

## **Caregiving burden and psychological distress among spouses of bipolar patients. Comparative analysis of subtype I and II**

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### **Summary**

**Aim.** To assess the level of caregiving burden and psychological distress among spouses of bipolar disorder – BD (type I and II) patients.

**Methods.** 77 subjects (41 women and 36 men) were enrolled in the study – 44 spouses of bipolar I (BD I) patients and 33 spouses of bipolar II (BD II). The whole group was divided into 4 subgroups: (I) the wives of BD I patients: n=27, (II) the husbands of BD I patients: n=17, (III) the wives of BD II patients: n=14, (IV) the husbands of BD II patients: n=19. The research methods: Involvement Evaluation Questionnaire – IEQ and General Health Questionnaire – GHQ-12.

**Results.** Manic phase of BD I is more burdensome than episodes of depressed mood (BD I) and hypomania (BD II). Depression in BD II results in a significantly greater burden than hypomania. Spouses of BD I patients experience a higher level of burden. Women are generally more burdened with the patient care regardless of the episode. Partners of bipolar patients (type I and II) experience the same high level of psychological distress.

**Conclusions.** The specific types of bipolar disorder (I and II) have the different impact on partners, which affects their subjective and objective burden and relationship with patients, indicating a real need to offer them an adequate help, depending on subtype of patient's bipolar disorder, as well as the spouse sex.

**Key words:** bipolar disorder, burden, marriage

## Introduction

In contrast to the families of patients treated for schizophrenia in which the early onset and progression often prevents starting a family and thus the responsibility for patient care belongs to parents or siblings, in the families of patients with affective disorders, these are the life partners or spouses who experience severe burden in the first place [1-3].

The life of close relatives (including spouses) of persons diagnosed with bipolar disorder (BD) is associated with emotional distress, depression and high frequency of use of mental health services [4-10]. Most caregivers of patients suffering from BD experience significant disruption in social activities and leisure time (especially when patient is unwell), which in particular refers to the partners. The negative impact of the illness also affects such issues as relationships with friends, family and acquaintances, which results in narrowing of social network and stigmatization. In addition, it should be emphasized that family members (especially spouses) of those with bipolar disorder feel isolated and forced to sacrifice their social life more often than in the case with other mental illness [11]. The caregiving role, apart from being very demanding, is harmful to health and decreases quality of life as well [12-13].

The research data show that in the context of different variables, the caregiving role compromises other social roles occupied by the caregiver, which demonstrates a special kind of psychosocial costs of bipolar disorders incurred by patient's close relatives. Few of these variables relate to the patient's gender (men suffering from BD are more likely to have substance abuse issue, to pathological gamble and to report behavioural problems – [14]) or the length of illness (longer duration is associated with a greater caregiving burden – [1, 15]). Burden is also affected by severity of illness (defined as percentage of time the patient is unwell) and specific symptoms related to phase of bipolar disorder (aggressive and violent behaviour during mania and depressed mood, withdrawal or suicidal thoughts and attempts in depression) [13, 16, 17].

There is no doubt that every episode of the illness is a stressful life event for all the family members and, even when the patient's condition is stable, the fear of new relapses and exacerbations of symptoms is constantly present. [17] According to Reinares et al. [18] partners also experience stress during patient's remission, because even in this phase, residual symptoms may still be present in a high proportion of patients and affect both sufferer's and partner's quality of life. Also in the Polish study, Borowiecka-Karpiuk [19] demonstrated that the level of burden among spouses of BD patients during euthymia – particularly in terms of subjective burden – is significant.

While the impact of affective disorders (including bipolar disorder) on the spouses has been the subject of many studies (unfortunately mostly based on small samples), we know much less about how the subtypes of bipolar disorder and their specific symptomatology as well as spouse sex (and consequently patient's sex) influence simultaneously. However, it seems that the diverse clinical picture of BD subtypes (I and II) and the partner's gender (different social roles, individual differences, gender stereotypes) may influence the potential differences in spousal burden.

It should be also noted that, the tools that are used in a significant part of the research concerning assessment of caregivers' burden among those who take care about BD patients don't take into consideration the cyclical nature of this illness. What is more, in the majority of analyses manic and hypomanic episodes are included into the same comparative group, which results in a lack of differentiation between the serious consequences of mania and potentially positive aspects of hypomania [20]. This study takes into account this issue by adjusting the measurement tools and including such variable as "bipolar subtype".

### Aim of the study

The aim of the study was to assess the impact of bipolar disorder (type I and II) on a healthy partner (male or female), including: the assessment of caregiving burden during the particular episodes of BD and the level of psychological distress

### Material and methods

77 subjects (41 women and 36 men) were enrolled in the study – 44 spouses of bipolar I (BD I) patients and 33 spouses of bipolar II (BD II) patients. The whole group was divided into 4 subgroups: (I) the wives of BD I patients:  $n = 27$ , (II) the husbands of BD I patients:  $n = 17$ , (III) the wives of BD II patients:  $n = 14$ , (IV) the husbands of BD II patients:  $n = 19$ . Study groups did not differ in terms of basic socio-demographic data, except for the rate of comorbidities related to BD. We reported that in group of ill spouses (patients) diagnosed with BD II there was a significantly higher percentage (57.6%) of persons with co-occurring disorders (such as panic disorder, generalized anxiety disorder, personality disorders and/or obsessive-compulsive disorder) than in group with BD I (25%), which was particularly revealed in comparison between female patients with BD II (68.5% persons with comorbidities) and male patients with BD I (18.5% persons with comorbidities) (see Table 1.). These differences correspond with the well-established knowledge about comorbidity of bipolar disorder [21].

Table 1. Characteristics of study groups (group I – the wives of BD I patients, group II – the husbands of BD I patients, group III – the wives of BD II patients, group IV – the husbands of BD II patients).

STUDY GROUPS	Group I ( $n = 27$ )	Group II ( $n = 17$ )	Group III ( $n = 14$ )	Group IV ( $n = 19$ )	I vs. II vs. III vs. IV
					ANOVA df = 73
Age (range)	$37.7 \pm 11.9$ 20–62	$43.8 \pm 12.2$ 21–62	$40.2 \pm 14.6$ 23–63	$34.0 \pm 11.2$ 24–66	$p = 0.13$
Patient's age (range)	$40.0 \pm 12.3$ 20–65	$39.9 \pm 12.8$ 21–59	$42.1 \pm 15.4$ 24–68	$32.3 \pm 11.0$ 21–63	$p = 0.11$

*table continued on the next page*

Duration of illness – years (range)	9.2 ± 9.0 1.5–35	9.8 ± 8.3 1.1–30	11.7 ± 9.4 1–36	6.3 ± 5.5 1–22	p = 0.40
Number of years married (range)	12.6 ± 10.3 0.5–40	16.1 ± 13.5 1–39	15.4 ± 15.0 2–44	10.0 ± 9.1 0.5–41	p = 0.52
					Test – $\chi^2$
Education					
Vocational	1 (3.7%)	3 (17.6%)	2 (14.3%)	2 (10.5%)	p = 0.31*
Secondary	7 (25.9%)	8 (47.1%)	3 (21.4%)	6 (31.6%)	
Higher	19 (70.4%)	6 (35.3%)	9 (64.3%)	11 (57.9%)	
Employment status					
Employees	17 (63.0%)	14 (82.4%)	10 (71.4%)	15 (78.9%)	p = 0.81*
Non-employees	3 (11.1%)	0 (0%)	0 (0%)	2 (10.5%)	
Retired/Pensioners	4 (14.8%)	2 (11.7%)	2 (14.3%)	1 (5.3%)	
Students	3 (11.1%)	1 (5.9%)	2 (14.3%)	1 (5.3%)	
Episode of illness					
Depression	4 (14.8%)	5 (29.4%)	8 (57.1%)	6 (31.6%)	p = 0.07*
Hypomania/Mania	12 (44.5%)	6 (35.3%)	4 (28.6%)	2 (10.5%)	
Remission	10 (37.0%)	5 (29.4%)	2 (14.3%)	10 (52.6%)	
Mixed	1 (3.7%)	1 (5.9%)	0 (0%)	1 (5.3%)	
Substance use <sup>1</sup> (patient)					
Absence	11 (40.7%)	9 (53.0%)	9 (64.3%)	12 (63.2%)	p = 0.41*
Substance misuse	13 (48.2%)	4 (23.5%)	4 (28.6%)	4 (21.0%)	
Addiction	3 (11.1%)	4 (23.5%)	1 (7.1%)	3 (15.8%)	
Comorbidity <sup>2</sup> (patient)					
Not known	9 (33.3%)	3 (17.6%)	4 (28.6%)	2 (10.5%)	<b>p = 0.03**</b>
No	13 (48.2%)	8 (47.1%)	4 (28.6%)	4 (21.0%)	
Yes	5 (18.5%)	6 (35.3%)	6 (42.8%)	13 (68.5%)	

<sup>1</sup>nicotine, alcohol, medications and/or illicit drugs

<sup>2</sup>panic disorder, generalized anxiety disorder, personality disorders and/or obsessive-compulsive disorder

\*Fisher's Exact Test (Freeman-Halton extension of the Fisher's exact probability test for 3x4 or 4x4 contingency table)

\*\*Results calculated for 2x4 contingency table (presence or absence of comorbidities)

Bolded "p" value denotes statistically significant results.

The following questionnaire survey was conducted among the subjects:

- 1) Involvement Evaluation Questionnaire – IEQ, which was designed in the Netherlands by a team led by Bob van Wijngaarden. It is a 31-item questionnaire. A total of 27 items can be summarized in four distinct sub-scales: tension (nine items), worrying (six items), supervision (six items), and urging (eight items) – two items belong to more than one domain. The results of the questionnaire are calculated as the mean value of each dimension and the total mean value of all 27 questions. All items are scored on 5-point Likert scale and answers are graded according to

- the intensity of the specific event (“never”, “sometimes”, “regularly”, “often”, and “always”). The results can be also dichotomized – 0 or 1 point means “no consequences” and 2 or more points – “serious consequences” [22-24]. In the original version of the tool, the questions refer to the last four weeks before the completion of questionnaire. For the purpose of this study, the time frame mentioned above has been modified, thus the questions referred to the specific phases of the disease, owing to which there is a possibility to differentiate caregiving burden in: a) depressive phase, b) hypomania/mania phase, c) remission phase, well as d) generally for all 3 phases of the disease (overall burden). The internal consistency (Cronbach’s  $\alpha$ ) of the modified version ranges from 0.53–0.84 for the sub-scales to 0.88 for the sum score (in version used to assess burden during depression); from 0.68–0.91 for the sub-scales to 0.90 for the sum score (in version used to assess burden during hypomania/mania) and from 0.61-0.90 to 0.91 for the sum score (in version used to assess burden during euthymia).
- 2) General Health Questionnaire – GHQ-12 developed by David Goldberger at the beginning of the 1970s. This version is a screening instrument to provide information on the mental wellbeing and measure the psychological distress. One of two basic ways to scale response is used to this method used. For the purpose of this study the scoring method proposed by Goldberg (0-0-1-1) was chosen over the simple Likert scale scoring method of assigning weights of 0-1-2-3 to the answerws, as this particular method has a strong discriminatory power. The results were measured on a scale from 0 to 12. According to the most common formula used to the shortest GHQ version, the cut-off point was at the level of 2/3 (a score of 2 or less indicating the absence of mental illness and score of 3 or higher – the presence of disorder) [25].

Statistical analysis was conducted on the basis of quantitative or qualitative data. Student’s t-test and two-way Analysis of Variance (ANOVA) – also with repeated measures, followed by appropriate post-hoc tests – were used for the comparison of quantitative variables. Comparisons between qualitative variables were performed using the  $\chi^2$  test [26-27].

## Results

### Involvement Evaluation Questionnaire (IEQ)

#### *Depression*

During the depressive episode of bipolar disorder, the total score of caregiver burden, as well as an experienced tension turned out to be significantly higher among women (respectively – women: 2.04 vs. men: 1.68;  $p \leq 0.01$  for total score; women: 1.77 vs. men: 1.32;  $p \leq 0.01$  for tension). It was also observed that the level of supervision during depression can be affected by subtype of BD (1.31 – spouses of BD I patients vs. 0.95 – spouses of BD II patients;  $p \leq 0.05$ ).

### *Hypomania/Mania*

Women were generally more burdened than men during the hypomanic/manic phase as well (it concerns such aspects of burden as total score, tension and supervision;  $p \leq 0.01 - \leq 0.001$ ). In addition, every sub-scale of caregiving burden (except for „urging”) was affected by subtype of BD (a higher burden among spouses of BD I patients;  $p \leq 0.001$  in each case).

### *Remission*

During remission, regardless of patient’s subtype of BD, women scored higher on each sub-scale of caregiving burden than men ( $p \leq 0.05 - \leq 0.001$ ) except for the sub-scale “worrying”– in this case the results turned out to be non-significant.

### *Overall burden (depression, hypomania/mania, remission) and comparison between phases of BD*

Two-way analysis of variance (ANOVA) for repeated measures showed that regardless of episode women were more burdened than men (women: 1.82 vs. men: 1.33,  $p \leq 0.001$ ) and that spouses of BD I patients experienced a higher burden than spouses of BD II patients (BD I: 1.73 vs. BD II: 1.38,  $p \leq 0.01$ ).

The results also indicate a significant difference in the overall level of burden depending on the phase of BD – depression and hypomania/mania caused a significantly higher load than remission ( $p \leq 0.001$ ). Additionally, the interactive effect of phase and subtype of BD was also significant:

- 1) depression in the course of BD I turned out to be:
  - a) significantly less burdensome for spouses than the manic phase ( $p \leq 0.05$ );
  - b) significantly more burdensome than remission (in BD I and BD II alike;  $p \leq 0.001$ );
  - c) significantly more burdensome than hypomania of BD II ( $p \leq 0.01$ );
- 2) manic phase in the course of BD I was:
  - a) significantly more burdensome than depression of BD I mentioned above ( $p \leq 0.001$ );
  - b) significantly more burdensome than remission (in BD I and BD II alike;  $p \leq 0.001$ );
  - c) significantly more burdensome than hypomania of BD II ( $p \leq 0.001$ );
- 3) depression in the course of BD II was more burdensome than hypomania and remission (in BD II) –  $p \leq 0.01 - \leq 0.001$ , while the two last phases also differed from each other (a higher burden during hypomania –  $p \leq 0.01$ );
- 4) depression in the course of BD I and BD II did not differ from each other in terms of burden experienced by spouses;
- 5) there was no difference between caregiving burden in remission among spouses of BD I patients and the burden experienced during hypomania in group of subjects involved with BD II patients;

### *Tension*

In the context of overall tension, higher scores were reported among:

- a) group of women in comparison with men (women: 1.99 vs. men: 1.26;  $p \leq 0.001$ );
- b) spouses of BD I patients in comparison with spouses of BD II patients (BD I: 1.81 vs. BD II: 1.39;  $p \leq 0.01$ ).

We also found that, in general, the episodes of elevated mood (regardless of subtype of BD and spouse sex) caused a greater tension than depressive episodes and remission ( $p \leq 0.001$ ), while these two last also differed from each other (a higher tension during depression –  $p \leq 0.001$ ).

Those who experienced the highest tension were spouses of BD I patients during manic phase ( $p \leq 0.001$ ). The analysis also showed that a significantly greater tension was present among spouses:

- a) during depression in the course of BD I in comparison with remission (in BD I –  $p \leq 0.001$  and BD II –  $p \leq 0.01$ );
- b) during depression and hypomania (BD II) in comparison with remission (in BD I –  $p \leq 0.01$  and BD II –  $p \leq 0.001$ ).

### *Worrying*

Significantly higher mean score on the sub-scale “worrying” among women in comparison with men (women: 2.52 vs. men: 2.13;  $p \leq 0.05$ ) was observed in this study.

The phases of BD had also a significant impact on this aspect of burden (regardless of subtype of illness and spouse sex) – a higher level of worrying during depression and hypomania/mania compared with remission ( $p \leq 0.001$ ) was reported.

One more time, spouses of BD I patients diagnosed as having a manic episode experienced the highest level of worrying, but at the same time this result did not differ from the assessment of spouses of BD II patients during depression.

Similarly to the sub-scale “tension”, during depression among patients with BD I or BD II spouses were more worried than during patient’s remission (BD I and BD II alike –  $p \leq 0.001$ ).

The level of worrying decreased among spouses of BD II patients during hypomania and remission (in comparison with depression:  $p \leq 0.01$  –  $\leq 0.001$ ), although the mean score on the same sub-scale during remission (BD II) is also lower than during episodes of elevated mood (BD II):  $p \leq 0.01$ .

The hypomanic phase in the course of BD II did not differ from remission in BD I in this area.

### *Supervision*

The level of supervision was significantly higher among:

- a) women in comparison with men (women: 1.26 vs. men: 0.81;  $p \leq 0.001$ );

b) spouses of BD I patients in comparison with persons involved with BD II patients (BD I: 1.21 vs. BD II: 0.78;  $p \leq 0.01$ ).

Those who had to supervise one's ill partner most often were spouses of BD I patients during manic episode. Depressive episodes (BD I) in comparison with remission (BD I and BD II) required more attention as well ( $p \leq 0.001$ ). The level of supervision increased also during depression and hypomania (BD II) in comparison with remission in BD II ( $p \leq 0.01$ ), but there was no difference in comparison with remission in BD I. Additionally, it is worth to mention that the level of supervision was the highest when the patient's mood was elevated (regardless of subtype and spouse sex).

### *Urging*

In case of sub-scale "urging", the analysis showed that women were characterized by a higher mean score on this scale than men (women: 1.62 vs. men: 1.28;  $p \leq 0.05$ ).

The phase of BD was also significant– the mean score on the scale "urging" was higher ( $p \leq 0.001$ ) when concerned depressive episodes than hypomania/mania or remission.

The analysis of qualitative data indicated that accepting attitude toward patient's mental illness was significantly more frequent among men than women, which concerned especially husbands of women with BD I and BD II in comparison with wives of patients diagnosed with BD I (see Table 2.).

The fact of being woman married to an ill person, as well as type I of bipolar disorder were also associated with a negative change in the relationship, which was due to the presence of the disorder. At the same time, women, more often than men, declared that during patient's hypomania/mania or remission they were able to take care of partner and pursue their own interests. This effect especially refers to the wives of BD II patients (see Table 2.)

In the context of coping with the patient's problems during the specific episodes of BD, it turned out that the significant difference concerned mainly the hypomanic/manic phase during which the majority of spouses of BD II patients declared that they coped with it more frequent than never or rarely (see Table 2.).

**Table 2. The results of Chi<sup>2</sup> test for IEQ questionnaire (MI – the husbands of BD I patients; MII – the husbands of BD II patients; FI – the wives of BD I patients; FII – the wives of BD II patients).**

IEQ	$\chi^2$ test	p	DIFFERENCES
Acceptance of illness	Sex: 6.28	<b>0.01</b>	M(72%) > F(44%)
	Type: 0.70	0.40	---
	Sex x Type: 8.04	<b>0.05</b>	MI(77%) > FI (37%)**; MII(68%) > FII(37%)*

*table continued on the next page*

Negative change in the relationship		Sex: 5.43	<b>0.02</b>	F(76%) > M(50%)
		Type: 3.67	<b>0.05</b>	I(73%) > II(52%)
		Sex x Type: 8.60	<b>0.04</b>	FI(78%) > MII(37%)*; MI(65%) > MII(37%)*; FII(71%) > MII(37%)*
Ability to pursue one's own interests	Sex	Depression: 2.78	0.10	---
		Hypomania/Mania: 4.38	<b>0.04</b>	F(73%) > M(50%)
		Remission: 5.29	<b>0.02</b>	F(90%) > M(69%)
	Type	Depression: 3.37	0.07	---
		Hypomania/Mania: 0.04	0.84	---
		Remission: 2.97	0.08	---
	Sex x Type	Depression: 4.84	0.18	---
		Hypomania/Mania: 8.01	<b>0.05</b>	FII(93%) > MI(53%), MII(47%)*
		Remission: ---	0.15 <sup>1</sup>	---
Coping with patient's problems	Sex	Depression: 0.06	0.80	---
		Hypomania/Mania: 0.09	0.76	---
		Remission: 0.74	0.39	---
	Type	Depression: 0.65	0.42	---
		Hypomania/Mania: 13.69	<b>&lt;0.001</b>	II(70%) > I(27%)
		Remission: 0.02	0.88	---
	Sex x Type	Depression: 3.35	0.34	---
		Hypomania/Mania: 17.92	<b>&lt;0.001</b>	MII(79%) > FI(37%)*, MI(12%)*; FII(57%) > MI(12%)*
		Remission: ---	0.18 <sup>1</sup>	---

\*p ≤ 0.05; \*\* p ≤ 0,01; \*\*\* p ≤ 0001; <sup>1</sup>Fisher's Exact Test (respectively for Freeman-Halton extension tables 2x2 or 2x4); Bolded "p" value denotes statistically significant results.

### General Health Questionnaire (GHQ-12)

Neither spouse sex nor type of bipolar disorder, and thus none of the subgroups of subjects differentiated the score of General Health Questionnaire (GHQ-12) and significantly affected the incidence of serious health consequences, since they were present in each case (regardless of the grouping variable) at least among 88% of the respondents (see Figure 1.).

### Conclusions and discussion

The results obtained during the investigation led to the following, generalized conclusions: 1) the episode of elevated mood results in a significantly higher caregiv-

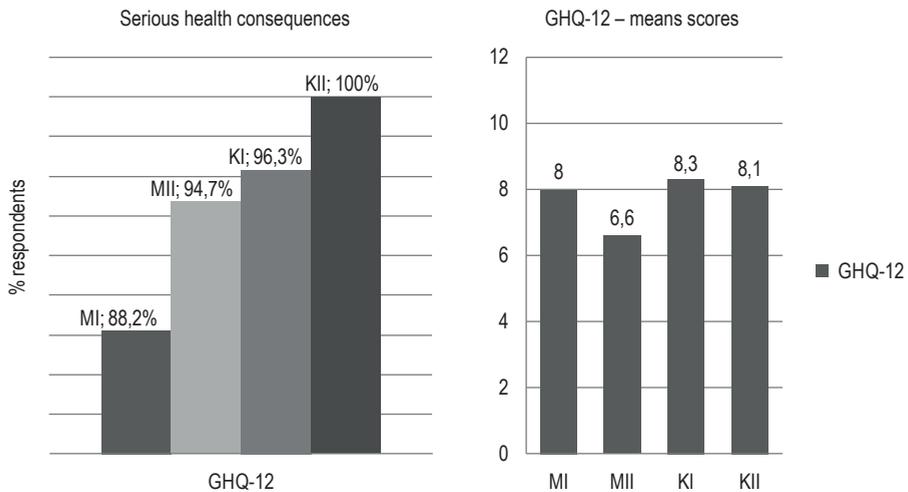


Figure 1. The results of GHQ-12 questionnaire (MI – the husbands of BD I patients; MII – the husbands of BD II patients; KI – the wives of BD I patients; KII – the wives of BD II patients).

ing burden among partners of BD I patients (in comparison with spouses of BD II patients) and is a significantly greater load than the patient care during depression (BD I); 2) among partners of persons diagnosed with BD II the patient care during the depressive episode is a significantly greater burden than during hypomania; 3) depression of BD I causes an increase in the level of supervision among spouses; 4) women feel generally more burdened with the patient care regardless of the episode; 5) spouses of BD I patients experience a higher level of overall burden; 6) the specific episodes of BD have impact on the particular aspects of burden; 7) men accept wife's mental illness more frequent than women; 8) BD I affects the relationship negatively; 9) women experience more negative changes in the relationship due to the presence of husband's illness; 10) women are able to reconcile the role of caregiver with other everyday tasks more frequent than men; 11) partners of BD patients (type I and II) experience the same high level of psychological distress (serious health consequences).

As the conclusions showed, the varied clinical course of bipolar disorder (type I and II), as well as patient and spouse sex have a fundamental impact on the experience of caregiving. In this study (as well as in other analyses – [1, 2, 17]) a high level of burden among spouses, which is caused primarily by specificity of particular episodes of BD, severity of symptoms and the dominant pathology (depending on the subtype of BD) was reported.

The results of the study prove that in the case of spouses of BD I patients, the leading cause of burden is manic episode, and thus correspond with the results obtained by Dore and Romans [17] who found that the manic episode was more burdensome for 30% caregivers (including spouses) of BD I patients (in comparison with 19% subjects who pointed the depressive episodes as the source of their problems). As regards to

the partners of patients diagnosed with BD II, in this case burden is primarily associated with depression.

In addition, episodes of elevated mood, depending on the clinical course of the subtypes of BD, lead to fundamental differences in the spouses' experience of patient's illness on the basis of which we can make a distinction between the effects of severe mania and milder, non-disabling hypomania [20].

In this analysis such factor as gender also deserves attention. As demonstrated in other studies [28], as well as in ours, being a woman was associated with a higher level of burden during each of the episodes (also during remission, which is consistent with the results obtained by Dore and Romans or Borowiecka-Karpiuk [17, 19]). It should be also noted that women were significantly less likely to accept the husband's mental illness, which seems to be very important conclusion for those couples, in which the illness affects men.

What is important, both women and men participating in the study, experience a high level of distress (above the cut-off point), resulting in serious health consequences and qualifying them to receive counselling, which indicates that burden is present among both sexes, but there are different sources of it. This conclusion is comparable to the results obtained by Lam et al. [13] who investigated the subjective burden as well as costs incurred due to the illness and found that 46% of subjects involved with BD patients scored above cut-off point on GHQ-28, which was the evidence of mental malaise.

Summing up, this study emphasizes the different impact of bipolar disorder (type I and II) on patients' partners, which affects their subjective (health, stress) and objective (e.g. relationships, leisure time) burden [29] as well as the relationship with ill partner, indicating a real need to offer them an adequate help, depending on the type of BD and spouse sex.

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