Eur. J. Psychiat. 2019;33(2):54–62

THE EUROPEAN JOURNAL OF PSYCHIATRY

www.elsevier.es/ejpsy

ORIGINAL ARTICLE

Burden of informal care for individuals with schizophrenia and affective disorders prior to hospital admission

D. Ignatova[a,*], **M. Kamusheva**[b], **G. Petrova**[b], **G. Onchev**[a]

[a] *Department of Psychiatry and Clinical Psychology, Faculty of Medicine, Medical University - Sofia, Bulgaria*
[b] *Department of Organization and Economics of Pharmacy, Faculty of Pharmacy, Medical University - Sofia, Bulgaria*

Received 5 July 2018; accepted 12 November 2018
Available online 24 December 2018

KEYWORDS
Informal care;
Caregiver;
Family burden;
Schizophrenia;
Affective disorders

Abstract
Background and objectives: Severe mental disorders require informal care, usually provided by family members of the affected. The aim of the study is to examine the burden of informal caregiving for individuals with schizophrenia and affective disorders prior to hospital admission in Bulgaria.
Methods: The study has an observational, cross-sectional, retrospective design. Individuals with schizophrenia and affective disorders and their caregivers are evaluated upon the patients' admission for inpatient treatment. The objective and subjective consequences of providing informal care are evaluated with the Burden Assessment Scale (BAS) as a primary outcome measure. Its factor structure and determinants of high burden of care are examined.
Results: 117 individuals with mental disorder and 117 caregivers are evaluated, dichotomized in two groups according to the patient's diagnosis. The time spent in informal care is 5.7 hours per day (SD = 2.9) for schizophrenia and 3.9 hours per day (SD = 3.0) for affective disorders, $p = .002$. The mean score on the BAS is 44.7 (SD = 11.0) and 42.0 (SD = 12.8) respectively, $p = .221$. A common pattern of the burden with a 5-factor solution explaining 66% of the variance is presented, including the factors Limitations, Conflicts, Guilt, Trap, and Stigma. Contributors for the increase in the BAS are stigma ($p < .001$), history of threats ($p = .014$), supervision for disturbing behaviour ($p < .048$), younger age of the caregivers ($p = .043$), spouses/partners to the patients ($p < .001$), less social contacts ($p = .017$) and provision of informal care on a daily basis ($p = .027$).
Conclusions: The caregivers of individuals with schizophrenia and affective disorders experience considerable objective and subjective burden.

* Corresponding author.
E-mail address: d.a.ignatova@gmail.com (D. Ignatova).

https://doi.org/10.1016/j.ejpsy.2018.11.002

Introduction

Severe mental disorders cause significant disability to the affected individuals and require complex treatment and care.[1] While formal care is carried out in specialized institutions or at home by qualified specialists (health and social workers), informal care is provided by unpaid non-professionals, most commonly family members.[2] With antipsychotic pharmacotherapy and deinstitutionalization allowing for a major reduction in the inpatient stay in acute psychiatric wards and long-stay mental hospitals, the involvement of the relatives with their mentally ill family members has increased.[3] Limitations in personal activities, impairment in the family and social functioning, financial problems as well as psychical and mental health problems are among the negative consequences for the caregivers.[4–6] A recommendation for inclusion of the family burden as a routinely measured outcome in the clinical practice has been suggested.[3,7–9] Among a number of instruments to assess the caregiver's burden,[10–13] the Burden Assessment Scale (BAS) by Reinhard et al.[9] has been pointed out as one of the potential routine carer outcome measurement, albeit modifications and further development have been suggested.[14]

The aim of the study is to examine the caregiver's burden associated with providing informal care for individuals with schizophrenia and affective disorders prior to the patients' admission for psychiatric inpatient treatment in Bulgaria.

Material and methods

Participants

Individuals with schizophrenia or affective disorder admitted for inpatient psychiatric treatment in Alexandrovska University Hospital in Sofia, Bulgaria, and their primary caregivers, were recruited for the study from January 2015 to January 2016. The inclusion criteria were: F2 or F3 ICD-10 patient's diagnosis; age $\geq$18 years, informed consent for participation from the patient and from the caregiver. Exclusion criteria were substance dependence, severe cognitive impairment or severe comorbid somatic illness which could impede the adequate participation in the study. The estimation of the required sample size was based on the possibility of detecting a medium effect size difference in the mean score of the Burden Assessment Scale as a statistically significant result.[15] For each month during the recruitment period, the first five consecutively admitted patients with the eligible diagnosis and their caregivers who meet the inclusion criteria were recruited.

Methods

The study has a cross-sectional retrospective observational design. The participants in were evaluated during the inpatient hospital stay of the patients. The instruments used in the study were: the Burden Assessment Scale (BAS) for evaluation of the caregiver's burden[9]; a modified version of the Clients Socio-Demographic and Service Receipt Inventory (CSSRI-EU)[16] for socio-economic information for the patients and the caregivers; the Clinical Global Impression – Severity Scale (CGI-S)[17] for assessing the severity of illness of the patients.

The Burden Assessment Scale (BAS)[9] is a standardized questionnaire for evaluation of the burden of the informal carers. The respondents are asked to state if they have experienced each of the 19 problems with regard to the caregiving situation in the past 6 months. Rating is made on a four-point scale: 1 (Not at all), 2 (A little), 3 (Some) and 4 (A lot). The total score on BAS is calculated as the sum of the scores of all items. Eight additional questions with yes/no answers with regard to the type of care provided by the caregivers during past 3 months were evaluated for this study. The instrument consist of 19 items, but factor analyses have demonstrated a more complex structure of the burden with five[9] or three underlying subscales.[18]

The CSSRI-EU[16] is a standardized instrument for collection of socio-demographic, economic and resource utilization data for people with severe mental disorders. We adapted the instrument for use with both patients and caregivers to capture the caregiver's loss of resources, i.e. hours per day spent in informal care, days absence from work or days unemployed due to the caregiving role and financial burden. The regular monthly household expenses for the mentally ill family member included spending on accommodation, rent, food, clothes, drugs, bills and other living expenses. Additional costs related to mental state exacerbation and the need for hospitalization of the patient included travel and accommodation costs of the caregiver, costs associated with patient's disruptive or hazardous behaviour such as destruction of property, gambling, excessive spending, etc. The caregivers were asked how much they have spent on these categories for predefined retrospective periods prior to the assessment. A three-month recall period was used for productivity losses, time spent in informal care and regular monthly expenses for the patients, and a six-month recall period for additional costs related to the exacerbation.

The CGI-S[19] scale is a brief instrument for evaluation of the overall severity of illness of any mental disorder, based upon symptoms, behaviour, and functioning in the past seven days. The clinician answers the question ''Considering your total clinical experience with this particular population, how mentally ill is the patient at this time?'' Rating is made on a seven-point scale: 1 (Normal, not at all ill), 2 (Borderline mentally ill); 3 (Mildly ill); 4 (Moderately ill); 5 (Markedly ill); 6 (Severely ill) and 7 (Among the most extremely ill patients).

All costs were converted from the national currency Bulgarian Lev (BGN) to Euro adjusted for the difference in price levels between Bulgaria and the European Union for 2015 using the nominal exchange rate from the European Central Bank (https://www.ecb.europa.eu/stats/policy_and_exchange_rates/euro_reference_exchange_rates/html/eurofxref-graph-bgn.en.html) and the purchasing power parities (PPP) from Eurostat

(http://appsso.eurostat.ec.europa.eu/nui/submitViewTableAction.do). 1 BGN = 0.57 PPP Euro 2015.

Statistical analyses

The statistical analyses used in the study are as follows: *t*-test for independent samples (for comparison of the mean differences between normally distributed variables), Mann–Whitney *U* test (for comparison of the mean differences when distribution is not normal), Chi-square test, Fisher's Exact test and Fisher–Freeman–Halton test (to test for association between categorical variables); principal component analysis with Varimax rotation with Kaiser normalization and extraction based on eigenvalue >1 (for evaluation of the factor structure of the BAS). The predictors of high burden of informal care were identified using a multiple linear (OLS) regression analysis.

Ethics statement

The study was conducted according to the Declaration of Helsinki and approved by the ethics committee of the Medical University of Sofia. All participants gave written informed consent prior to their inclusion in the study. The patients' consent was requested first, followed by caregivers' consent.

Results

Sample characteristics

117 individuals with the evaluated mental disorders and 117 caregivers were recruited for the study. The individuals with schizophrenia ($N = 57$) and affective disorder ($N = 60$) did not differ significantly in age ($t(115) = 1.7$, $p = .093$), gender ($\chi^2(1) = 2.45$, $p = .117$) and severity of illness (''moderately ill'', as measured by the CGI-S: M = 5.2 (SD = 0.9) for the patients with schizophrenia and M = 5.1 (SD = 1.0) for the patients with affective disorder ($U = 1566.5$, $p = .411$). The socio-demographic and economic characteristics were less favourable for the patients with schizophrenia than for the patients with affective disorder. Detailed comparisons of the socio-demographic and economic characteristics of the patients and their caregivers are presented in Table 1.

The caregivers of individuals with schizophrenia were significantly older (M = 55 years, SD = 15) than the caregivers of individuals with affective disorders (M = 49 years, SD = 16 years), $t(115) = -2.02$, $p = .046$). The informal care for individuals with schizophrenia was provided primarily by parents (65% of the caregivers), with the next relatives involved being siblings (12% of the caregivers). In contrast ($p = .001$), providing informal care for individuals with affective disorders was evenly distributed between parents (33% of caregivers), spouses/partners (32%) and children (25% of caregivers). No difference in gender ($\chi^2(1) = 0.001$, $p = .969$), family status ($p = .215$), education ($p = .112$), employment ($p = .735$), and net income of the caregivers ($U = 1235.5$, $p = .191$) was observed.

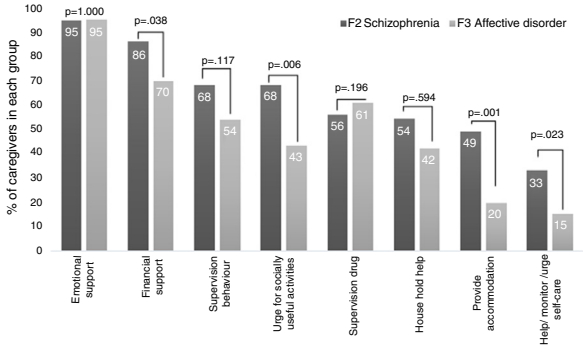

Figure 1 Types of care and % of caregivers providing each type of care for the patients with schizophrenia and affective disorder prior to their hospital admission. *Legend*: Statistically significant *p*-values of the χ^2-test are presented in bold: financial support ($\chi^2(1) = 4.31$, $p = .038$), accommodation ($\chi^2(1) = 11.02$, $p = .001$), urging for socially useful activities ($\chi^2(1) = 7.45$, $p = .006$) and self-care ($\chi^2(1) = 5.18$, $p = .023$).

Informal care

The caregiving situation was complex for both the caregivers of individuals with schizophrenia (F2) and affective disorders (F3). Approximately three-fourths (79% and 73% respectively) have lived with the patient in the past 3 months ($p = .477$); one-third (35% and 30%) have provided informal care also for another individual (including a child, elderly or chronically ill relative), $p = .557$. 34% in the F2 group and 23% in the F3 group have reported lack of any support in providing care for the mentally ill family member ($p = .206$). 35% and 25% have reported threats by the patient during the course of the illness ($p = .324$), without statistical significance in these variables. A higher proportion of the caregivers of patients with schizophrenia provided informal care on a daily basis: 84% compared to 63% of the caregivers of individuals with affective disorders ($p = .042$). They also have had less social contacts in the last 3 months: only 24% have had daily social constants, compared to 51% of the caregivers of individuals with affective disorders ($p = .004$).

The proportion of caregivers providing different types of care is presented in Fig. 1. A relatively similar pattern is observed, with emotional and financial support being provided by the largest proportion of the caregivers in both diagnostic groups, followed by urging the patient to participate in socially useful activities and supervision for disturbing behaviour and compliance with pharmacotherapy. Financial support ($\chi^2(1) = 4.31$, $p = .038$), accommodation ($\chi^2(1) = 11.02$, $p = .001$), urging for socially useful activities ($\chi^2(1) = 7.45$, $p = .006$) and self-care ($\chi^2(1) = 5.18$, $p = .023$) are more often a burden for the caregivers of individuals with schizophrenia.

Some of the objective consequences of the informal caregiving are presented in Table 2. The caregivers of individuals with schizophrenia have spent more time (6 hours per day) providing informal care than the caregivers of individuals with affective disorders (4 hours per day), $U = 1092$, $p = .002$. Two-thirds of the caregivers in each group have had to take time off work during the past 3 months in order to provide informal care ($\chi^2(1) = 0.498$, $p = .481$).

Table 1 Comparison of the socio-demographic characteristics of the patients and caregivers.

Variables	Patients			Caregivers		
% or mean ± SD	F2 ($n = 57$)	F3 ($n = 60$)	p-Value	F2 ($n = 57$)	F3 ($n = 60$)	p-Value
Age (years)	38 ± 15	43 ± 15	.093[a]	55 ± 15	49 ± 16	$t(115) = -2.02$, $p = .046$[a]
Female gender (%)	44	58	.117[b]	60	60	.969[b]
Relation to the patient (%)						$\chi^2(4) = 19.946$, $p = .001$[c]
Parent of the patient				65	33	
Child of the patient				7	25	
Sibling				12	8	
Spouse/partner				9	32	
Other				7	3	
Family status (%)			$\chi^2(3) = 22.012$, $p < .001$[c]			.215[c]
Single (not married)	75	35		12	12	
Married/in partnership	12	47		60	58	
Divorced	12	17		11	5	
Widowed	0	1		18	10	
Children (% yes)	25	53	$\chi^2(1) = 10.140$, $p = .001$[b]	84	73	.180[b]
Education (% high)	28	47	$\chi^2(1) = 4.314$, $p = .038$[b]	58	57	.112[b]
Usual living situation (%)			$\chi^2(3) = 28.227$, $p < .001$[b]			
Lives alone	19	17				
Lives with spouse/partner	12	57				
Lives with parents	60	23				
Lives with other people	9	3				
Employment (%)			$\chi^2(6) = 22.726 < .001$[c]			.735[c]
Employed or self-employed	18	47		65	73	
Volunteer	0	2		0	0	
Sheltered employment	2	2		0	0	
Unemployed	68	28		12	7	
Student	12	5		5	0	
Homemaker	0	3		2	2	
Pensioner	0	13		26	22	
Main source of income (%)			$\chi^2(4) = 22.918 < .001$[c]			
Wage	15	45				
Disability benefits	16	7				
Pension	4	13				
Family	66	32				
Other	0	3				
Receives state benefits (%)	42	25	$\chi^2(1) = 3.380$, $p = .049$[c]	5	0	.114[c]
Net income from all sources (PPP Euro per month)	282 ± 198	408 ± 216	$U = 945.500$, $p = .001$[d]	454 ± 340	541 ± 403	.191[d]

[a] Independent samples t-test.
[b] χ^2.
[c] Fisher's Exact test.
[d] Mann–Whitney U test.

The financial burden on the families of the mentally ill is substantial for both groups. A larger proportion of the caregivers of patients with schizophrenia have to cover for the patient's monthly expenses: 45 (79%) of the caregivers of patients with schizophrenia compared to 35 (58%) of the caregivers in the affective disorder group, $\chi^2(1) = 5.744$, $p = .017$. However, the net amount of provided monthly support, for those who did provide it do not differ: 184 Euro (SD = 97) per month for schizophrenia and 204 Euro (SD = 140) per month for affective disorders ($U = 759$, $p = .781$). Additional costs related to mental state exacerbations are present for smaller percentage of the caregivers, but when present, such costs pose a huge financial burden: 1055 Euro (SD = 1140) for the last 6 months for the caregivers of individuals with schizophrenia (min = 68, max = 3401, median = 567) and 3778 Euro (SD = 9496) for the last 6 months for the caregivers of individuals with affective disorders (min = 74, max = 42,511, median = 567), $U = 94.5$, $p = .521$.

Total burden of care measured with the Burden Assessment Scale (BAS)

The mean score on the BAS is 44.7 (SD = 11.0) for the caregivers of patients with schizophrenia and 42.0 (SD = 12.8)

Table 2 Objective consequences of caregiving: time spent in care, productivity losses and financial burden for the caregivers of the individuals with schizophrenia (F2) and affective disorders (F3).

Caregiver's objective burden	F2[d]			F3[e]			*p*-Value for	
	Valid *N*	*N* (%)	Mean ± SD[f]	Valid *N*	*N* (%)	Mean ± SD[f]	*N* (%)	Mean ± SD[f]
Time spent in informal care (hours per day)	57	55 (97)	5.7 ± 2.9	60	59 (98)	3.9 ± 3.0	1.000	***U*** = 1092, ***p*** = .002[c]
Productivity losses								
Missed days at work (for the employed)	37	26 (70)	7 ± 9	43	27 (63)	9 ± 14	.481[b]	.905[c]
Days unemployed because of the caregiver role	57	1 (2)	66 ± 0	60	1 (2)	66 ± 0	1.000[b]	1.000[c]
Financial burden	57	49 (86)		60	42 (70)		$\chi^2(1) = 4.31$, ***p*** = .038[a]	
Patient's monthly expenses (Euro per month)	57	45 (79)	184 ± 97	60	35 (58)	204 ± 140	$\chi^2(1) = 5.744$, ***p*** = .017[a]	.781[c]
Additional out-of-pocket costs (Euro for last 6 months)	57	11 (19)	1055 ± 1140	60	20 (33)	3778 ± 9496	.086[a]	.521[c]

[a] χ^2.
[b] Fisher's Exact test.
[c] Mann–Whitney *U*-test.
[d] Caregivers of individuals with schizophrenia.
[e] Caregivers of individuals with affective disorders.
[f] Mean ± SD only for those caregivers who reported the evaluated losses.

for the caregivers of patients with affective disorders without statistical significance of the difference ($t(115) = 1.231$, $p = .221$). No statistically significant difference in the mean BAS score in each diagnostic groups is present between the caregivers:

- living with the patient last 3 months ($t(55) = -1.691$, $p = .096$ for schizophrenia, $t(58) = -0.779$, $p = .442$ for affective disorders)
- patients with lower (<5) and higher (≥5) CGI-S score ($t(55) = 0.446$, $p = .667$ for schizophrenia; $t(58) = -0.078$, $p = .938$ for affective disorders)
- patients in acute and rehabilitation ward ($t(55) = 1.426$, $p = .159$ for schizophrenia; $t(57) = -1.479$, $p = .145$ for affective disorders)

The individual scores on each item of the BAS and the difference between caregivers of patients with schizophrenia and affective disorders are presented in Fig. 2. The burden of care shows a similar pattern for both diagnostic groups. Only two items differ significantly – the caregivers of individuals with schizophrenia have experienced more changes in personal plans ($U = 1343.5$, $p = .038$) and have been more worried about the future of the patient ($U = 1311$, $p = .010$) as compared to the caregivers of patients with affective disorders.

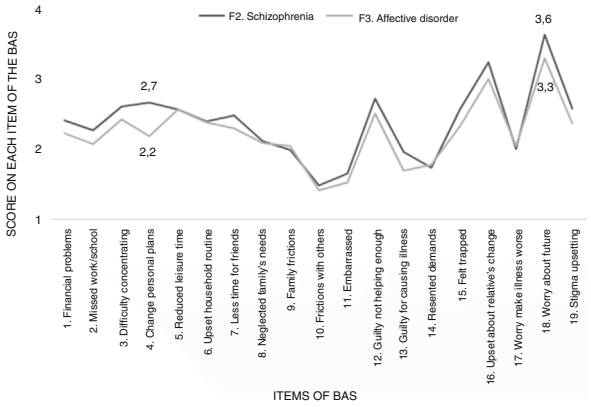

Figure 2 Scores on each item of the Burden Assessment Scale (BAS). *Legend*: The question that the caregivers answer is: ''To what extent did you have any of the following experiences in the past six months?'' Rating of items is 1 = not at all, 2 = a little, 3 = some, 4 = a lot. Statistically significant differences found for item 4 ($U = 1343.5$, $p = .038$) and item 18 ($U = 1311$, $p = .010$).

Factor structure of BAS

The Burden Assessment Scale shows excellent internal consistency as measured by Cronbach's α for all participants (items 19, $\alpha = .886$) as well as separately for each diagnostic group ($\alpha = .898$ for F2 and $\alpha = .871$ for F3). Principal component analysis revealed a five-factor solution explaining

Table 3 Factor structure of the Burden Assessment Scale.

No.	Items of the BAS	Factors and factor loadings				
		1	2	3	4	5
1	Financial problems	0.533				
2	Missed work/school	0.533				
3	Trouble concentrating	0.794				
4	Change personal plans	0.682				
5	Reduced leisure time	0.791				
6	Upset household routine	0.545				
7	Less time for friends	0.660				
8	Neglected other family members	0.712				
9	Family conflicts		0.735			
10	Conflicts with other people		0.756			
11	Felt embarrassed		0.578			
12	Felt guilty for not helping enough			0.606		
13	Felt guilty for causing the illness			0.893		
14	Resented demands		0.688			
15	Felt trapped				0.513	
16	Upset about relative's change				0.739	
17	Worry make illness worse			0.854		
18	Worry about the future				0.719	
19	Found stigma upsetting					0.700
Name of the factors		Limitations	Conflicts	Guilt	Trap	Stigma
% of variance explained		33.5	11.6	7.9	6.8	5.8
Cumulative %		33.5	45.1	53.0	59.9	**65.6**

Principal component analysis. Varimax rotation with Kaiser normalization.

Table 4 Multiple linear regression model for predicting the burden of care, with the mean score of the Burden Assessment Scale (BAS) as the dependent variable.

Predictors	β	t	p-Value
Age of patient	−.095	−.953	.343
Gender of patient (female)	.039	.491	.625
Diagnosis (schizophrenia)	.046	.594	.554
Ever felt threatened (yes)	.202	2.495	**.014**
Age of caregiver	−.206	−2.054	**.043**
Gender of caregiver (female)	.046	.586	.559
Caregiver's social contacts (<daily)	−.193	−2.421	**.017**
Stigma of mental illness (yes)	.311	3.929	**.000**
Frequency of informal care (daily)	.192	2.251	**.027**
Caregiver is parent of the patient (yes)	.151	1.120	.266
Caregiver is spouse of the patient (yes)	.373	3.911	**.000**
Supervision for disturbing behaviour (yes)	.155	2.005	**.048**
(Constant)		5.659	.000

Dependent variable: BAS.

approximately two-thirds (66%) of the variance of the data. The results are presented in Table 3.

Predictors of high burden of informal care (BAS)

A statistically significant multiple linear regression model ($F(11,94) = 9.223$, $p < .001$; $R^2 = 0.548$) with mean BAS score as a dependent variable and the examined predictor variables is presented in Table 4. Statistically significant contributors for the increase in the BAS score are: younger age of the caregivers ($\beta = -0.206$, $p = .043$), spouses or partners of the patient ($\beta = 0.373$, $p < .001$), caregiving on a daily basis ($\beta = 0.192$, $p = .027$), less social contacts ($\beta = -0.193$, $p = .017$), history of threats ($\beta = 0.202$, $p = .014$), supervision for disturbing behaviour ($\beta = 0.155$, $p < .048$) and stigma ($\beta = 0.322$, $p < .001$).

Discussion

The results of the study confirm that the burden of informal care prior to hospital admission is substantial and multifaceted.[9,12,20,21] The time spent in informal care is equivalent to two-thirds of the full working day hours for the caregivers' of individuals with schizophrenia and half the working hours per day for caregivers' of patients affective disorders.[4] While emotional and financial support are the predominant type of care provided, a large proportion of the informal care is in terms of supervision for disturbances in behaviour or compliance with pharmacotherapy, which in other studies is described as the main difference between the informal care provided for individuals mental and somatic illness.[22,23]

The financial support for patient's monthly expenses is considerable as it is equivalent to the gross minimum monthly wage in Bulgaria for 2015 which was 215 PPP Euro per month.[24] A small proportion of the individuals have a disproportionately large amount of financial burden when additional costs related to the exacerbations are present.[25,26] Exclusion of the costs of informal care in economic evaluations can lead to underestimation of the total cost of mental illnesses.[27]

The total burden of care measured by the Burden Assessment Scale is equivalent for the two diagnostic groups. This is in contrast with other studies demonstrating higher burden in schizophrenia caregivers.[28] The difference might be explained by the evaluation of outpatient rather than inpatient treatment, thus proving that hospital admissions and exacerbation in the mental state in both diagnostic groups cause similar levels of burden in the caregivers. The history of threats and supervision for current disturbing behaviour are both significant predictors for burden, which confirms findings of other studies,[3,29,30] where authors have proposed that these items should be incorporated in the Burden Assessment Scale.[31]

Contrary to other studies reporting higher levels of burden among female caregivers,[4,32] in our study the caregivers' gender has no effect on the burden, but their age, relation to the patient and social life does: younger caregivers, spouses/partners of the patients and caregivers with less social contacts experience higher levels of burden.[3] Also, living with the patients is not a determinant of burden, which confirms the original BAS design not to link the burden to the caregiving situation in order to prevent underestimation of the burden of caregivers not living with the patients.[9]

Although some differences in the aspects of burden experienced by the caregivers in the two diagnostic groups exist, a common pattern is identified in confirmation to other studies.[6,33] The exploratory factor analysis of the BAS confirms a five-factor structure, similarly to the originally described by Reinhard et al.[9] factors. However, in our study the stigma of mental illness forms a separate factor, pointing out that considerable levels of stigmatization of mental illness and probably psychiatric admissions in the country exist, making the stigma of mental illness a significant contributor to the caregiver's burden.[34]

Limitations of the study include a sample size from one university clinic and the generalization of the patients' diseases in two major categories. Further investigation of the effect of specific subgroups based on patients' psychiatric

disorder or prevailing symptoms has to be conducted with larger and samples.

Conclusion

The informal care for individuals with schizophrenia and affective disorders has a significant objective and subjective consequences for their caregivers. The implementation of programmes aimed at the reduction of the negative impact on the caregivers should consider addressing the predictors described in the study in order to alleviate the burden.

Conflict of interest

None to declare.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Acknowledgments

Thanks to Prof. Allan V. Horwitz and Prof. Susan C. Reinhard for their permission to translate and use the Burden Assessment Scale.

References

1. Whiteford HA, Degenhardt L, Rehm J, Baxter AJ, Ferrari AJ, Erskine HE, et al. Global burden of disease attributable to mental and substance use disorders: findings from the Global Burden of Disease Study 2010. Lancet. 2013;382(9904):1575–86, http://dx.doi.org/10.1016/S0140-6736(13)61611-6.
2. Hoenig J, Hamilton MW. The schizophrenic patient in the community and his effect on the household. Int J Soc Psychiatry. 1966;12(3):165–76, http://dx.doi.org/10.1177/002076406601200301.
3. Lauber C, Eichenberger A, Luginbühl P, Keller C, Rössler W. Determinants of burden in caregivers of patients with exacerbating schizophrenia. Eur Psychiatry. 2003;18(6):285–9.
4. Flyckt L, Löthman A, Jörgensen L, Rylander A, Koernig T. Burden of informal care giving to patients with psychoses: a descriptive and methodological study. Int J Soc Psychiatry. 2013;59(2):137–46, http://dx.doi.org/10.1177/0020764011427239.
5. Gupta S, Isherwood G, Jones K, Van Impe K. Productivity loss and resource utilization, and associated indirect and direct costs in individuals providing care for adults with schizophrenia in the EU5. Clin Outcomes Res. 2015;7:593, http://dx.doi.org/10.2147/CEOR.S94334.
6. von Kardorff E, Soltaninejad A, Kamali M, Eslami Shahrbabaki M. Family caregiver burden in mental illnesses: the case of affective disorders and schizophrenia – a qualitative exploratory study. Nord J Psychiatry. 2016;70(4):248–54, http://dx.doi.org/10.3109/08039488.2015.1084372.
7. Lauber C, Keller C, Eichenberger A, Rössler W. Family burden during exacerbation of schizophrenia: quantification and determinants of additional costs. Int J Soc Psychiatry. 2005;51(3):259–64, http://dx.doi.org/10.1177/0020764005057376.
8. Falloon IR, Pederson J. Family management in the prevention of morbidity of schizophrenia: the adjustment of the family unit. Br J Psychiatry. 1985;147(2):156–63, http://dx.doi.org/10.1192/BJP.147.2.156.
9. Reinhard SC, Gubman GD, Horwitz AV, Minsky S. Burden assessment scale for families of the seriously mentally ill. Eval Program Plann. 1994;17(3):261–9, http://dx.doi.org/10.1016/0149-7189(94)90004-3.
10. Hoefman RJ, van Exel NJA, Looren de Jong S, Redekop WK, Brouwer WBF. A new test of the construct validity of the CarerQol instrument: measuring the impact of informal care giving. Qual Life Res. 2011;20(6):875–87, http://dx.doi.org/10.1007/s11136-010-9829-8.
11. Pai S, Kapur RL. The burden on the family of a psychiatric patient: development of an interview schedule. Br J Psychiatry. 1981;138:332–5.
12. van Wijngaarden B, Schene AH, Koeter M, V zquez-Barquero JL, Knudsen HC, Lasalvia A, et al. Caregiving in schizophrenia: development, internal consistency and reliability of the Involvement Evaluation Questionnaire – European Version EPSILON Study 4. European Psychiatric Services: Inputs Linked to Outcome Domains and Needs. Br J Psychiatry Suppl. 2000;(39):s21–7. http://www.ncbi.nlm.nih.gov/pubmed/10945074 [accessed June 15 2018].
13. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist. 1980;20(6):649–55. http://www.ncbi.nlm.nih.gov/pubmed/7203086 [accessed June 15 2018].
14. Dare A, Hardy J, Burgess P, Coombs T, Williamson M, Pirkis J. Carer outcome measurement in mental health services: scoping the field; 2008. Brisbane.
15. Julious SA. Sample sizes for clinical trials with normal data. Stat Med. 2004;23(12):1921–86, http://dx.doi.org/10.1002/sim.1783.
16. Chisholm D, Knapp MR, Knudsen HC, Amaddeo F, Gaite L, van Wijngaarden B. Client Socio-Demographic and Service Receipt Inventory – European Version: development of an instrument for international research EPSILON Study 5. European Psychiatric Services: inputs linked to outcome domains and needs. Br J Psychiatry Suppl. 2000;(39):s28–33.
17. Guy W, editor. Clinical Global Impression. In ECDEU Assessment Manual for Psychopharmacology (revised). Rockville, MD: U.S. Department of Health, Education, and Welfare; 1976. p. 217–21.
18. Ivarsson A-B, Sidenvall B, Carlsson M. The factor structure of the Burden Assessment Scale and the perceived burden of caregivers for individuals with severe mental disorders. Scand J Caring Sci. 2004;18(4):396–401, http://dx.doi.org/10.1111/j.1471-6712.2004.00298.x.
19. Busner J, Targum SD. The clinical global impressions scale: applying a research tool in clinical practice. Psychiatry (Edgmont). 2007;4(7):28–37.
20. Fadden G, Bebbington P, Kuipers L. The burden of care: the impact of functional psychiatric illness on the patient's family. Br J Psychiatry. 1987;150:285–92.
21. Schene AH. Objective and subjective dimensions of family burden. Towards an integrative framework for research. Soc Psychiatry Psychiatr Epidemiol. 1990;25(6):289–97.
22. Ampalam P, Gunturu S, Padma V. A comparative study of caregiver burden in psychiatric illness and chronic medical illness. Indian J Psychiatry. 2012;54(3):239–43, http://dx.doi.org/10.4103/0019-5545.102423.
23. Flyckt L, Fatouros-Bergman H. Burden of informal care giving to patients with schizophrenia – it's magnitude and determinants. Eur Psychiatry. 2015;30:270, http://dx.doi.org/10.1016/S0924-9338(15)30220-0.

24. NSSI. National Social Security Institute. National Minimal Wage 2015. http://nssi.bg/legislationbg/decrees/3651-pms1392015 [accessed 13 May 2017].
25. Jablensky A. Worldwide burden of schizophrenia. In: Sadock BJ, Sadock VA, Ruiz P, editors. Kaplan & Sadock's comprehensive textbook of psychiatry. 9th ed. Philadelphia, PA, USA: Lippincott Williams & Wilkins; 2009. p. 1451–62.
26. Knapp M, Mangalore R, Simon J. The global costs of schizophrenia. Schizophr Bull. 2004;30(2):279–93.
27. Andersson A, Levin L-A, Emtinger BG. The economic burden of informal care. Int J Technol Assess Health Care. 2002;18(1):46–54.
28. Vasudeva S, Sekhar CK, Rao PG. Caregivers burden of patients with schizophrenia and bipolar disorder: a sectional study. Indian J Psychol Med. 2013;35(4):352–7, http://dx.doi.org/10.4103/0253-7176.122224.
29. Loughland CM, Lawrence G, Allen J, Hunter M, Lewin TJ, Oud NE, et al. Aggression and trauma experiences among carer-relatives of people with psychosis. Soc Psychiatry Psychiatr Epidemiol. 2009;44(12):1031–40, http://dx.doi.org/10.1007/s00127-009-0025-5.
30. Vaddadi KS, Soosai E, Gilleard CJ, Adlard S. Mental illness, physical abuse and burden of care on relatives: a study of acute psychiatric admission patients. Acta Psychiatr Scand. 1997;95(4):313–7, http://dx.doi.org/10.1111/j.1600-0447.1997.tb09637.x.
31. Matías-Carrelo LE, Chávez LM, Negrón G, Canino G, Aguilar-Gaxiola S, Matías-Carrelo LE. The Spanish translation and cultural adaptation of five mental health outcome measures. Cult Med Psychiatry. 2003;27(3):291–313, http://dx.doi.org/10.1023/A:1025399115023.
32. Weimand BM, Hedelin B, Sällström C, Hall-Lord M-L. Burden and health in relatives of persons with severe mental illness: a Norwegian cross-sectional study. Issues Ment Health Nurs. 2010;31(12):804–15, http://dx.doi.org/10.3109/01612840.2010.520819.
33. Wolff N, Perlick DA, Kaczynski R, Calabrese J, Nierenberg A, Miklowitz DJ. Modeling costs and burden of informal caregiving for persons with bipolar disorder. J Ment Health Policy Econ. 2006;9(2):99–110.
34. Sartorius N. Stigma and mental health. Lancet (London, England). 2007;370(9590):810–1, http://dx.doi.org/10.1016/S0140-6736(07)61245-8.