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Schizophrenia and family burden in Morocco: assessment in a sample of 150 caregivers

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Abstract

Background There have been few studies conducted in Africa about the burden on families of patients with schizophrenia. This study had two main objectives: assessing the burden of those families and identifying the socio-demographic factors associated with this one.

Methods We included 300 participants: 150 were primary family caregivers of 150 patients with schizophrenia. A questionnaire was used to collect their sociodemographic and clinical characteristics, and their objective burden using the FBIS (Family Burden Interview Schedule).

Results Patients were mostly men ($n = 122$, 81%), the mean age was 32.4 years \pm 10.1, and more than half of the patients were psychoactive substance users. Participants (caregivers) were mostly women ($n = 90$, 60%). Their mean age was 51.9 \pm 12.8 years, with a percentage of 62 (41%) illiteracy, while 98 (65%) were parents. The mean score of the family burden was 21.82 (0–48). The most affected categories were family routine, family interaction, and finances. The burden of families was associated with five sociodemographic variables: the female gender of the caregiver ($p = 0.01$), the male gender of the patient ($p = 0.02$), his young age ($p = 0.004$), his education level ($p < 0.0001$), and his psychoactive substance use (PAS) ($p < 0.0001$).

Conclusion The three main constraints encountered by families caring for a patient with schizophrenia were disruption of daily activities, deterioration in the quality of family interactions with those around them, and lastly financial difficulties. These results highlighted the need to set up intermediary socio-medical structures, which would act as a link between conventional hospital services and families.

Keywords Schizophrenia, Caregiver, Family burden

Introduction

Schizophrenia was described more than 100 years ago. It is still one of the most mysterious disorders in psychiatry [1]. This psychiatric disorder is a real public health problem that is responsible for a lot of suffering for the patient, his family, and society [1]. It is a universal disease which ranked the 8th most common disability in the world in the age group of 15–44 years by the WHO (World Health Organization) [2]. Its worldwide prevalence is estimated at 1% [3]. The family's role in the psychiatric context has been evolving over the past decades. The relationship between healthcare professionals and

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patient's families is increasingly collaborative, and it helps to improve patient follow-up also to prevent relapses [4]. A caregiver is defined as a person who is actively taking care of someone with a medical condition. In our context, this refers to a patient family member who looked after this patient's daily needs, supervised his/her treatment, brought him/her to the hospital, and cooperated with the treating medical team. In Morocco, mental health professionals and material resources are limited [5], making the role of caregivers crucial in caring for patients with schizophrenia. Their contribution is vital in ensuring effective care for these patients. The family burden is linked to the caregiving psychosocial and financial burdens. Many physical and mental illnesses place enormous demands on a caregiver's resources, which can lead to depression, social isolation, and physical illness [6]. Although the burden on families is significant, few studies have been conducted in our country on this topic [7]. We conducted one of the first studies of the burden on families of patients with schizophrenia in Morocco. The objective of this study was to highlight the suffering of these families by evaluating this burden in all aspects: emotional, social, and financial. We also measured the impact of the stigmatization and the influence of the disease on the physical and mental health of family members.

Material and methods

Our cross-sectional study was conducted among families of patients with schizophrenia admitted to a psychiatric department of a public university hospital in Morocco during a period of three months and a half in 2016. The study principle and questionnaire as a part of a medical thesis were reviewed and approved by the scientific committee responsible for theses at the Medicine Faculty of Rabat in Morocco. This thesis was registered under the number M3022016 at the library of the Medicine Faculty of Rabat, Mohammed V University [8]. The sample size was calculated by referring to data from the only national epidemiological study conducted in 2006 to estimate the current prevalence of mental disorders in the general population, where 48.9% of the population aged 15 and over had at least one recurrent disorder, including 5.6% of psychotic disorders (schizophrenia, delusional disorder, etc.) considered over a lifetime. It was almost identical for both sexes [9]. The calculated sample size at a 99% confidence level with 5% variability was 138. Our study included 150 participants representing family members of 150 patients with schizophrenia. The participant was the patient's primary or among the primary family carers of a patient diagnosed with schizophrenia. This diagnosis was established by a psychiatrist according to the criteria of the Diagnostic and

Statistical Manual of Mental Disorders, fifth edition (DSM-5). The disorder was evolving for 6 months or more following diagnosis. We agreed that this period was sufficient for the participant to feel a significant burden. However, many studies did not specify this minimum duration after diagnosis [10–12], while others fixed it at 1 year [13, 14].

All participants gave their verbal informed consent before entering the survey. A designed questionnaire for this study that included three sections was used. The first part concerned the sociodemographic characteristics of the patient (gender, age, marital status, education level, employment status, and type of insurance) and those of the participants (gender, age, marital status, education level, employment status, monthly family revenue, and relationships with the patient). The second one was about the clinical data of the patient (age at diagnosis, duration of the disorder, number of hospitalizations, medication, and psychoactive substance (PAS) use: tobacco excluded). The last part was represented by the 24-item FBIS (Family Burden Interview Schedule). This scale was developed in 1981 by Indian authors (Pai and Kapur) for families of patients with mental disorders, particularly schizophrenia, to assess the family burden of the disease [15]. It consists of a semi-structured interview with 24 questions grouped into 6 categories representing the objective burden of schizophrenia. For each item, the response was scored from 0 to 2 (0, no burden; 1, moderate burden; 2, severe burden). The burden of each category was then obtained by calculating the total of the scores of its items as follows: finances (6 items scored from 0 to 12), domestic activities (5 items scored from 0 to 10), leisure (4 items scored from 0 to 8), family interactions (5 items scored from 0 to 10), physical health (2 items scored from 0 to 4) and mental health (2 items scored from 0 to 4). The overall objective burden score was obtained by calculating the total of the scores for the six categories (from 0 to 48). The higher the score, the more severe the burden. The interview was in dialectal Arabic by one interviewer "face to face" who checked off the answers himself.

Data was collected in conditions of participant and patient anonymity and confidentiality. It was transcribed and interpreted by the SPSS-24 application. The qualitative variables were expressed as headcount (n) and percentage (%), and the quantitative variables were expressed as the mean and standard deviation (SD). Univariate analysis was performed using Student's t test (comparison of two groups) and ANOVA test (comparison of more than two groups). A value of $p < 0.05$ was considered significant, and a value of $p < 0.0001$ was considered highly significant.

Results

The mean age of the patients was 32.4 years \pm 10.2. More than 80% of them were males, 73% were single, and 75% were unemployed. The mean age at diagnosis was 22.3 years \pm 7.5. The median duration of the disease was 8 years. Fifty-three percent of the patients used psychoactive substances. Most of the family caregivers were

women with an average age of 51.9 years \pm 12.8. The participants were mainly parents of the patient (65%) (See Table 1).

In terms of objective family burden, the average global burden score in our sample was 21.82. For each item, the average score was 3.73 for financial burden, 6.23 for family domestic activities, 4.33 for leisure

Table 1 Sociodemographic and clinical characteristics of patients and their caregivers

Characteristics	Patients, <i>n</i> = 150 <i>n</i> (%) / Mean \pm SD	Family caregiver, <i>n</i> = 150 <i>n</i> (%) / Mean \pm SD
Gender		
Man	122 (81)	60 (40)
Woman	28 (19)	90 (60)
Age	32,4 \pm 10,1	51,9 \pm 12,8
Marital status		
Single	109 (73)	10 (7)
Married	32 (21)	110 (73)
Divorced	9 (6)	7 (5)
Widowed	0 (0)	23 (15)
Level of education		
Illiterate	15 (10)	62 (41)
Primary	38 (25)	38 (25)
Secondary	78 (52)	31 (21)
Hight	19 (13)	19 (13)
Employment status		
In activity	36 (24)	65 (43)
Retired	2 (2)	19 (13)
Unemployed	112 (75)	66 (44)
Medical insurance coverage		
Yes	105 (70)	-
No	45 (30)	-
Family relationship		
Paternity	-	98 (65)
Brotherhood	-	30 (20)
Partner	-	6 (4)
Descent	-	3 (2)
Other	-	13 (9)
Monthly income (MAD)		
< 3000	-	96 (64)
3000 \leq and \leq 7000	-	35 (23)
> 7000	-	19 (13)
Age at the time of diagnosis (years)	22.3 \pm 7.5	-
Duration of the disease		
< 5 years	60 (40)	-
5 \leq and \leq 10 years	28 (19)	-
> 10 years	65 (43)	-
Number of hospitalizations		
< 2	123 (82)	-
\geq 2	27 (18)	-
Treatment compliance	115 (77)	-
Use of psychoactive substances	80 (53)	-

n headcount; % percentage, *SD* standard deviation, *MAD* Moroccan Dirhams

activities, 5.61 for family interactions, 0.97 for the effect on physical health, and 0.97 for the effect on mental health.

The analysis of the results showed that there was a significant relationship between financial burden and the following socio-demographic variables: low monthly family income (<3000 MAD; $p=0.007$), no medical insurance coverage ($p=0.01$), patient's lower education levels ($p=0.009$), and patient's substance use ($p=0.008$).

There were six factors significantly related to the burden of family domestic activities. Three of them were highly significant: patient's age (<25 years; $p<0.0001$), caregiver's relationship with the patient (parents; $p<0.0001$), caregiver's gender (woman; $p<0.0001$), patient's age at diagnosis (<18 years; $p=0.043$), patient's use of psychoactive substances ($p=0.014$), and caregiver's education level (illiterate or university graduates; $p=0.032$). Five factors were significant in the burden in the leisure category: the caregiver's employment status (working participant; $p<0.0001$), the caregiver's age (between 40 and 50 years old; $p=0.04$), the patient's gender (man; $p=0.01$), the patient's education level (lower levels; $p=0.001$), and the patient's use of psychoactive substances ($p=0.01$).

A statistically significant relationship was found between the burden of family interactions and four socio-demographic variables: patient's substance use ($p<0.0001$), patient's age (<25 years; $p=0.009$), patient's marital status (divorced; $p=0.02$), and caregiver's marital status (divorced; $p=0.02$). The analysis revealed only one significant variable about physical health. It was the caregiver's gender (woman; $p=0.006$). Indeed, women reported significantly more burden (1.12 ± 0.79) on their physical health than men. Mental health burden was associated with the patient's gender (man; $p=0.006$), patient's age at diagnosis (<25 years; $p=0.04$), patient's use of psychoactive substances ($p=0.02$), and the caregiver's relationship with the patient (brothers or partners; $p=0.04$).

The categories that generated the most burden in our survey were respectively family domestic activities (99%), family interactions (95%), and the financial dimension (92%). The factors that were strongly significant in the overall objective burden were the patient's psychoactive substance use and the education level. Indeed, patients with psychoactive substance use were responsible for a higher burden (23.98 ± 5.41), while illiterate or university-educated patients were responsible for significantly less burden compared to patients with primary or secondary education (19.67 ± 6.75 and 16.6 ± 7.83 vs 22.53 ± 5.66 and 23.15 ± 5.62 , respectively) (See Tables 2 and 3).

Discussion

Recent studies have shown that the burden experienced by families of patients with schizophrenia was significantly higher than that experienced by families of patients with chronic physical illness [16, 17]. Schizophrenia also was the most burdening mental illness for families according to several studies [18]. In terms of global objective burden, the mean score, in our sample, was 21.82 which was considered moderate (score ranges from 0 to 48). This score placed our sample among the caregivers who reported less burden on their relative patients with schizophrenia. Many studies had shown that caregivers of patients with schizophrenia suffered from moderate to severe burden [19–25]. Factors that were most implicated in the burden include the severity of the patient's symptoms, the low level of education of the caregiver [26–30], and the lack of social support [31].

In our study, five significant factors were associated with family burden: the female gender of the caregiver, the male gender of the patient, the patient's young age, the patient's education level, and the patient's PAS use. There was a highly significant relationship between PAS use and overall objective burden. Indeed, patients who used psychoactive substances had more psychiatric hospitalizations, relapses, and suicidal behavior [32–35]. All these factors made substance use a strong determinant of family burden.

The analysis of the results showed that the younger the patient, the greater the burden. This fact was in line with data from many articles on the same subject [36, 37]. Often, the young age of the patient was a source of big disappointment about the prospects of his future. The fact that male patients generated more burden, was rare in the literature. Indeed, most studies have not found a significant relationship between patient gender and burden [38]. In contrast, a study in Kuwait found that female patients were responsible for more overall burden, due to the special status of women in Gulf countries [23]. However, women, especially mothers, were more burdened. That was consistent with the literature [39, 40]. The nature of the caregiver-patient relationship seemed to play an important role in the family burden. In our study, most participants were parents. That result was similar to many other studies, where parents constituted more than two thirds of caregivers, with no difference between developed and developing countries [13, 26].

The financial burden in our sample was one of the lowest in the literature with a mean score of 3.72 (0–12), while it was 5.85 in Nigeria [41], 8.63 in India [18], and 9.54 in China [24]. Factors related to financial burden differed between countries and cultures. For example, a study in Nigeria showed that the duration of the disorder and the time spent with the patient were significantly

Table 2 Results of univariable analysis: caregiver's socio-demographic characteristics

Characteristics	Mean scores of family burden																	
	Financial dimension			Domestic activities			Leisure			Family interactions			Effect on physical health		Effect on mental health		Total scores	
	Score±SD	p	Score±SD	p	Score±SD	p	Score±SD	p	Score±SD	p	Score±SD	p	Score±SD	p	Score±SD	p	Score±SD	p
Gender	Man	3.70±2.20	0.926	5.17±1.67	0.000	4.30±2.55	0.906	5.55±2.98	0.847	0.75±0.82	0.006	0.83±0.74	0.084	20.30±6.31	0.016			
	Woman	3.73±2.13		6.93±1.65		4.34±1.72		5.64±2.89		1.12±0.79		1.06±0.78		22.83±6.18				
Age	<40 ans	3.84±2.08	0.744	5.78±2.00	0.297	4.69±2.53	0.040	5.56±2.98	0.842	0.84±0.88	0.210	0.97±0.90	0.696	21.69±6.57	0.350			
	40–50	7.22±2.17		10.0±1.81		7.58±2.15		9.33±3.07		3.58±0.81		4.19±0.75		25.19±6.95				
Marital status	>50	3.74±2.18		6.14±1.82		4.24±1.87		5.61±2.98		1.07±0.79		0.96±0.74		21.70±6.04				
	Single	2.70±1.64	0.432	5.50±1.35	0.108	4.30±2.50	0.973	3.90±2.23	0.029	0.80±0.92	0.365	1.10±0.74	0.574	18.30±4.32	0.304			
Level of education	Married	3.74±2.19		6.27±1.89		4.36±2.13		5.95±2.83		0.93±0.82		0.98±0.82		22.23±6.37				
	Divorced	4.00±2.89		5.00±2.58		4.00±2.00		6.43±3.36		1.29±0.95		1.14±0.90		21.86±7.65				
Employment status	Widowed	4.00±1.88		6.70±1.55		4.26±1.84		4.48±3.09		1.17±0.72		0.78±0.42		21.39±1.34				
	Illiterate	4.03±2.05	0.430	6.76±1.62	0.032	4.34±1.66	0.915	5.94±3.08	0.447	1.11±0.77	0.329	0.94±0.67	0.877	23.11±5.99	0.182			
Family relationship	Primary	3.68±2.24		5.84±1.82		4.47±2.30		5.42±2.57		0.89±0.80		0.92±0.75		21.24±6.04				
	Secondary	3.42±2.16		5.77±2.00		4.29±2.24		4.97±2.82		0.81±0.95		1.03±0.98		20.29±6.84				
Monthly income	Hight	3.26±2.28		6.00±2.21		4.05±2.72		5.95±3.21		0.95±0.78		1.05±0.78		21.39±1.34				
	In activity	3.89±2.14	0.713	6.23±2.07	0.207	5.20±2.45	0.000	5.94±2.73	0.378	0.86±0.86	0.281	0.98±0.76	0.614	23.11±6.80	0.141			
Family relationship	Retired	3.78±2.62		5.44±1.82		3.56±1.76		5.72±3.34		1.06±0.87		0.89±0.68		20.44±6.61				
	Unemployed	3.52±2.04		6.45±1.63		3.68±1.38		5.30±2.98		1.08±0.75		0.98±0.81		21.02±5.62				
Family relationship	Paternity	3.83±2.17	0.897	6.68±1.76	0.000	4.33±1.85	0.908	5.78±3.04	0.589	1.05±0.78	0.329	0.99±0.71	0.043	22.65±6.22	0.212			
	Brotherhood	3.40±2.06		4.93±2.03		4.53±2.74		4.87±2.65		0.77±0.90		1.13±0.94		19.63±6.47				
Monthly income	Partner	4.00±3.16		6.50±0.55		3.83±2.04		5.67±2.25		1.00±1.10		1.17±0.98		22.17±7.31				
	Descend	6.67±1.53		6.00±1.00		4.67±1.15		5.00±4.36		1.33±1.15		0.67±0.58		21.33±8.96				
Monthly income	Other	3.54±2.03		5.69±1.38		4.00±2.45		6.15±2.58		0.77±0.73		0.38±0.51		20.54±5.33				
	<3000 MAD	4.03±1.97	0.007	6.29±1.74	0.326	4.29±2.04	0.503	5.81±2.84	0.488	1.06±0.79	0.203	0.86±0.61	0.069	22.35±5.94	0.124			
Monthly income	3000–7000	3.60±2.46		6.37±1.85		4.63±2.10		5.34±2.88		0.80±0.87		1.09±0.98		21.83±6.91				
	>7000	2.37±1.95		5.63±2.45		3.95±2.32		5.05±3.41		0.84±0.83		1.26±0.99		19.11±6.81				

score headcount, % percentage, SD standard deviation, MAD Moroccan Dirhams

Table 3 Results of univariable analysis; patient's sociodemographic and clinical characteristics

	Mean scores of family burden																				
	Financial dimension		Domestic activities		Leisure		Family interactions		Effect on physical health		Effect on mental health		Total								
	Score	SD	Score	SD	Score	SD	Score	SD	Score	SD	Score	SD	Score	SD							
Gender																					
Man	3.84	±2.26	0.077	6.22	±1.92	0.942	4.46	±2.04	0.011	5.82	±2.87	0.620	0.98	±0.82	0.750	1.05	±0.80	0.006	22.37	±6.46	0.026
Woman	3.21	±1.47		6.25	±1.65		3.75	±2.24		4.68	±2.99		0.93	±0.79		0.61	±0.5		19.43	±5.22	
Age																					
< 25	6.35	±2.23	0.969	9.83	±1.75	0.000	7.17	±1.80	0.187	9.26	±2.75	0.009	3.17	±0.80	0.786	3.57	±0.80	0.122	25.78	±5.47	0.004
25 ≤ and ≤ 40	3.95	±2.19		6.14	±1.85		4.34	±2.7		5.30	±3.08		0.84	±0.80		0.98	±0.76		21.49	±6.90	
> 40	3.48	±1.86		5.45	±1.88		3.97	±2.31		5.21	±2.62		1.21	±0.86		0.79	±0.77		20.10	±5.79	
Marital status																					
Single	3.50	±1.97	0.134	6.33	±1.93	0.290	4.25	±2.16	0.641	5.46	±2.94	0.020	1.03	±0.82	0.327	0.99	±0.79	0.753	21.56	±6.09	0.369
Married	4.31	±2.66		6.13	±1.72		4.44	±1.79		5.38	±2.79		0.78	±0.83		0.88	±0.83		21.91	±7.51	
Divorced	4.22	±1.92		5.33	±1.50		4.89	±2.26		8.22	±1.86		1.00	±0.71		1.00	±-		24.67	±4.18	
Widowed	0			0			0			0			0			0			0		
Level of education																					
Illiterate	3.47	±1.92	0.009	6.20	±1.61	0.420	3.53	±2.80	0.001	4.80	±3.00	0.050	1.00	±0.93	0.659	0.67	±0.49	0.065	19.67	±6.75	0.000
Primary	4.21	±1.99		6.24	±1.58		4.76	±1.95		5.61	±2.81		0.92	±0.85		0.79	±0.58		22.53	±5.66	
Secondary	3.88	±2.21		6.38	±1.89		4.63	±1.74		6.10	±2.94		1.04	±0.78		1.12	±0.85		23.15	±5.62	
Higher	2.26	±1.85		5.58	±2.41		2.84	±2.34		4.21	±2.57		0.79	±0.85		0.95	±0.85		16.63	±7.38	
Work situation																					
In activity	3.39	±2.36	0.363	5.56	±2.20	0.097	3.92	±2.30	0.488	4.86	±2.98	0.335	0.72	±0.91	0.120	1.06	±0.98	0.551	19.50	±7.77	0.053
Retired	6.00			7.00			6.00			7.00			1.00						27.00		
Unemployed	3.79	±2.08		6.43	±1.72		4.44	±2.02		5.82	±2.90		1.04	±0.78		0.95	±0.70		22.46	±5.66	
Type of medical insurance																					
RAFA mutual insurance	2.83	±2.23	0.018	5.83	±2.04	0.915	4.67	±1.03	0.319	6.00	±3.03	0.116	0.83	±0.98	0.213	0.83	±1.17	0.197	21.00	±4.60	0.069
CNSS ^b	2.00	±2.07		6.25	±1.67		4.63	±0.92		4.75	±1.39		0.38	±0.74		1.0	±1.31		19.00	±5.10	
CNOPS ^c	2.84	±2.57		6.00	±2.45		3.47	±2.39		4.05	±3.06		0.84	±0.76		1.32	±1.11		18.53	±8.34	
RAMED ^d	4.06	±2.04		6.36	±1.75		4.28	±2.10		5.86	±2.86		1.06	±0.80		0.85	±0.62		22.46	±6.47	
None	3.98	±1.94		6.16	±1.86		4.67	±2.14		5.96	±3.01		1.02	±0.84		1.02	±0.62		22.80	±5.05	
Age at diagnosis																					
< 18	3.38	±2.09	0.223	6.60	±1.78	0.043	4.34	±1.87	0.330	6.08	±2.55	0.358	1.00	±0.76	0.857	1.04	±0.90	0.040	22.44	±5.32	0.506
18 ≤ and ≤ 30	4.12	±2.15		6.26	±1.73		4.54	±2.03		5.48	±3.09		0.95	±0.86		0.99	±0.66		22.34	±6.26	
> 30	2.60	±1.84		4.80	±2.34		3.07	±2.71		4.73	±2.99		1.00	±0.85		0.60	±0.83		16.80	±7.94	
Duration of disorder (years)																					
< 5	3.68	±2.37	0.726	6.36	±1.85	0.130	4.27	±2.06	0.933	5.80	±3.27	0.063	0.83	±0.81	0.175	0.88	±0.79	0.212	21.81	±7.00	0.187
5 ≤ and ≤ 10	3.89	±1.76		6.67	±1.75		4.59	±2.27		6.33	±2.57		1.22	±0.85		1.19	±0.83		23.89	±5.72	
> 10	3.69	±2.11		5.92	±1.90		4.27	±2.06		5.13	±2.66		1.00	±0.80		0.95	±0.72		20.95	±5.80	
Number of hospitalizations																					
< 2	3.62	±2.39	0.797	6.11	±1.69	0.120	4.34	±2.12	0.965	5.41	±2.82	0.237	0.90	±0.83	0.212	0.91	±0.78	0.415	21.29	±7.18	0.140
≥ 2	4.19	±2.04		6.74	±1.92		4.26	±2.08		6.52	±2.93		0.30	±0.79		1.22	±0.77		24.22	±5.82	
Use of antipsychotics																					
Yes	3.71	±2.11	0.943	6.30	±1.77	0.358	4.46	±1.97	0.154	5.38	±2.98	0.088	0.96	±0.81	0.650	0.96	±0.79	0.772	21.77	±6.05	0.872
No	3.74	±2.32		5.97	±2.16		3.89	±2.41		6.34	±2.62		1.03	±0.86		1.00	±0.73		21.97	±7.27	

Table 3 (continued)

Patient's characteristics		Mean scores of family burden													
		Financial dimension		Domestic activities		Leisure		Family interactions		Effect on physical health		Effect on mental health		Total	
		Score±SD	p	Score±SD	p	Score±SD	p	Score±SD	p	Score±SD	p	Score±SD	p	Score±SD	p
PAS use	Yes	4.15±2.17	0.008	6.58±1.81	0.014	4.71±1.78	0.015	6.40±2.76	0.000	1.04±0.85	0.306	1.10±0.76	0.023	23.98±5.41	0.000
	No	3.23±2.03		5.83±1.86		3.89±2.33		4.70±2.85		0.90±0.78		0.81±0.77		19.36±6.44	

score headcount, % percentage, SD standard deviation

^a RAF, Royal Armed Forces' mutual insurance

^b CNSS, National Social Security Fund medical insurance

^c CNOPS, National Fund for Social Welfare Organizations' medical insurance

^d RAMED, Regime for Medical Assistance to the most deprived; PAS use, psychoactive substance use

related to the financial burden [41]. Another study realized by a Belgium team found a significant relationship between kinship and financial contributions [19].

Domestic activities were one of the most affected categories in such studies [19, 41]. This result was perfectly consistent with our survey. Indeed, in our sample, parents expressed a higher burden on daily activities than partners and sisters or brothers. This finding in our sample was related to the fact that many parents gave up their activities, and sometimes their jobs, to take care of their diseased children. However, other studies, notably in India and Australia, found that parents reported less burden than partners [23, 25]. Mothers were the most affected caregivers in terms of activities and daily life. These findings were common in countries where society is still patriarchal [10, 13]. Mothers had a special status. They were the primary, if not the only, caregivers. This status was largely due to their psychological and practical commitment to their responsibilities [42], also an aspect that mental health professionals should consider [43].

The caregiver's level of education was also found to be a highly significant factor in the interruption of daily household activities, with illiterate participants recording the highest burden. Indeed, it was one of the most prominent factors in this regard [44, 45]. It has been suggested that a high level of education in the family caregiver served as a "protective factor" against severe burden [46].

Living with a patient with schizophrenia can be extremely stressful. In this survey, many family caregivers reported a decrease in leisure activities. However, this dimension was modestly affected, both in our study and in the literature, with mean scores between 4 and 6 (0–8) [18, 24]. Our results showed that the younger the caregiver was, the greater the burden on leisure time was. Working caregivers showed a much higher burden than those who were unemployed or retired, which was also reported in the literature [41].

Although the family interaction dimension represented the intertwining of several concepts, it explored the impact of schizophrenia on the relationship between family members. It also highlighted the different feelings that family caregivers can experience such as guilt, shame, or despair. Almost, half of the caregivers said that the term used to describe the patient was "crazy." Shame and guilt related to schizophrenia have been widely reported in the literature, with no distinction between Western and non-Western countries [47]. Although the link between patient and caregiver's marital status and burden had not been established in several studies [41, 48], our analysis showed that divorced patients, as well as divorced caregivers, were significantly related to more burden. Also, the use of psychoactive substances increased the burden of the family's interactions with the environment. Thus,

the patient with schizophrenia and psychoactive substance use suffered from a double stigma: the first one was linked to addiction and related problems, and the second one was related to mental disease.

Few studies have investigated the effect of schizophrenia on the physical health of caregivers [30, 49]. One study reported that family members caring for a patient with schizophrenia suffered from low back pain, ulcers, high blood pressure, and headaches [50]. In our study, caregivers reported moderate physical health, especially through the worsening of a pre-existing chronic illness. This worsening was generally due to neglect of their health condition. Caregivers in our study reported symptoms such as insomnia and weight loss and also described in other studies [24, 41]. The only factor significantly related to physical health in our sample was the female gender of the caregiver. These results were consistent with the literature [36, 51]. Contrary to our expectations and the results of several studies [41, 52], the age of the family caregiver was not correlated with physical health burden.

Regarding the impact on mental health, the mean score of our sample in this category was one of the lowest in the literature [18, 24]. Several studies had found depressive symptoms in most family caregivers [53, 54]. A study in Sri Lanka found that depression in family caregivers of patients with schizophrenia was related to the interruption of their work, the deterioration of their relationships with others, and the amount of time spent with the patient [55].

Finally, there was a highly significant relationship between psychoactive substance use and the global objective burden. Indeed, patients who used PAS had more psychiatric hospitalizations [32]. Another study found that the 1-year relapse rate was significantly higher in the group of patients who continued to use substances than in the abstinent group (68.0 versus 33.3%) [33]. An association between substance abuse and suicidal behavior in schizophrenia was also found in several studies [34, 35]. All these factors made PAS use a strong determinant of family burden.

Although the role of families of patients with schizophrenia was known to be determined in the overall prognosis, it remained an unorganized system of "informal care." To compensate for the lack of experience of caregivers, health systems tried to develop psycho-educational programs to inform families about schizophrenia [56], to help them adapt to their environment, and to foster a mode of communication that minimizes the patient's symptoms and relapses. The most widely used psycho-educational program in the French-speaking world was the Profamily model, which was essentially based on the needs of the parents. It was developed in

1987 by Cormier in Quebec, brought to Europe in 1993 [57], and was also used in Morocco by a network of associations helping families of patients with schizophrenia. A lot of work is needed to alleviate the burden on families, especially by helping these families reach the status of “care partner” that was already acquired for years in many Western countries.

Limitations

The complex nature of the concept of burden made it very difficult to assess. Indeed, its different dimensions included some variables that were difficult to collect, considering their subjective and non-quantitative nature. Almost all the tools used for families of patients with schizophrenia were confronted with two problems: on the one hand, the weakness of the theoretical framework in which they were developed, and on the other hand, considerable shortcomings in the process of construction and validation of the instrument.

Conclusion

Despite the lack of material and human resources in the mental health sector in Morocco, the burden on the families of patients with schizophrenia was relatively moderate compared with many other countries. This finding underlines the particularity of the Moroccan context, where the social tissue is still tightly linked and the family represents a system of support and solidarity. This study highlighted the three main constraints encountered by families caring for a relative with schizophrenia that were disruption of daily activities, deterioration in the quality of family interactions with those around them, and financial difficulties. These results illustrated the need to set up intermediary socio-medical structures, which would act as a link between conventional hospital services and families. The aim of these structures would be the social reintegration of patients with schizophrenia and their rehabilitation for better functioning in society. In addition, these structures will help support the families by contributing to relieving their fear and anxiety and improving their knowledge and ability to deal with the various problematic situations encountered when caring for a family member with schizophrenia.

Abbreviations

CNOPS	National Fund for Social Welfare Organizations medical insurance
CNSS	National Social Security Fund medical insurance
DSM 5	Diagnostic and Statistical Manual of Mental Disorders, 5th edition
FBIS	Family Burden Interview Schedule
MAD	Moroccan Dirhams
PAS	Psychoactive substances
RAF	Royal Armed Forces' mutual insurance
RAMED	Regime for Medical Assistance to the Most Deprived
SPSS-24	Statistical Package for Social Sciences 24th edition
WHO	World Health Organization

Acknowledgements

Not applicable

Authors' contributions

M.S. collected the data and analyzed the results as part of her doctoral medical thesis which was supervised by M.K. Y.O., and M.K. oversaw every drafting stage of this paper and corrected all the text. All authors have read and approved the final version of the manuscript.

Funding

The study received no funding.

Availability of data and materials

All data generated or analyzed during this study are included in this published article (and its supplementary information files).

Declarations

Ethics approval and consent to participate

All participants consented to participate in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Received: 2 June 2023 Accepted: 30 August 2023

Published online: 15 November 2023

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