers. Five of the six studies focused on carers of persons with borderline personality disorder. The findings indicated that carers experience elevated objective and subjective burden, grief, impaired empowerment, and mental health problems, including depression and anxiety. Scores on objective and subjective burden were half a standard deviation above the mean compared to carers of inpatients with other serious mental illnesses.

**Conclusions:** This study is the first to report data on a large, aggregated sample of carers of persons with personality disorders. Significant gaps in the literature remain, and it is recommended that future research focus on the burden and support needs of carers of persons across different personality disorders, that attention be paid to the gender balance of patients, and that data be reported in a way to allow meta-analysis.

**Keywords:** borderline personality disorder, burden, carer, intervention, personality disorder, support

## INTRODUCTION

Personality disorders occur in the context of relationships<sup>1</sup> and may be characterized by chronically dysfunctional patterns in relating to others. For example, the most widely researched personality disorder, borderline personality disorder (BPD), is defined by the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) as involving a pervasive pattern of instability within interpersonal relationships, poor self-image, affect dysregulation, and marked impulsivity.<sup>2</sup> BPD symptoms, such as impulsive anger and self-harm, and consequent burdens, such as therapy bills and a disharmonious household, would likely have adverse effects on relationship patterns, particularly with close relatives, partners, families, and carers. Likewise, the other personality disorders defined by DSM-IV all include problems in interpersonal relationships and maladaptive relational styles as essential criteria.<sup>2</sup> It is therefore perhaps surprising that so little research has been directed at understanding the experience of families, partners, and carers of persons with personality disorders.<sup>3,4</sup>

The prevalence of personality disorders in community samples has varied from 4.4%<sup>5</sup> to as high as 20%,<sup>6,7</sup> and a recent review found a prevalence of approximately 11% in community samples.<sup>8</sup> Considering that each of these persons with a personality disorder likely has at least one partner, carer, or family member supporting him or her, these figures imply that a substantial number of persons in the broader community are affected by personality disorders.

Despite the high prevalence of personality disorders, carers of people with personality disorders have been stigmatized and not given adequate attention in the research literature. Early research regarding families of persons with BPD was dominated by findings of family trauma, abuse, neglect, and psychopathology.<sup>9-11</sup> These findings resulted in the perception of carers of persons with BPD as toxic to the patient's recovery and as causing their difficulties.<sup>12,13</sup> However, the ongoing trend toward community-based care and away from

hospital-based care has resulted in families and carers taking on more and more responsibility for the care of those with mental illness, including personality disorders.<sup>13</sup> Research on, and understanding of, carers of persons with mental illness has consequently increased, serving to modify negative attitudes about carers.<sup>14</sup> For instance, support groups for families and carers of people with schizophrenia have been found to reduce carer psychological distress, increase family functioning, and benefit the caregiving relationship.<sup>14-16</sup> At present, however, the unique burden and support needs experienced by families, partners, and carers of persons with personality disorders have remained under-researched.<sup>3,4</sup>

The etiology of personality disorders is no longer considered to be the direct result of parental style, trauma, abuse, or neglect, but rather an interaction of many factors that define a biopsychosocial model of BPD development.<sup>17-21</sup> Although parental mental illness and harsh parental style may be associated with personality disorder development,<sup>22</sup> further research is needed to determine how these experiences contribute to the development of adult psychopathology.<sup>20,23,24</sup> The biopsychosocial model of personality disorder development recognizes that many factors, including biological (such as genetic heritability) and psychosocial experiences (such as adverse childhood experiences and temperament) may contribute to personality disorder development.<sup>23,25</sup> In view of this changed understanding, families and carers have come to be seen as important collaborators in the recovery effort for patients with personality disorders.<sup>12,13</sup> The model also recognized that carers may experience negative effects from the maladaptive relational dynamics characteristic of those with personality disorders. Research has begun to focus on the unique experience of burden, support needs, and demands placed upon families, partners, and carers of those with personality disorders.

The present study aims to systematically review and synthesize the emerging literature on this topic, and to identify any gaps that need to be addressed in future research. For the

purpose of the study, carer was defined as any person (biologically or nonbiologically related) who provides regular ongoing care, support, and assistance to persons with personality disorders.

## **METHODS**

### **Protocol and Registration**

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) Statement for Reporting Systematic Reviews<sup>26</sup> and additional guidelines for conducting and reporting systematic reviews.<sup>27</sup> Methods of data collection and inclusion criteria were predetermined and documented in a protocol (available at [http://www.crd.york.ac.uk/PROSPERO/Display\\_record.asp?ID = CRD42012001961](http://www.crd.york.ac.uk/PROSPERO/Display_record.asp?ID = CRD42012001961)). The protocol was registered by the International Prospective Register of Systematic Reviews (PROSPERO; registration number CRD42012001961).

### **Data Sources**

Studies were identified in three phases: electronic databases were searched; reference lists were scanned; and experts were consulted. The three phases were completed from January to March 2012.

### **Searching electronic databases**

Psychology and Behavioral Sciences Collection, PsycInfo, PubMed, Scopus, and Web of Science were searched for eligible studies. Search terms used for each database included the following: (Carer OR family) AND (personality disorder or borderline personality disorder or personality traits) AND (support OR intervention OR therapy OR treatment OR counselling OR service) AND (burden OR grief OR wellbeing OR guilt).

### **Scanning reference lists**

The reference lists of studies included from the electronic database phase were scanned for further eligible studies.

### **Consultation with experts**

A list of the included studies was sent to experts in the area of research, inviting contribution of any further studies that may meet criteria. Experts were determined as having authored or co-authored three or more included studies from the initial search of electronic database phase.

### **Study Selection**

One author reviewed the identified studies, which were then checked by an expert in personality disorders who was blind to prestige factors, including authors, institutions, journal titles, and publishers. No disagreements of inclusion were experienced. The inclusion criteria were as follows:

1. Carers or families of persons with personality disorders,
2. Intervention involving the carers or families (predominately for carer or family outcome),
3. Burden on carers or families (or related construct, such as grief or guilt),
4. Empirical studies (excluding anecdotal accounts, reviews, book chapters, and editorials),
5. Published during the last 15 years (1996 to 2011),
6. Published in English.

Inclusion required the study to meet criteria 1, either 2 or 3, and 4 through 6. In this way, the studies must have involved research into the burden experienced by families and carers of



persons with personality disorders, or a study of a support intervention for carers of persons with personality disorders, and also be empirical in design, and published during the last 15 years in English.

### **Data Extraction and Risk of Bias**

One reviewer extracted data from the included studies. The data-extraction form listed the source, design, aim, participants, findings, and limitations. Due to the small number of studies that met inclusion criteria, no validity assessment techniques were used. Risk of selection bias was minimized by using a blind rater and varied methods of study sourcing.

## **RESULTS**

### **Search Results**

#### *Search of electronic databases*

The search of electronic databases resulted in the identification of 504 studies (437 with duplicates removed). Of these, 421 were excluded as their titles or abstracts clearly indicated that they did not meet the inclusion criteria. Of the remaining 16 studies, 11 were excluded because they were not specific to personality disorders ( $n = 9$ ) or because they mixed personality disorders with other diagnoses ( $n = 2$ ). This phase thus identified 5 studies for inclusion in the systematic review.

#### *Scanning of reference lists*

The scanning of reference lists identified a total of 145 citations from the 5 studies generated from the search of electronic databases (129 after duplicates and studies already included were removed). Of these, 123 studies were excluded as their titles or abstracts clearly indicated that they did not meet the inclusion criteria. Of the remaining 6 studies, 5 were excluded because the study was not specific to personality disorders ( $n = 3$ ) or the study

was not empirical (n = 2). Therefore, this phase resulted in one further study included in the systematic review.

#### *Consultation with experts*

Three experts were identified and contacted, however no additional studies were suggested or included in the study.

#### *Total studies included*

Based on the above process, 6 studies were included in the systematic review. Figure 1 depicts the flow of identified and eligible studies.

### **Study Characteristics**

Since the included six studies were heterogeneous in both design and methodology, statistical aggregation in the form of a meta-analysis was not indicated. Three of the included studies met all six criteria, being pre/post evaluations of support interventions for carers of persons with personality disorders.<sup>1,28,29</sup> These three studies were not randomized and included small sample sizes. Additionally, two of these studies included short follow-up periods when compared to studies evaluating interventions with carers of persons with Axis I disorders,<sup>30-32</sup> and the same two studies were specific to carers of persons with BPD.<sup>1,29</sup> The third of these three studies, while providing only minimal data, included carers of persons with any personality disorder.<sup>28</sup>

The remaining three of the included studies met criteria 1 and 3 through 6; as such, they used constructs such as burden and well-being to assess the impact of caring for persons with personality disorders.<sup>33-35</sup> These three studies were specific to carers of persons with BPD.

It is worth noting that the included studies were published from 2003 to 2010, and that four of the six studies were published from 2007 to 2010. The characteristics of the included studies are summarized in Table 1.

Finally, though the methodology was designed to capture relevant studies on carers of persons with any personality disorder, five of the six included studies specifically focused on carers of persons with BPD. Consequently, though the results and discussion will sometimes refer to personality disorders rather than BPD, it should be understood that the results are primarily focused on BPD.

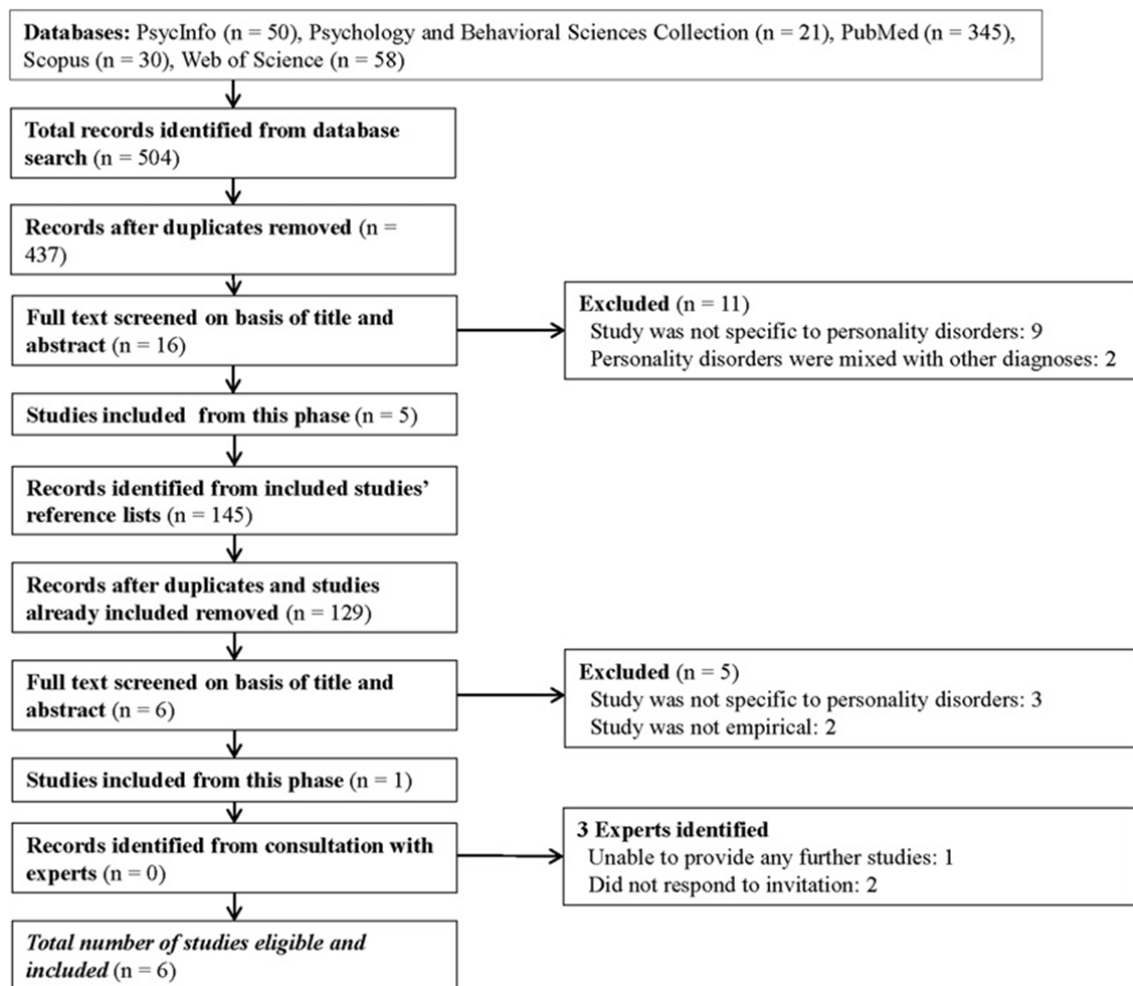


Figure 1: Flow diagram of information through the different phases of the systematic review.

## **Sample Characteristics**

The six included studies reported on a total of 465 carers. However, demographic and empirical data that could be aggregated were available only for carers of persons with BPD. Table 2 outlines the available aggregated data on the characteristics of the carers, and Table 3 outlines the available aggregated data on the characteristics of the persons with BPD.

## **Main Findings**

### *Burden*

Carer burden was measured by five of the six included studies (see Table 1). Data from the Burden Assessment Scale (BAS)<sup>36</sup> was used by three included studies for carers of persons with BPD. The BAS is a 19-item measure of objective and subjective burden, in which higher scores indicate greater burden. Objective burden relates to the observable behavioral effects of caregiving (such as financial problems and household disruption), whereas subjective burden involves feelings, attitudes, and emotions expressed about the caregiving experience (such as embarrassment and guilt).<sup>36,37</sup> The aggregated BAS data resulted in an average score of 43.91 ( $n = 131$ ; standard deviation [SD] = 11.62) for carers of persons with BPD. By contrast, using the same measure of burden (the BAS), average scores have been reported as 38.54 ( $n = 135$ ; SD = 13.27) for carers of psychiatric inpatients with mood, substance, neurotic, and psychotic disorders.<sup>38</sup> These mean scores were significantly different, with a small to medium effect size:  $t(264) = 3.51$ ;  $p < .01$ ;  $r = 0.21$ . Therefore, the results indicate that carers of persons with BPD experience elevated objective and subjective burden approximately half a standard deviation above the mean compared to carers of inpatients with other serious mental illnesses, suggesting that this difference is likely of clinical significance.

Table 1: Summary of the included studies.

<b>Source</b>	<b>Design</b>	<b>Aims</b>	<b>Participants</b>	<b>Findings</b>	<b>Limitations</b>
Hoffman et al. (2003) <sup>34</sup>	Cross-sectional interviews	Explore the extent to which family members' knowledge of BPD is correlated with well-being	32 family members of persons with BPD (59% female; 69% parents; mean age 51 years)	Over a third of family members were unaware of the diagnosis; a further third could not accurately describe the symptomatology  Greater knowledge was correlated with higher depression, burden, psychological symptom scores & hostility	Small sample size; causality cannot be inferred  Family members' sources of information (e.g., Internet, books, professionals) were not indicated  Limited to carers of persons with BPD
Hoffman et al. (2005) <sup>29</sup>	Pre- & post-intervention	Pilot study evaluating the 12-week Family Connections intervention for carers of persons with BPD	44 carers representing 34 families of persons with BPD (88.6% parents, of which 61.4% were mothers; mean age 55.5 years)	Overall burden & grief decreased significantly from pre- to post-intervention; mastery significantly increased; depression & perceived burden did not change  During the 6-month post-baseline follow-up, overall burden continued to significantly decrease; gains in mastery & grief were maintained	Included a short follow-up period compared to evaluations of Axis I carer-support interventions <sup>30-32</sup>  HLM analysis indicated that a significant amount of variation in change over time could be explained by family variables (which was not explored)  Limited to carers of persons with BPD
Hoffman et al. (2007) <sup>1</sup>	Pre- & post-intervention	To replicate previous Family Connections findings & to evaluate whether pre- & post-intervention measures demonstrate gender differences	55 carers of persons with BPD (unclear how many unique families represented; 57% female; 77% parents; mean age 53.4 years)	Findings of previous research were replicated:  During the 6-month, post-baseline follow-up, grief continued to significantly decrease; all other improvements were maintained	Includes a short follow-up period, with no measure of change in the caregiving relationship or patient symptom severity  Initial & present study contained generally modest

				<p>New findings:</p> <p>At pre-intervention, women endorsed significantly higher grief &amp; subjective burden</p> <p>Controlling for baseline scores, no significant gender differences were identified at post-intervention</p> <p>Women showed significantly greater reductions in subjective burden &amp; grief post-intervention</p>	<p>effect sizes for outcome variables</p> <p>Limited to carers of persons with BPD</p>
Scheirs & Bok (2007) <sup>35</sup>	Cross-sectional survey	To investigate the influence of BPD on the psychological well-being of carers	64 Dutch carers of persons with BPD (44 female; mean age 44.8 years); 36 were biologically related (e.g., parents) & 28 unrelated (e.g., partners)	<p>Carers scored significantly higher than the general Dutch population on all SCL-90 symptom dimensions</p> <p>No significant difference between caregiver groups, except for somatization (those biologically related to patient scored higher) &amp; hostility (those unrelated to patient scored higher). Older age &amp; being female was associated with higher depression scores</p>	<p>Included no measure of the relationship's duration &amp; therefore of potential exposure to the person with BPD</p> <p>Causality cannot be inferred</p> <p>Limited to carers of persons with BPD</p>
Sanders & Pearce (2010) <sup>28 2828</sup>	Pre- & post-intervention	Describe & evaluate a group intervention for carers of persons with personality disorders (OFAFE) & children of persons with personality disorders (YFAFE)	28 carers in OFAFE group, 9 in YFAFE group (10–17 years old); no demographic information was provided specific to these samples; carers were supporting a person with any	<p>OFAFE evaluation showed nonsignificant trends toward a reduction in isolation &amp; burden</p> <p>No empirical data were provided regarding the evaluation of YFAFE</p>	<p>Pilot study with a small sample size</p> <p>Minimal empirical data provided for evaluating OFAFE; no data provided for evaluating YFAFE</p>

Goodman et al. (2011) <sup>33</sup> 3333	Cross-sectional Internet survey	To measure the level of subjective burden experienced by parents of a daughter with BPD & determine correlates of parental burden	personality disorder 233 parents of daughters with BPD (95% female; mean age 51 years)	The majority endorsed emotional health as being most affected, followed by physical health & deleterious impact on marriage & social life  Retrospective reports of adolescent acting-out behavior, property destruction, delusional symptoms & hallucinatory symptoms were significantly correlated with intensity of parental burden  The median out-of-pocket expense of caregiving was U.S.\$10,000	Limited to the United States (e.g., used US\$)  Empirically validated measure of burden not used  Results limited by self-selection & retrospective bias  Limited to carers of persons with BPD
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*Note.* BPD, borderline personality disorder; HLM, hierarchical linear modeling; OFAFE, Oxford Friends and Family Empowerment; SCL-90,

Symptom Checklist-90, YFAFE, Young Friends and Family Empowerment.

In two of the included studies with carers of persons with BPD, grief was measured using the Grief Scale,<sup>39</sup> which is a 15-item measure of current feelings of grief associated with the mental illness of a loved one. The carer data resulted in an average score of 54.01 (n = 99; SD = 11.14) on the Grief Scale, with potential scores ranging from 15 to 75. This average score approximates to a mean anchor rating of 3.60 (SD = 0.74; between “Sometimes True” and “Often True”). Previous research with carers of inpatients with schizophrenia or major affective disorders have resulted in mean anchor ratings of 3.30 (n = 180; SD = 0.95).<sup>39</sup> The mean anchor ratings were significantly different, with a small effect size:  $t(277) = 2.72$ ;  $p < .01$ ;  $r = 0.16$ . Therefore, the results suggest that carers of persons with BPD experience elevated grief compared to carers of persons with other serious mental illnesses.

Empowerment was measured by two of the included studies with carers of persons with BPD using the Family Empowerment Scale (FES)<sup>40</sup> a 34-item scale based on two dimensions: the level of empowerment (family, service system, community/political) and the way that empowerment is expressed (attitudes, knowledge, behaviors). The measure was originally developed for use with families of children with emotional disabilities. The aggregated FES data for carers of persons with BPD resulted in an average score of 38.74 (n = 99; SD = 13.09). Previous research has reported average scores of 119.43 (n = 67; SD = 14.49) for a sample of carers for disabled children in the United States.<sup>41</sup> These mean scores were significantly different, with a large effect size:  $t(164) = 37.31$ ;  $p < .0001$ ;  $r = 0.95$ . This finding indicates not only that carers of persons with BPD are burdened and grieving, but that their sense of empowerment is seriously impaired. This lack of empowerment is likely of clinical significance since it is four standard deviations lower than the mean endorsed by carers of disabled children.



Table 2: Available data on the characteristics of carers.

Studies	Sample size (n)	Characteristics of carers	n (percentage of sample)	Mean (standard deviation)
Hoffman et al. (2003); <sup>34</sup>	329	Female	275 (83.6%)	
Scheirs & Bok (2007); <sup>35</sup>				
Goodman et al. (2011) <sup>33</sup>				
Hoffman et al. (2003); <sup>34</sup>	428	Age		Mean = 51.2 years
Hoffman et al. (2005); <sup>29</sup>				
Hoffman et al. (2007); <sup>1</sup>				
Scheirs & Bok (2007); <sup>35</sup>				
Goodman et al. (2011) <sup>33</sup>				
Hoffman et al. (2003); <sup>34</sup>	352	Parents	316 (89.8%)	
Hoffman et al. (2005); <sup>29</sup>				
Hoffman et al. (2007); <sup>1</sup>				
Goodman et al. (2011) <sup>33</sup>				
Hoffman et al. (2003); <sup>34</sup>	131	Mothers	74 (56.5%)	
Hoffman et al. (2005); <sup>29</sup>				
Hoffman et al. (2007) <sup>1</sup>				
Hoffman et al. (2003); <sup>34</sup>	131	Fathers	29 (22.1%)	
Hoffman et al. (2005); <sup>29</sup>				
Hoffman et al. (2007) <sup>1</sup>				
Hoffman et al. (2003); <sup>34</sup>	131	Partner/spouse	20 (15.3%)	
Hoffman et al. (2005); <sup>29</sup>				
Hoffman et al. (2007) <sup>1</sup>				
Hoffman et al. (2003); <sup>34</sup>	131	Sibling/children	8 (6.1%)	
Hoffman et al. (2005); <sup>29</sup>				
Hoffman et al. (2007) <sup>1</sup>				
Hoffman et al. (2003); <sup>34</sup>	256	College graduate or above	158 (61.7%)	
Goodman et al. (2011) <sup>33</sup>				
Hoffman et al. (2003); <sup>34</sup>	291	Income > U.S.\$50,000	213 (73.2%)	
Hoffman et al. (2005); <sup>29</sup>				
Goodman et al. (2011) <sup>33</sup>				
Hoffman et al. (2003); <sup>34</sup>	87	Living with the person with BPD	55 (63.2%)	
Hoffman et al. (2007) <sup>1</sup>				
Hoffman et al. (2003); <sup>34</sup>	131	Burden (Burden Assessment Scale)		Mean = 43.9 (SD = 11.62) <sup>a,b</sup>
Hoffman et al. (2005); <sup>29</sup>				
Hoffman et al. (2007) <sup>1</sup>				

Hoffman et al. (2005); <sup>29</sup>	99	Depression (Revised Center for Epidemiologic Studies Depression Scale)	Mean = 27.1 (SD = 8.8) <sup>b</sup>
Hoffman et al. (2007) <sup>1</sup>			
Hoffman et al. (2005); <sup>29</sup>	99	Grief (Grief Scale)	Mean = 54.0 (SD = 11.1) <sup>b</sup>
Hoffman et al. (2007) <sup>1</sup>			
Hoffman et al. (2005); <sup>29</sup>	99	Mastery (Family Empowerment Scale)	Mean = 38.7 (SD = 13.1) <sup>b</sup>
Hoffman et al. (2007) <sup>1</sup>			

<sup>a</sup> Sanders and Pearce (2010)<sup>28</sup> also measured burden with the Burden Assessment Scale but provided no descriptive statistics; that study is therefore not included in the calculation of this mean total.

<sup>b</sup> Hoffman et al. (2005, 2007)<sup>1, 29</sup> provided descriptive statistics for multiple time points; only baseline measures were included in the calculation of this total data.

### *Carer well-being*

The carers' own mental health and well-being was measured in five of the six included studies (see Table 1). Two of the studies measured depression experienced by carers of persons with BPD with the Revised Center for Epidemiological Studies Depression Scale,<sup>39</sup> yielding an average score of 27.10 (SD = 8.84), with a potential range of 0 to 60. Previous research with carers of persons with schizophrenia or major affective disorder resulted in an average score of 15.84.<sup>39</sup> Unfortunately, the previous data with carers of persons with schizophrenia or major affective disorder did not report the standard deviation, which would have allowed statistical analysis of the difference in mean scores on carer well-being. However, the difference between the above means is clinically significant. Scores higher than 16 have been interpreted as indicating clinical depression,<sup>39,42</sup> which was exceeded by carers of persons with BPD (mean = 27.10) yet not by previous research with carers of persons with schizophrenia or major affective disorders (mean = 15.84). Therefore, carers of persons with BPD experience symptoms consistent with samples with clinical depression.

Table 3: Available data on the characteristics of persons with BPD.

Studies	Sample size (n)	Characteristics of person with BPD	n (percentage)	Mean
Hoffman et al. (2003); <sup>34</sup>	329	Female	315 (95.7%)	
Scheirs & Bok (2007); <sup>35</sup>				
Goodman et al. (2011) <sup>33</sup>				
Hoffman et al. (2003); <sup>34</sup>	354 <sup>a</sup>	Age		27.0 years
Hoffman et al. (2005); <sup>29</sup>				
Hoffman et al. (2007); <sup>1</sup>				
Goodman et al. (2011) <sup>33</sup>				
Hoffman et al. (2005); <sup>29</sup>	89 <sup>a</sup>	Years since onset of disorder		10.8 years
Hoffman et al. (2007) <sup>1</sup>				
Hoffman et al. (2003); <sup>34</sup>	320 <sup>a</sup>	Hospitalizations		3.7 times
Hoffman et al. (2007); <sup>1</sup>				
Goodman et al. (2011) <sup>33</sup>				

<sup>a</sup> Since Hoffman et al. (2007)<sup>1</sup> did not specify the number of persons with BPD in their study, the number of persons with BPD was assumed to be equal to that of the sample size of carers (n = 55).

One study used the Symptom Checklist–90 and found that Dutch carers of persons with BPD were elevated on all subtests of anxiety, agoraphobia, depression, somatization, insufficiency of thinking and acting, distrust, hostility, and sleeping problems compared to the general Dutch population.<sup>35</sup>

Taken together, the included studies indicate that carers of persons with BPD experience objective and subjective burden, grief, impaired empowerment, and their own mental health problems, including depression and anxiety.

### *Generalizability*

Five of the six included studies were specific to carers of persons with BPD, and as noted earlier, data that could be aggregated were available only for carers of persons with BPD. Further, the majority of reviewed research has focused on carers of female patients (see

Table 3), and the majority of identified carers are parents, particularly mothers (see Table 2). The search strategy and intention was to study all personality disorders and to study patients and their carers of both genders; the outcome of this strategy revealed large gaps in the literature about other personality disorders.

## **DISCUSSION**

The present study aimed to systematically review and synthesize the available demographic and empirical data on the burden and support needs of families, partners, and carers of persons with personality disorders. Although the study aimed to research the broad impact of caregiving for any personality disorder, data on the experience of carers of persons with personality disorders other than borderline are nonexistent. However, this study is the first to report demographic and empirical data on the largest aggregated sample size in the literature regarding carers of persons with BPD, resulting in important clinical and research implications. Six studies were eligible by the inclusion criteria.

As expected, research in the area has increased in recent years; indeed, the earliest study included here dates from 2003. The findings suggest that carers of persons with BPD experience elevated objective and subjective burden, grief, and impaired empowerment, and that they may also report suffering depression and anxiety. Interestingly, much of the available research has been specific to parents, often mothers, caring for persons with BPD. Further, the majority of research on the experience of carers has been limited to those supporting a female person with BPD. These limitations affect the generalizability of the findings. Moreover, the included studies did not share common methods or outcomes; meta-analysis was not feasible.

The included studies allow some empirical insight into the experience of supporting persons with BPD. Three of the included studies measured the experience of burden with carers of persons with BPD using the Burden Assessment Scale. Carers of persons with BPD

endorsed elevated objective and subjective burden approximately half a standard deviation above the mean compared to carers of inpatients with other serious mental illnesses.<sup>38</sup> Items of objective burden include financial problems, limitations on carer activity, disruption of household routines and social functioning (including significant changes in work and in social and family life). The implication is that carers are significantly altering their lifestyles to take into account the needs of their relatives. In terms of subjective burdens, the attitudes and emotions expressed about the caregiving experience include shame, stigma, guilt, worry, and resentment.<sup>36</sup> Therefore, not only are carers burdened in observable ways (e.g., financially or through disrupted routines), but they are also burdened in their internal experience (including conflicts around love and resentment). Previous qualitative research by Giffin<sup>43</sup> (p135) with parents of persons with BPD has documented the intense mother-daughter caregiving relationship as characterized by conflicting emotions of love and anger; as one mother noted, she “gave so much, but got nothing in return.” Further, carers of persons with BPD have been reported by Ekdahl and colleagues<sup>44</sup> (pp e71, e72) to describe the experience as “I don’t dare to live my own life in the same way as before, I adjust all the time and I worry, worry every minute,” and as living life “on tiptoes.”

Grief and empowerment were also important themes. Carers of persons with BPD endorsed elevated grief compared to carers of inpatients with schizophrenia or major affective disorders.<sup>39</sup> The experience of grief has been described in previous qualitative research by Ekdahl and colleagues<sup>44</sup> (p e72) as having two dimensions. One is the loss of the potential life that persons with BPD could have had—a grief described as “[p]owerlessness, not being able to help, to watch her youth go down the drain and know that my daughter also knows.” The other is *lifelong grief*, in which carers express concern for the future, especially about who will care for the person with personality disorder once the carers themselves are no longer able to do so. Therefore, carers of persons with BPD endorsed that they are

burdened and grieving, including being concerned for the future. Ideally, burden and grief would be somewhat alleviated through effective interactions with mental health services, but carers also endorsed impaired empowerment, suggesting that this is currently not occurring.

The aggregated Family Empowerment Scale data indicated not only that carers of persons with BPD are burdened and grieving, but that they experience a sense of impaired empowerment. Carers have reported difficulties with the mental health system in previous qualitative research—including that the system has provided inconsistent or contradictory advice, lacked empathy, and failed to include carers in treatment and in discharge planning.<sup>43,44</sup> Further, carers have endorsed dissatisfaction with the clinical treatment of their daughters with BPD.<sup>33</sup> Therefore, carers of persons with BPD experience elevated objective and subjective burden, grief, and impaired empowerment—which, combined, would likely affect the carers' own well-being.

The included studies also provided data specifically on the carers' own mental health and well-being. Data from the Revised Center for Epidemiological Studies Depression Scale indicated that carers of persons with BPD experience their own mental health problems, including symptoms consistent with depression and anxiety. A further study reported that Dutch carers of persons with BPD endorsed elevated anxiety and depression compared to the general Dutch population.<sup>35</sup> Qualitatively, carers have described the ongoing “tension” involved in caring for BPD patients, with the consequence that “you don't sleep some nights very much at all,” as reported by Giffin.<sup>43 (p134)</sup> Likewise, the rollercoaster milieu of parents is evident in the remark that “we live through our children, if they feel good we feel good,” as reported by Ekdahl and colleagues.<sup>44 (p e72)</sup> It nevertheless remains unclear to what extent carers' compromised sense of well-being preceded the caregiving relationship (and thus was a preexisting source of carer psychological distress contributing to the results) and to what extent it reflects the burden of the caregiving role itself. That said, previous research has

reported the chronic and traumatic stress of families and carers who have witnessed self-harm, impulsive anger, and other destructive behaviors of their loved ones with BPD—events that would surely cause repeated distress, even trauma, and seriously affect carers' well-being.<sup>43</sup> Therefore, notwithstanding some uncertainty as to cause and effect regarding carers' sense of well-being, they experience elevated objective and subjective burden, grief, impairments in empowerment, and difficulties in their own mental health and well-being.

Interestingly, the majority of identified carers in the included studies have been parents (and specifically mothers) to female daughters with BPD. The mean age of the persons with BPD in the present aggregated sample was 27.02 years, and the average number of years since onset was 10.76 (see Table 3). The average age of symptom emergence was therefore approximately 16 years, which is consistent with previous research on the development of BPD.<sup>45</sup> From a psychosocial perspective, this age is crucial in developing both a sense of identity (often significantly impaired in persons with BPD) and intimacy with others outside of the immediate family—and thus in separating from parents. Specifically, Erik Erikson's psychosocial theory of development described the adolescent and early adulthood stages as involving ego conflicts of identity versus role confusion and of intimacy versus isolation.<sup>46</sup> It is therefore possible that during the emergence of BPD symptoms in adolescence, which would presumably present difficulties in developing a sense of self and in transitioning into early adulthood (including forming intimate relationships), the parent-child (in particular, the mother-child) dyad may remain the patient's primary relationship. In qualitative research, for example, the mother-daughter relationship has been described as intensified when the daughter developed symptoms of BPD.<sup>43</sup> Further, an influential case study regarding a complex female client with BPD described the therapeutic importance of exploring the relationship with her mother and of creating separation in the recovery process—which facilitated the development of an intimate relationship with a suitable partner.<sup>47</sup> Psychosocial

development theory may also be relevant in understanding the high proportion of parents (particularly mothers) who identified as the primary carers.

The present review served to identify the existing limitations of research concerning carers of persons, of either gender, with personality disorders. The majority of research has focused on carers of persons with BPD in particular, and data on the experience of burden, grief, empowerment and well-being of carers of persons with other personality disorders is nonexistent. Since all personality disorders are characterized by maladaptive interpersonal styles, it is likely that carers of persons with other personality disorders (such as antisocial, histrionic, or narcissistic personality disorder) would experience similar burdens, grief, and interpersonal challenges in their supportive role. Further, the high comorbidity among the DSM-IV personality disorders suggests that patients often suffer from more than one personality disorder.<sup>6,48</sup> Although these considerations suggest that the findings of studies specific to carers of persons with BPD could possibly be generalized to carers of persons with personality disorders, future research may benefit by comparing the burden and support needs of carers of persons with different personality disorders.

In the studies reviewed here, the carers of female persons with BPD are overrepresented. Although clinical samples have found a larger prevalence of females diagnosed with personality disorders in general,<sup>48-50</sup> epidemiological research with community samples has indicated that personality disorder diagnoses (in particular, of BPD) are balanced across gender.<sup>6,8</sup> Thus, whereas clinical services (and by the same token, the studies presented here) may engage more female patients— perhaps as a result of differences in personality disorder manifestation, with females presenting as internalized, and males as externalized, in impulsivity and affective dysregulation<sup>6,51</sup>—carers in the community may be supporting more evenly divided populations of males and females with borderline or other



personality disorders. It is a challenge for the field to identify and include males in future studies.

The present study is the first to systematically review previous research and to present the empirical data on a large, aggregated sample of carers of persons with BPD. The findings indicate that carers of a person with BPD are burdened (both objectively and subjectively), grieving, and impaired in their sense of empowerment, and that they may experience their own mental health problems. Importantly, it appears that objective and subjective burden and grief in the aggregated sample of carers of persons with BPD may be more elevated compared to carers of persons with other serious mental illnesses. The research also suggests that support interventions may be beneficial to carer well-being, though the small sample sizes and short follow-up periods necessitate further research in order to reach firm conclusions. The present findings were limited due to five of the six included studies being specific to carers of persons with BPD. Further research is needed on other personality disorder diagnoses, and the carers of male patients with personality disorders need to be included. In the meantime, however, it is clear that carers of persons with BPD are seriously burdened. Developing effective means of support would obviously improve carer well-being and would also, most likely, benefit the patients themselves.

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