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Burden of caregivers of people suffering from schizophrenia versus symptom severity, social functioning and treatment satisfaction of patients treated by a CMHT

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Summary

Aim. This study aims to assess the caregivers' burden in schizophrenia amongst patients treated by Community Mental Health Teams (CMHTs) and its relation to patients' demographic, clinical and social characteristics, with emphasis on their satisfaction with care, and to evaluate the correlation of selected characteristics of caregivers with the level of their burden.

Method. A total of 65 patient-caregiver dyads remaining in home treatment were included. Caregivers were assessed with demographic questionnaires and the Caregiver Burden Inventory (CBI). The patients were assessed with the Positive and Negative Syndrome Scale (PANSS), the Verona Service Satisfaction Scale (VSSS-54), the Disability Assessment Schedule (WHODAS 2.0), the Social Network Index (SNI) and with the UCLA Loneliness Scale. Data were analysed using multiple linear regression.

Results. Increased caregiver burden was associated with: greater symptom severity in patients, lower satisfaction with staff professionalism, and a high level of emotional expressiveness in relationships. The regression model explaining 57% of the variance in the caregivers' emotional burden consisted of four factors: the patient's positive syndrome intensity, patient's remaining in an emotional relationship, gender i.e. higher burden amongst female caregivers of male patients, and smaller social network.

The study was approved by the Jagiellonian University Bioethics Committee and was conducted by the Krakow Psychosis Research Group COGITO

Conclusions. The caregivers' burden severity is related to patients' sociodemographic, clinical and social characteristics and their satisfaction with treatment. The emotional burden of caregivers is impacted by: greater symptom severity, especially the positive syndrome, lower patient satisfaction with staff professionalism, and a high expression of emotions in family relationships. The patient's and caregiver's gender and education level, the patient's degree of disability, them being in a relationship and social support network size are also significant.

Key words: caregiver burden, CMHT, schizophrenia

Introduction

The aim of the study was to assess the burden declared by people caring for those close to them suffering from schizophrenia in the group undergoing treatment by a Community Mental Health Team (CMHT). Our next goal was to identify predictors of the caregivers' burden among patients' sociodemographic, clinical and social data, as well as based on an assessment of patients' satisfaction with care and baseline characteristics describing caregivers.

Caregiver burden is a psychological state resulting from a combination of physical work, emotional and social pressures, and economic restrictions that arise as a result of caring for a patient [1]. Among the main sources of burden, carers mention [2] the overload of daily responsibilities, limited social communication, significant psychological stress and economic strain, and the feeling of not having enough support in caring for the ill person.

Increased psychopathological symptoms are one of the greatest sources of burden for families caring for patients with schizophrenia [3-5]. Provencher and Mueser [6] note the greater impact of negative symptoms on patients' difficulties in functioning in family roles, resulting in families adopting an attitude of resignation regarding a sense of lack of influence over the patient's symptoms and taking on the responsibilities of the ill relative. Similarly, Gopinath and Chaturvedi [7] note that it is the ill family member's inactivity in household chores and inadequate personal hygiene that place an even greater burden on families than their aggressive behaviour related to symptom severity. Roick et al. [8] note that both positive and negative psychotic symptoms of patients under family care should be addressed, as each significantly affects the functioning of patients' families.

High emotional expression level in the relationship with the ill family member exacerbating the risk of psychosis relapse has also been associated with increased levels of objectively and subjectively experienced burden by carers [9]. Runions and Prudo [10] noted, however, that most of the relatives' criticisms related to behaviours such as social withdrawal and lack of communication rather than more severe symptoms such as delusions or hallucinations.

The marital relationship appears not to be a protective factor either for subjectively perceived burden or for overall health or functioning [1]. Jungbauer et al. [11] note that spouses perceive the relationship as maintainable when the deterioration of the partner's functioning does not exceed the individual partner's ability to bear it,

and psychotic episodes do not occur frequently. Spouses also appear to be [12] more forgiving of their spouses' behaviour than formal carers.

Parents caring for children with schizophrenia, similarly to spouses, report a significant caregiving burden [13]. Caqueo-Urízar and Gutiérrez-Maldonado [14] note that mothers are particularly burdened by caregiving, especially those mothers who are older, unemployed and have received basic education only. These reports are also supported by other studies [13], which note that a greater sense of care burden applies to mothers caring for their ill children especially in situations of lower education and increased child hospitalisation.

Malakouti et al. [3] note that both men and older people of both sexes caring for a family member with schizophrenia, especially when faced with increased patient care needs, report higher levels of burden. Educational attainment also appears to influence the level of caregiver burden, which is often significantly associated with lower household income [15]. Caregivers with primary education report higher levels of burden than caregivers with higher education [4].

Differences in the ability of caring relatives to cope with patients' symptoms and difficulties are also associated with a sense of caregiver burden [8]. Möller-Leimkühler [16] notes that emotion-focused coping strategies and generalised negative reaction to stress are significant predictors of burden.

The findings presented in this paper highlight the predictors of caregiver burden primarily related to broadly analysed patient characteristics. Particular attention was paid to the role of treatment satisfaction assessed also from the patients' perspective in the context of a significant increase in the availability of home care services.

Materials and method

The study was conducted between 01.03.2019 and 31.12.2019 after obtaining the consent of the Bioethics Committee of Jagiellonian University Medical College in Krakow. Sixty-five patients with schizophrenia treated by CMHTs and sixty-five caregivers were investigated. Complete data were obtained from 65 patients. Eighteen patients and/or caregivers refused to participate in the study.

Regarding patients, the study included 31 females and 34 males with schizophrenia. The mean age of the patients was 49.5 (\pm 12.9). The youngest person was 18 years old, and the oldest person -72. Most of the caregivers (70%) were female. The mean age of the caregivers was 60.6 (\pm 13.4), with a range of 26–86. In most cases, the caregivers were parents (58.5%). Family members living together with the patient were included in the study.

Basic demographic data describing the studied group of patients can be found in Table 1, and clinical characteristics and levels of social functioning in Table 2.

Table 1. Sociodemographic characteristics of the study group of patients

	N (%)		N (%)
Gender of the patient		Employment (patient)*	
female	31 (47.7)	employed	17 (26.0)
male	34 (53.3)	disability pension	51 (78.0)
Patient's place of residence		retirement pension	7 (10.8)
city/town	52 (80.0)	Children (patient)	
rural area	13 (20.0)	yes	20 (30.8)
Patient's marital status		no	45 (69.2)
married	15 (23.1)	Medications in a depot form	
in an informal relationship	2 (3.1)	no	37 (56.9)
divorced	3 (4.6)	yes	28 (43.1)
widower	2 (3.1)	Patient's comorbidities	
single	43 (66.1)	no	34 (52.3)
Patient's education		yes	31 (47.7)
primary	4 (6.15)	Housing status (patient)*	
junior high school	4 (6.15)	with a partner	16 (24.6)
vocational	16 (24.6)	with children	1 (1.55)
secondary	25 (38.5)	solo	7 (10.8)
post-secondary	7 (10.8)	with parents	37 (56.9)
university	9 (13.8)	with siblings	3 (4.6)
Gender of the caregiver		other	1 (1.55)
female	46 (70.8)	Relationship of the caregiver to the patient	
male	19 (29.2)	partner	12 (18.5)
		parent	38 (58.5)
		siblings	8 (12.3)
		child	4 (6.2)
		further relative/ unrelated person	3 (4.5)
		1	

^{*} does not add up to 100, as multiple answers are possible

The mean length of psychiatric treatment in the group of patients cared for by their families was almost 20 years (± 11.8), and the mean length of treatment by a CMHT was more than 5 years (± 4.6). The study patients underwent more than 5 psychiatric hospitalisations on average. In the assessment of mental status with the PANSS, the mean total for the study group was 79, while PANSS-POS symptoms averaged 14.7,

and PANSS-NEG averaged 24.4. Social assessment was presented in three dimensions: social network, level of loneliness and level of disability (Table 2).

Table 2. Clinical and social characteristics of the patient group and the assessment of their satisfaction with care (N = 65)

N = 65	М	Me	SD	Min.	Max.	N = 65	М	Ме	SD	Min.	Max.
Duration of psychiatric treatment	19.32	18.00	11.80	0.50	45.00	VSSS-54 mean	4.35	4.36	0.42	3.09	5.00
Duration of treatment by a CMHT	5.58	5.00	4.60	0.50	25.00	VSSS-54 overall satisfaction	4.52	4.67	0.46	3.67	5.00
Total number of psychiatric hospitalisations	5.14	3.00	6.08	0.00	40.00	VSSS-54 professionalism	4.25	4.38	0.37	3.25	4.69
Number of psychiatric medications taken	2.26	2.00	1.20	0.00	5.00	VSSS-54 information	4.24	4.33	0.55	2.33	5.00
Number of antipsychotic medications taken	1.63	2.00	0.86	0.00	4.00	VSSS-54 access	4.06	4.00	0.71	1.50	5.00
PANSS – total	79.68	78.00	27.87	33.00	172.00	VSSS-54 efficacy	4.22	4.25	0.55	2.63	5.00
PANSS – POS	14.72	13.00	7.08	7.00	41.00	VSSS-54 intervention types	4.22	4.33	0.55	2.75	5.00
PANSS- NEG	24.45	24.00	8.79	8.00	41.00	VSSS-54 relative's involvement	4.18	4.20	0.60	2.20	5.00
SNI-diversity	4.38	4.00	1.62	2.00	9.00						
SNI-size	9.06	9.00	4.19	3.00	12.00						
SNI-role-activity	1.34	1.00	0.57	0.00	3.00						
UCLA	28.23	26.00	14.75	3.00	58.00						
WHODAS 2.0	34.74	34.03	17.49	3.47	85.42						

Key: M – mean; Me – median; SD – standard deviation; Min. – minimum; Max. – maximum; CMHT – Community Mental Health Team; SNI — social network index, range: diversity 0-12, size of social network 0-12, activity in roles 0-8, higher scores indicate higher diversity/size of social network/activity in roles; UCLA – Loneliness Scale, range 0-60, higher scores indicate higher loneliness; WHODAS 2.0 — disability assessment schedule, range 36-180, higher scores indicate higher disability level; VSSS-54 – Verona Service Satisfaction Scale, range for subscales 1-5, higher scores indicate higher satisfaction in a given area, PANSS – Positive and Negative Syndrome Scale,

range: total 30-210, positive symptoms 7-49, negative symptoms 7-49, higher scores indicate greater severity of symptoms.

The following tools were used in the study:

- Sociodemographic and clinical data questionnaire.
- The Caregiver Burden Inventory (CBI [17]). It consists of 24 questions. It assesses the level of family burden overall (on a scale from 0 to 96 points) and in five dimensions: time-dependence burden (from 0 to 20) an objective burden assessing the stress caused by the limitation of personal time; developmental burden (from 0 to 20) referring to the sense of failure in one's own goals and expectations; physical burden (from 0 to 16) referring to physical stress and somatic disorders; social burden (from 0 to 20) caused by role conflict concerning work or family; and emotional burden (from 0 to 20) referring to embarrassment or sense of shame caused by the patient. Cronbach's alpha index value: 0.96.
- Family Emotional Expressiveness Index which assesses the intensity of emotions in the family. Overinvolvement, criticism and hostility were considered collectively as an indicator of high intensity of emotions. Assessments were made on a Likert scale based on the decision of competent judges members of the therapeutic team who have known the family for many years.
- Positive and Negative Syndrome Scale (PANSS), which consists of 30 items assessing the severity of symptoms in three subscales: positive symptoms (7 items), negative symptoms (7 items) and general psychopathology symptoms (16 items) on a scale from 1 to 7, where 1 means the absence of a specific symptom and 7 its extreme severity [18]. Cronbach's alpha index value: 0.95.
- The Verona Service Satisfaction Scale (VSSS-54) [19] is used to assess patient satisfaction with medical services. The scale consists of 54 close-ended questions and two open-ended questions. It assesses patient satisfaction in terms of seven areas: overall satisfaction, professionals' skills and behaviour, information, access, efficacy, types of interventions, and relative's involvement. The patient makes a rating on a scale from 1–5, where 5 is the maximum rating. Cronbach's alpha index value: 0.93.
- The WHO Disability Assessment Schedule 2.0 (WHODAS 2.0 36-item) [20]. It consists of 36 questions assessing the level of disability on a scale from 1–5, where 1 means no difficulty in performing the task and 5 means extreme effort or inability to perform the task. Six areas are assessed: understanding and communication, mobility, self-care, getting along with others, life activities, and participation. Cronbach's alpha index value: 0.95.
- The Social Network Index (SNI) [21] a questionnaire used to assess the patient's social participation. It assesses:
 - a) social network diversity, i.e. an assessment of the number of social role categories (out of 12 available) with which the patient has regular contact at least once every two weeks. The possible score ranges from 0–12, where a higher score indicates more social roles;

- b) the size of the patient's social network, i.e. the sum of the number of persons out of the 12 available categories with whom the patient has regular contact at least once every two weeks. Scoring range: 0-12, where a higher score indicates a larger social network;
- c) role-activity, "embeddedness" in the social network i.e. the number of different categories of social roles in which the patient is active. Activity was defined as a minimum of 4 regular contacts in a given social group, except for family, where activity was defined as a minimum of 3 regular contacts. The possible score on this scale ranges from 0–8, where a higher score indicates greater activity in roles.
- The UCLA Loneliness Scale [22]. It is a scale measuring respondents' emotional reactions to the perceived discrepancy between the desired and achieved degree of social contact, defining loneliness as a subjective feeling. It consists of 20 questions. The patient indicates how often certain situations affect him/her on a four-point scale: often, sometimes, rarely, never. The possible score ranges from 0–60. Cronbach's alpha index value: 0.95.

The tools used, i.e. PANSS, WHODAS 2.0, SNI, UCLA, VSSS-54, CBI have been previously used in Polish studies and translated into Polish [23-28].

SPSS ver. 26 and STATISTICA 13.3 packages were used to statistically process the results. Univariate linear regression models were used to examine the relationship between burden level and a selected group of potential predictors (see: Supplement), and then a multivariate model was built based on the stepwise progressive method (with a maximum number of steps: 5, due to the small size of the study group). The accepted level of statistical significance in all analyses was $\alpha = 0.05$.

Results

First, descriptive statistics were analysed for the results of the CBI questionnaire in the study group of caregivers. Detailed data are presented in Table 3.

Table 3. Descriptive statistics for the result of careging			onnaire in	the study	group
N = 65	М	Me	SD	Min.	Max.

N = 65	М	Me	SD	Min.	Max.
CBI-total	28.74	23.00	24.61	0.00	88.00
CBI – factor 1 (time-dependence burden)	7.87	6.00	6.84	0.00	20.00
CBI – factor 2 (developmental burden)	6.85	6.00	6.16	0.00	20.00
CBI – factor 3 (physical burden)	4.98	3.00	4.91	0.00	16.00
CBI – factor 4 (social burden)	4.68	3.00	5.31	0.00	19.00
CBI – factor 5 (emotional burden)	4.37	2.00	5.49	0.00	19.00

Key: M – mean, Me – median, SD – standard deviation, Min. – minimum, Max. – maximum, CBI – Caregiver Burden Inventory

The burden declared by the caregivers was 1/3 of its maximum value. The highest level of burden was indicated by the caregivers in time-dependence burden and developmental burden scales.

In the next step, in order to select the variables entering the multivariate models, for the sum of the CBI questionnaire scores and its separate dimensions, a series of simple linear regression analyses were performed using sociodemographic data of patients (patient's gender, age, education, place of residence, marital status, having children, employment status, psychiatric treatment in years, treatment by a CMHT in years, total number of psychiatric hospitalisations, depot medications, number of psychiatric medications taken, number of antipsychotic medications taken, comorbidities), data concerning the caregiver (caregiver's gender, age, degree of relationship to patient), along with clinical (PANSS-total, PANSS-POS, PANSS-NEG) and social data (UCLA Loneliness Scale, WHODAS 2.0, SNI-diversity, SNI-size, SNI-activity in roles), and patients' satisfaction with care (VSSS-54 - mean, VSSS-54 - overall satisfaction, VSSS-54 – professionalism, VSSS-54 – information, VSSS-54 – access, VSSS-54 - efficacy, VSSS-54 - types of intervention, VSSS-54 - relative's involvement) (for a detailed description of the variables' typing for models, see: Supplement). Further, the association of the above-mentioned factors with higher burden of caregivers of patients with schizophrenia in the study group was analysed by stepwise regression (up to 5 steps) (Table 4).

Table 4. Multiple regression models for the caregiver burden variable including sociodemographic variables, clinical data, schizophrenia symptom severity, and questionnaires assessing social functioning and satisfaction with care

		В	SE	Beta	t	Р	corR ²	sem. corr.
Multivariate model (step. progress.) CBI – total	1. PANSS – total	0.48	0.08	0.53	5.84	<0.001		0.49
	2. VSSS-54 professionalism	-20.90	6.21	-0.36	-3.91	<0.001	0.54 p < 0.001	-0.33
	3. EE (high)	5.75	2.18	0.23	2.64	0.010		0.22
Multivariate model (step. progress.) CBI – 1 time	1. WHODAS 2.0	0.19	0.04	0.48	5.07	<0.001	0.48 p < 0.001	0.46
	2. VSSS-54 access	-3.05	0.92	-0.32	-3.32	0.002		-0.30
	Patient's education (lower)	-1.76	0.72	-0.22	-2.44	0.018		-0.22
Multivariate model (step. progress.) CBI – 2 developmental	1. PANSS – total	0.10	0.02	0.45	4.52	<0.001		0.42
	2. VSSS-54 professionalism	-5.46	1.62	-0.33	-3.36	0.001	0.45 p < 0.001	-0.31
	Caregiver's sex (female)	1.36	0.63	0.20	2.17	0.034		0.20

table continued on the next page

Multivariate model (step. progress.) CBI – 3 physical Multivariate model (step. progress.) CBI – 4 social Multivariate (step. progress.) CBI – 5 emotional	1. PANSS – total	0.09	0.02	0.51	4.98	<0.001		0.48
	2. EE (high)	1.36	0.49	0.27	2.77	0.007	0.42	0.27
	3. VSSS-54 professionalism	-2.92	1.35	-0.22	-2.15	0.035	p < 0.001	-0.21
	1. PANSS – total	0.08	0.02	0.42	4.13	<0.001		0.40
	VSSS-54 overall satisfaction	-3.73	1.21	-0.32	-3.08	0.003	0.40 p < 0.001	-0.30
	3. EE (high)	1.65	0.55	0.30	3.01	0.004		0.29
	1. PANSS-pos	0.49	0.07	0.63	6.65	<0.001		0.55
	Patient's marital status (in a relationship)	2.95	0.57	0.48	5.15	<0.001	0.57	0.42
	3. Patient's sex (male)	1.34	0.47	0.25	2.87	0.006	p < 0.001	0.24
	4. SNI – size	-0.28	0.13	-0.21	-2.16	0.034		-0.21

Key: EE – emotional expressiveness, B – unstandardised regression coefficient, SE – standard error, Beta – standardised regression coefficient, t – t-statistic for the regression coefficient, p – significance level, corR² – adjusted determination coefficient, sem. corr. – semi-partial correlation, CBI – Caregiver Burden Inventory, PANSS – Positive and Negative Syndrome Scale, pos – positive, VSSS-54 – Verona Service Satisfaction Scale

For the CBI total score, the model demonstrated the significance of three predictors of caregiver burden level. Higher overall caregiver burden was associated with higher schizophrenia symptom severity, lower patient satisfaction with the professionalism of the team, and high emotional expressiveness in the relationship between the patient and family members, the simultaneous inclusion of which helped explain 54% of the variance in the dependent variable. Identical results, however, with a lower level of an explained variance (42%), were obtained for subscale 3 on physical burden. Similar indicators (symptom severity and professionalism rating) were also significant in the model assessing developmental burden (subscale 2), but in this case, the female gender of the caregiver was also significant (females were more burdened), and the emotional expressiveness index was not significant. The model explained 45% of the variance of the dependent variable (carers' burden level).

The model that stood out against the above-mentioned ones and explained 48% of the variance in burden was the time-dependence burden model (subscale 1). Higher levels of burden were associated with higher levels of patient's disability, lower patient satisfaction with the availability of community care staff and patient's higher level of education.

The model that best described the variation in burden was that for emotional burden – subscale 5 (57% of the explained variance). Predictors of higher burden were higher severity of positive symptoms, the patient's male gender and being in a relationship, as well as the size of the social network (a narrower network was associated with a higher burden).

The model for subscale 4 (referring to the social aspect of the burden), while explaining the lowest percentage of variance (40%), indicates the importance of higher patient symptom severity, lower overall treatment satisfaction, and higher emotional expressiveness between the patient and family members.

Discussion

In our study, the severity of caregiver burden was between low and medium. Lower caregiver burden compared to other studies [12,14] may be related to the fact that the group of respondents were chronically ill patients, so over time the caregiver adaptation process may have occurred. The reduction of family burden in home care may also be due to the good and long-lasting cooperation with the CMHT, but we also need to take into account the possible reluctance among caregivers to disclose difficult emotions because of the relationship with the patient and the fear of making the patient uncomfortable. Parabiaghi et al. [5] also noted a decreasing level of burden during a three-year follow-up after the introduction of a community-based treatment intervention at initially high levels of burden.

The highest mean level of burden in our study was indicated by caregivers in time-dependence burden and developmental burden scales, while the model that best explained the variance in the level of caregivers' burden was related to the emotional burden of caregivers. The developmental factor describes the caregivers' feeling that their development is delayed compared to their peers, the time factor relates to the caregiver's time constraints associated with having to perform caregiving activities for the ill person, and the emotional factor relates to the caregivers' negative feelings towards the cared-for [17]. Thus, it might be inferred that caregivers declared experiencing negative emotions due to the belief that they have to spend too much time with patients and as a result they feel that they have no time to pursue their own developmental goals. Also Chen et al. [2] note that one of the most important sources of caregiver burden is the overload of daily responsibilities, which affects many areas of their lives, while Lauber et al. [29] emphasize the importance of the emotional burden of caregivers and the resulting reduction in social life and leisure opportunities.

In our study, the higher severity of schizophrenia symptoms, especially the positive syndrome, was found to be a key factor related to the emotional burden of caregivers. The above result is consistent with the findings of other studies in this area [3-5, 30], which noted that severity of patients' psychopathological symptoms is associated with increased feelings of caregiving burden in relatives. Roick et al. [8] also note the significant impact of increased positive symptoms on family functioning, although

they also highlight the impact of negative symptoms, which in contrast were found to be key in the Provencher and Mueser study [6]. The difference in the results obtained compared to the aforementioned study may be due to the use of a different type of scale to assess symptoms and the authors' own doubts [6] about the representativeness of the study group.

We observed that the higher caregiver burden was associated with higher levels of patient disability, especially in the area of time-dependence. This result is also consistent with that obtained by Caserta et al. [31], who found that a similar relationship explained almost 37% of the variance between the severity of deterioration in the care recipient's daily functioning and time burden.

Satisfaction with patients' treatment related to the availability and professionalism of staff was also found to be a significant factor in carers' sense of burden. A study by Merinder et al. [32] similarly noted a high score for overall satisfaction with care of both patients and relatives, although relatives appeared to be significantly less satisfied than patients in the sub-dimension 'Information and involvement of relatives'. This confirms the result obtained showing the relationship of relatives' burden with the level of staff availability and professionalism.

In our study, lower caregiver education appeared to be associated with lower levels of caregiver burden. This situation could be understood as a result of the burden associated with the need to devote more time to the patient in relation to continuing education and its impact on the carer's time constraints, especially as it was the area of time that proved to be important in this area. It is also possible that the carer's level of education contributes to a more adequate perception of the complexity of caring for a patient with schizophrenia. Previous studies have assessed that the level of education was not associated with an increased sense of caregiver burden [1]. However, the assessment was made using other research tools measuring the overall intensity of burden. Perhaps what is important is whether the level of caregiver burden is assessed by an overall score or whether there is a distinction between different types of burden. With such a distinction, it may be possible to observe phenomena not available with generic scales. This is certainly a topic that requires further exploration.

The gender of the carer and patient also appeared to be important. Women caring for ill relatives experienced a greater level of burden in the area assessing developmental capacity, while male patients were a greater source of caregiver burden in the emotional domain. Both Zahid and Ohaeri [4] as well as Hsiao and Tsai [33] observed in their studies that women caring for sick relatives declared higher levels of burden. Similarly, in studies conducted by both Caqueo-Urízar together with Gutiérrez-Maldonado [14] and Litvan et al. [34], it was found that mothers in particular reported higher levels of burden. However, the higher burden on carers due to the gender of the ill relative is, according to research, a rather contentious issue, as there are studies reporting a higher burden of care for men [13], for women [35], and also finding no difference in burden in relation to the gender of the ill family member [36]. Perhaps, therefore, a more precise assessment of the type of burden, more gender-specific, could be the decisive factor, or

it would be necessary to analyse this factor in relation to the individual interpersonal relationships occurring between family members.

In our study, a narrower support network was associated with higher levels of burden. Similarly, elevated levels of burden associated with insufficient social support were observed by Magliano et al. [37]. In contrast, a different result was observed by Roick et al. [8], where the amount of social support was found not to predict caregiver burden. However, an important limitation of their study is the criteria adopted, as the social support defined then did not include emotional support and the extent of social contacts, but only practical aspects.

Also the fact of being in a marital relationship is significantly associated with increased levels of burden. Spouses feel a greater burden of caregiving, which confirms previous findings by Roick et al. [13] and Jungbauer et al. [11], who similarly observed a greater burden on spouses to care for their partners.

We also observed that excessive emotional burden, emotion-focused coping strategies and a negative critical attitude of the caregiver were significantly associated with higher levels of their burden and this is in line with a study by Möller-Leimkühler [16]. Gutiérrez-Maldonado et al. [1] also note that high levels of objectively and subjectively experienced burden are associated with high emotional intensity between the patient and family members.

However, our study is limited in some respects. The small size of the groups studied, as well as the cross-sectional nature of the analyses conducted, make unambiguous interpretation of the results obtained and causal inference impossible. Therefore, it is recommended that further research in this area be longitudinal and conducted on larger groups.

The study and its conclusions prove the validity of including the patient in community-based treatment and the involvement of family caregivers in the treatment process. It is necessary to undertake multidimensional interventions that will make a real-life contribution to improving the quality of life of both patients and carers of people with schizophrenia.

Conclusions

In conclusion, the results of our study indicate that community-based treatment plays an important role in supporting families in the treatment process. Given that the subjective assessment of family burden is an important qualitative indicator of treatment outcomes for patients with schizophrenia, treatment programmes should be oriented in parallel to help both patients and their families.

References

- Gutiérrez-Maldonado J, Caqueo-Urízar A, Kavanagh DJ. Burden of care and general health in families of patients with schizophrenia. Soc. Psychiatry Psychiatr. Epidemiol. 2005; 40(11): 899–904.
- 2. Chen L, Zhao Y, Tang J, Jin G, Liu Y, Zhao X et al. *The burden, support and needs of primary family caregivers of people experiencing schizophrenia in Beijing communities: A qualitative study.* BMC Psychiatry 2019; 19(1): 75.
- 3. Malakouti SK, Nojomi M, Panaghi L, Chimeh N, Mottaghipour Y, Joghatai MT et al. Case-management for patients with schizophrenia in Iran: A comparative study of the clinical outcomes of Mental Health Workers and Consumers' Family Members as case managers. Community Ment. Health J. 2009; 45(6): 447–452.
- 4. Zahid MA, Ohaeri JU. Relationship of family caregiver burden with quality of care and psychopathology in a sample of Arab subjects with schizophrenia. BMC Psychiatry 2010; 10: 71.
- 5. Parabiaghi A, Lasalvia A, Bonetto C, Cristofalo D, Marrella G, Tansella M et al. *Predictors of changes in caregiving burden in people with schizophrenia: A 3-year follow-up study in a community mental health service.* Acta Psychiatr. Scand. Suppl. 2007; (437): 66–76.
- 6. Provencher HL, Mueser KT. *Positive and negative symptom behaviors and caregiver burden in the relatives of persons with schizophrenia*. Schizophr. Res. 1997; 26(1): 71–80.
- 7. Gopinath PS, Chaturvedi SK. *Distressing behaviour of schizophrenics at home*. Acta Psychiatr. Scand. 1992; 86(3): 185–188.
- 8. Roick C, Heider D, Toumi M, Angermeyer MC. *The impact of caregivers' characteristics, patients' conditions and regional differences on family burden in schizophrenia: A longitudinal analysis.* Acta Psychiatr. Scand. 2006; 114(5): 363–374.
- 9. Wang X, Chen Q, Yang M. Effect of caregivers' expressed emotion on the care burden and rehospitalization rate of schizophrenia. Patient Prefer. Adherence 2017; 11: 1505–1511.
- 10. Runions J, Prudo R. *Problem behaviours encountered by families living with a schizophrenic member.* Can. J. Psychiatry 1983; 28(5): 382–386.
- 11. Jungbauer J, Wittmund B, Dietrich S, Angermeyer MC. *The disregarded caregivers: Subjective burden in spouses of schizophrenia patients.* Schizophr. Bull. 2004; 30(3): 665–675.
- 12. Lasebikan VO, Ayinde OO. Family burden in caregivers of schizophrenia patients: Prevalence and socio-demographic correlates. Indian J. Psychol. Med. 2013; 35(1): 60–66.
- 13. Roick C, Heider D, Bebbington PE, Angermeyer MC, Azorin JM, Brugha TS et al.; EuroSC Research Group. *Burden on caregivers of people with schizophrenia: Comparison between Germany and Britain.* Br. J. Psychiatry 2007; 190: 333–338.
- 14. Caqueo-Urízar A, Gutiérrez-Maldonado J. Burden of care in families of patients with schizo-phrenia. Qual. Life Res. 2006; 15(4): 719–724.
- 15. Li J, Lambert CE, Lambert VA. *Predictors of family caregivers' burden and quality of life when providing care for a family member with schizophrenia in the People's Republic of China*. Nurs. Health Sci. 2007; 9(3): 192–198.
- Möller-Leimkühler AM. Burden of relatives and predictors of burden. Baseline results from the Munich 5-year-follow-up study on relatives of first hospitalized patients with schizophrenia or depression. Eur. Arch. Psychiatry Clin. Neurosci. 2005; 255(4): 223–231.
- 17. Novak M, Guest C. *Application of a multidimensional caregiver burden inventory.* Gerontologist 1989; 29(6): 798–803.

- 18. Kay SR, Fiszbein A, Opler LA. *The positive and negative syndrome scale (PANSS) for schizo-phrenia*. Schizophr. Bull. 1987; 13(2): 261–276.
- 19. Ruggeri M, Dall'Agnola R. The development and use of the Verona Expectations for Care Scale (VECS) and the Verona Service Satisfaction Scale (VSSS) for measuring expectations and satisfaction with community-based psychiatric services in patients, relatives and professionals. Psychol. Med. 1993; 23(2): 511–523.
- 20. Ustün TB, Chatterji S, Kostanjsek N, Rehm J, Kennedy C, Epping-Jordan J et al.; WHO/NIH Joint Project. *Developing the World Health Organization Disability Assessment Schedule 2.0.* Bull. World Health Organ. 2010; 88(11): 815–823.
- 21. Cohen S, Doyle WJ, Skoner DP, Rabin BS, Gwaltney JM Jr. Social ties and susceptibility to the common cold. JAMA 1997; 277(24): 1940–1944.
- 22. Russell D, Peplau LA, Ferguson ML. *Developing a measure of loneliness*. J. Pers. Assess. 1978; 42(3): 290–294.
- 23. Banaszkiewicz K, Sitek EJ, Rudzińska M, Sołtan W, Sławek J, Szczudlik A. *Huntington's disease from the patient, caregiver and physician's perspectives: Three sides of the same coin?*J. Neural. Transm. (Vienna) 2012; 119(11): 1361–1365.
- 24. Kliś M. *Adaptacyjna rola empatii w różnych sytuacjach życiowych* [The adaptive role of empathy in different life situations]. Horyzonty Psychologii 2012; 2: 147–171.
- 25. Kretek-Kamińska A, Kukulak-Dolata I, Krzewińska A. *Wsparcie osób niesamodzielnych. Perspektywa opiekunów i podopiecznych* [Support of dependent persons. Caregiver and caretaker perspectives]. Łódź: Wydawnictwo Uniwersytetu Łódzkiego; 2020.
- Madeja-Bień K, Gamian-Wilk M. Wybrane skutki wykluczenia społecznego [Selected effects of social exclusion]. Teraźniejszość – Człowiek – Edukacja 2017; 20(4(80)): 45–58.
- 27. Prot K, Anczewska M, Indulska A, Raduj J, Pałyska M. *Satysfakcja pacjentów i rodzin z opieki środowiskowej badanie pilotażowe* [Patients' and families' satisfaction from services provided in community care-pilot study]. Psychiatr. Pol. 2011; 45(6): 799–809.
- 28. Prot-Klinger K, Pawłowska M. *The effectiveness of community care for people with severe mental disorders*. Arch. Psychiatry Psychother. 2009; 11(4): 43–50.
- 29. 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): 285–289.
- 30. Winefield HR, Harvey EJ. *Determinants of psychological distress in relatives of people with chronic schizophrenia*. Schizophr. Bull. 1993; 19(3): 619–625.
- 31. Caserta MS, Lund DA, Wright SD. Exploring the Caregiver Burden Inventory (CBI): Further evidence for a multidimensional view of burden. Int. J. Aging Hum. Dev. 1996; 43(1): 21–34.
- 32. Merinder LM, Laugesen HD, Viuff AG, Espensen B, Misfelt S, Clemmensen K. *Satisfaction with services in patients with schizophrenia and their relatives at two community mental health centres*. Nordic Journal of Psychiatry 1999; 53(4): 297–303.
- 33. Hsiao CY, Tsai YF. Caregiver burden and satisfaction in families of individuals with schizophrenia. Nurs Res. 2014; 63(4): 260–269.
- 34. Litvan Z, Friedrich F, Wancata J. Differences in the level of burden put on mothers and fathers of patients suffering from schizophrenia. Eur. Psychiatry 2015; 30(Suppl 1): 1391.
- 35. 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: 285–292.

- 36. Baronet AM. Factors associated with caregiver burden in mental illness: A critical review of the research literature. Clin. Psychol. Rev. 1999; 19(7): 819–841.
- 37. Magliano L, Fadden G, Madianos M, de Almeida JM, Held T, Guarneri M et al. *Burden on the families of patients with schizophrenia: Results of the BIOMED I study.* Soc. Psychiatry Psychiatr. Epidemiol. 1998; 33(9): 405–412.

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