CAREGIVER BURDEN AND PERCEIVED SOCIAL SUPPORT OF THE MAIN CAREGIVER OF PEOPLE WITH SEVERE MENTAL DISORDER IN CATALONIA: TYPE OF CARE TASKS AND ASSOCIATED DISCOMFORT

Emilio Rojo
Hospital Benito Menni CASM, Hermanas Hospitalarias, Sant Boi de Llobregat, Barcelona, Catalonia, Spain.
Department of Medicine, Universitat Internacional de Catalunya, Sant Cugat del Valles, Barcelona, Catalonia, Spain.
Pacte Nacional de Salut Mental de Catalunya, Generalitat de Catalunya, Barcelona, Catalonia, Spain
erojo.hbmenni@hospitalarias.es
emiliorojo@uic.es
María Jesús San Pío
Federació Salut Mental Catalunya, Barcelona, Catalonia, Spain.
Gemma Marcet
Federació Salut Mental Catalunya, Barcelona, Catalonia, Spain.
Francisco José Eiroa-Orosa
First-Person Research Group, Federació catalana de entitats de salut mental en 1ª persona – Veus, Barcelona, Catalonia, Spain.
Personality, Evaluation and Psychological Treatment Section, Department of Clinical. Psychology and Psychobiology, Faculty of Psychology, University of Barcelona, Barcelona, Catalonia, Spain.
Josep Rojo
Fundacio Privada Panacea, Barcelona, Catalonia, Spain.

Conflict of interest: All authors have no conflicts of interest to declare.

Abstract

The aim of this study is to show the type of care tasks related to the burden and the social support of the caregiver of a person with a mental disorder.

Methods: Cross-sectional study in which data were collected from 224 care units (primary caregiver/patient) who were being followed up in Catalonia. Interviews were conducted using the Family Burden Interview Schedule and the Duke Functional Social Support Scale. An explanatory model of the results was sought using multiple linear regression or binomial logistic models.

Results: The patient is a 40-year-old single male, while the main caregiver is a 60-year-old married woman. Daily living tasks, enforcement of the patient's schedules and routines, and the suicidal behavior explain the increased objective and subjective caregiver burden.

Conclusions: Daily living tasks represents a important part of the objective and subjetive care burden. The perceived social suport is related to concerns about the patient.

Key words: objective caregiver burden; subjective caregiver burden; mental disorders; activities of daily living; perceived social support; caregiver burnout.

Resumen

El objetivo de este estudio es mostrar el tipo de tareas de cuidado relacionadas con la carga y el apoyo social del cuidador de una persona con un trastorno mental.

Métodos: Estudio transversal en el que se recogieron datos de 224 unidades de cuidados (cuidador principal/paciente) que estaban en seguimiento en Cataluña. Se realizaron entrevistas utilizando el Family Burden Interview Schedule y la Duke Functional Social Support Scale. Se realizó regresión lineal múltiple o logística binomial para obtener un modelo explicativo de los resultados.

Resultados: El paciente es un hombre soltero de 40 años, mientras que el cuidador principal es una mujer casada de 60 años. Las tareas de la vida diaria, el cumplimiento de los horarios y rutinas del paciente y la conducta suicida explican el aumento de la carga objetiva y subjetiva del cuidador.

Conclusiones: Las tareas de la vida diaria representan una parte importante de la carga objetiva y subjetiva del cuidador. El apoyo social percibido está relacionado con la preocupación por el paciente.

Palabras clave: carga objetiva del cuidador; carga subjetiva del cuidador; trastornos mentales; actividades de la vida diaria; apoyo social percibido; agotamiento del cuidador.

Introduction

Since the 1970s, thanks to new treatments and the assertive community model, care of serious and chronic mental disorders has largely been undertaken by the individual and his or her family environment, generating a significant burden of care.

The family environment is usually the setting where the patient lives, where he/she exercises self-care, and where he/she generally restarts his/her life project and resumes his/her duties and rights after an accident or illness. The role of the family and the caregiver is key to the growth of the person having experienced a relevant loss of functions, such as may result from brain or spinal cord injuries (1,2) but also those secondary to severe mental disorders, a relevant point for the WHO from the 21st century onwards (3).

Caregiver burden refers to the strain endured by a person who cares for a chronically ill individual (4) and it has an objective component (quantifiable tasks and responsibilities, time spent) and a subjective component (own level of discomfort in performing the task) (5). These components are influenced by different aspects of caregiving, and their overload has been linked to increased symptoms, especially negative type, and disruptive behaviors, hospital admissions and use of health services by patients, and to lower self-perception of caregivers in terms of their caregiving skills, a lower likelihood of getting help to care for the patient and poorer social functioning and health (4-18). The caregiver burden could be summed up in a single value but it is important to know the distribution of the objective and subjective burden among the different responsibilities and tasks in order to allocate resources and actions appropriately in the care of mental illness so that a good standard of care is maintained, and the functioning and well-being of the patient and caregiver is improved.

In this paper, we present the different type of tasks about a large sample of caregivers of a person with severe mental disorder in Catalonia in relation to the following question: Which variables explain the higher subjective and objective burden and perceived social support of the main caregiver of a person with severe mental disorder?

Methods

This study is based on the pilot phase of the Catalan Department of Health’s Activa't project (19,20), which has been applied in 12 areas of Catalonia that have a community mental health centre and an active carers' association. Data were collected from 1 April 2015 to 31 January 2016.

Sample

The sample size calculated indicated that 222 care units (primary caregiver/patient) were sufficient for the detection of a moderate Minimum Detectable Effect (MDE) according to Cohen (21) and Boruch et al (22). The study involved 224 family units (patient and primary caregiver).

Inclusion criteria for the care unit

Patient: 1) between 18 and 63 years of age, 2) diagnosis of chronic affective disorder (bipolar disorder and severe recurrent depression) or psychotic disorder (schizophrenia, schizoaffective and delusional disorder), 3) illness duration > 2 years, 4) moderate level of functioning (GAF/EEAG ≤ 60: moderate symptoms or moderate difficulties in social, professional or educational activity).

Caregiver: 1) primary caregiver (the caregiver who was most intensively and extensively involved in the care of the patient according to the patient and the referring health professional).

Patient and caregiver: 1) willingness and actual ability to participate 2) give their informed consent to participate.

Exclusion criteria for the care unit

Patient: 1) diagnosis of borderline personality disorder or intellectual disability, 2) being legally incapacitated;

Caregiver: 1) another member of the household requires care due to mental or somatic illness;

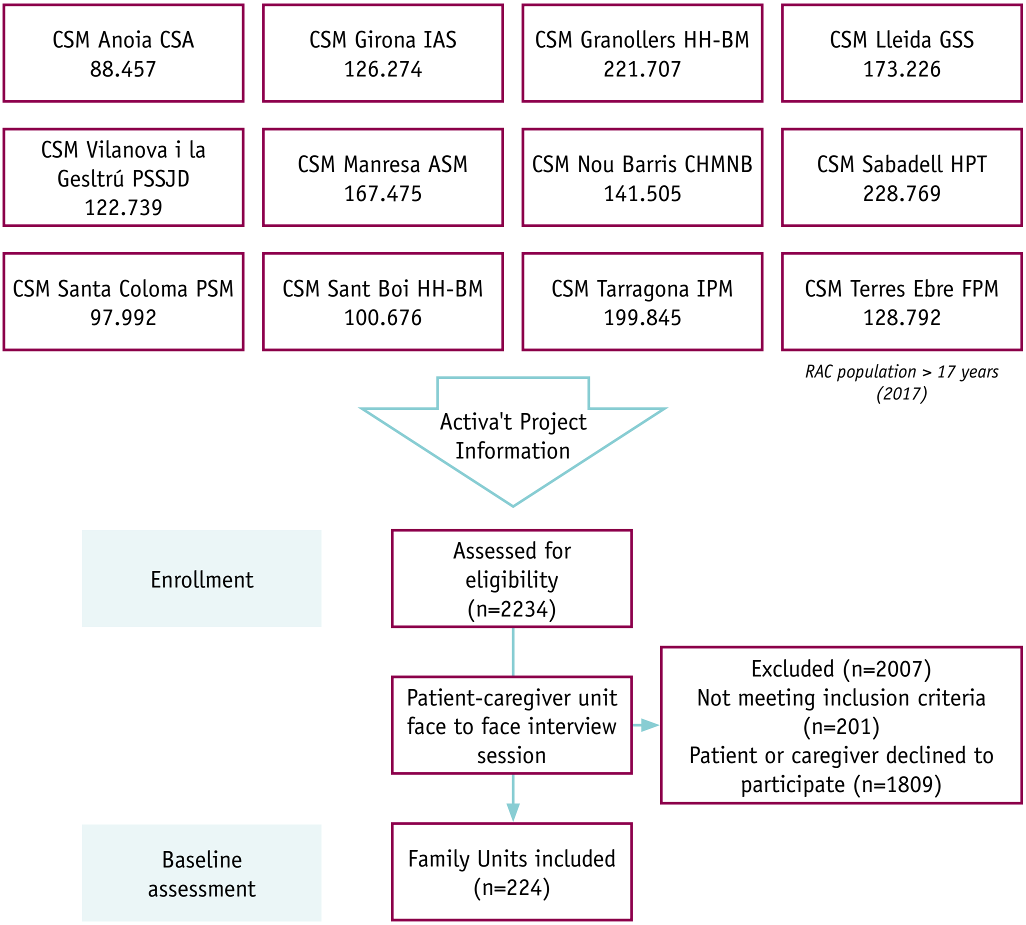
Both: 1) have a severe or decompensated somatic illness, 2) have received structured psychoeducational training within the last year.

Procedure

The study followed the conditions of the Declaration of Helsinki (23) and was approved by the Clinical Research Ethics Committee of the Sisters Hospitallers in Barcelona.

Information was provided in 12 mental health centres. Families wishing to participate (user and main caregiver) were required to read and sign the informed consent document. A total of 2,234 care units (patient/primary caregiver) were informate; 1,809 care units (caregiver or patient) refused to participate and 201 cases were excluded after a first interview on account of not meeting the inclusion criteria (Figure 1). After the first individual interview, we proceeded to the evaluation interviews of the study where data were recorded, including questionnaires heteroadministered by trained health personnel.

Figure 1. Flow diagram. Information, enrollemt and assessment phases


CSM Anoia CSA
88.457
CSM Girona IAS
126.274
CSM Granollers HH-BM
221.707
CSM Lleida GSS
173.226
CSM Vilanova i la Gesltrú PSSJD
122.739
CSM Manresa ASM
167.475
CSM Nou Barris CHMNB
141.505
CSM Sabadell HPT
228.769
CSM Santa Coloma PSM
97.992
CSM Sant Boi HH-BM
100.676
CSM Tarragona IPM
199.845
CSM Terres Ebre FPM
128.792
RAC population > 17 years (2017)
Activa't Project Information
Enrollment
Assessed for eligibility (n=2234)
Patient-caregiver unit face to face interview session
Excluded (n=2007)
Not meeting inclusion criteria (n=201)
Patient or caregiver declined to participate (n=1809)
Baseline assessment
Family Units included (n=224)

CSM (Mental health centers for adult population): CSA: Consorci Sanitari de l'Anoia, **IAS:** Institut d'Assistència Sanitària, **HH-BM:** Germanes Hospitalàries-Benito Menni, **GSS:** Gestió de Serveis Sanitaris Lleida, **PSSJD:** Parc Sanitari Sant Joan de Déu, **ASM:** Althaia-Salut Mental, **CHMNB:** Associació Centre Higiene Mental Nou Barris, **HPT:** Corporació Hospital Parc Taulí, **PSM:** Parc de Salut Mar, **IPM:** Institut Pere Mata, **FPM:** Fundació Pere Mata Terres de l'Ebre

Caregivers and people with own experience associations: ActivaMent Catalunya, Veus, Salut Mental Catalunya Anoia, Equilibri, Imagina, Salut Mental Catalunya–Bages, Famílies per la Salut Mental Nou Barris, Matissos, Amics del malalt mental, La muralla, Aurora, Familiars i Afectats per Malaltia Mental del Garraf, Família i Salut Mental, Salut Mental Ponent, Familiars de Malalts Mentals de les Terres de l'Ebre, Salut Mental Sabadell, Daruma

Measures

Sociodemographic, clinical and living-arrangement variables were collected from participants, both patients and caregivers.

Objective and subjective caregiver burden was assessed using the FBIS-II questionnaire (Family Burden Interview Schedule-Short Form) in its validated Spanish-language version (ECFOS II) (24). This structured interview was heteroadministered by expert staff (60 minutes) and provides different quantifiable scales on objective and subjective aspects of the caregiver of a patient with a serious mental disorder over the preceding month. It takes into account the time spent, the discomfort felt and the need for help in each assessed aspect (care for daily activities, containment of behavioral disturbances, financial burden, routines and life of the carer, concerns, help available, effects on his/her own health and overall impact on caregiver and family patient’s interaction). Most of the items are answered on a four or five points Likert scale from none/never to too much (value to subjective mesures) or all days/always (value to objective mesures).

In this work, in order to facilitate the analysis, the items of each module have been grouped into summary variables. Thus, the "Caregiver activity required" variable refers to the number of aspects of each module where the presence of the caregiver is necessary. The "Frequency" variable refers to the average number of times per week in the preceding month that the caregiver needs to intervene or that there is an impact on him/her. The "Caregiver discomfort" variable refers to the average amount of discomfort felt by the carer when carrying out the tasks. The approximate total hours of care per week are also collected.

Perceived social support was assessed using the version of the Duke-UNC-11 questionnaire validated for the Spanish population (25). This instrument gives measures of confidential social support (the degree to which one can count on people close to him/her), affective social support (the degree to which a person receives demonstrations of love, affection and empathy) and overall social support; responses are expressed on a Likert scale from 1 to 5.

Analysis

A descriptive study of the variables was carried out, checking normality and homoscedasticity (Kolmogorov-Smirnov and Levene test). The relationship between the variables was based on contingency tables for the qualitative variables (Chi-square or Fisher's exact test), on the Student's t-test or Kruskal-Wallis test for the quantitative/qualitative relationship, and on Pearson and Spearman's correlation test, represented graphically by means of scatter plots, for the quantitative variables.

A regression analysis was performed with the variables exhibiting a significant association (less than 0.05) and no collinearity in order to propose a model indicating which socio-demographic, housing, clinical or caregiving variables explained the variance for the variables of burden of care (FBIS II) and perceived social support (Duke UNC 11). Multiple linear regression was used for the "caregiver activity required", "Frequency " and "Caregiver discomfort" variables of modules “care for daily activities”, “containment of behavioral disturbances”, “routines and life of the carer”, “concerns” and “overall impact on the life of the carer and their family” (FBIS II) and the total Duke value (perceived social suport) and binomial logistic regression was used for the variables of modules “financial burden”, “help available” and “effects on his/her own health” (FBIS II).

After an initial exploratory linear or logistic regression that eliminated non-significant variables and those that did not meet the assumptions of collinearity or correlation, a stepwise backward regression was performed according to similarity ratio until the variables and the final, best-fit explanatory model were obtained.

SPSS version 25 for Windows (SPSS Inc., Chicago, IL) was used for statistical analysis and G*Power 3.0.0 for statistical power and effect size (26).

Results

Patient characteristics

Patients’ mean age is 40.91 (±10.03), and 62.5% are male. Forty-two point nine percent have completed primary education, 42.9% secondary education, 11.1% are educated to university level and 3.1% have no educational certificate. Most patients (52.7%) are single, 25% are married or in a stable relationship and 4.9% are separated or divorced. The most frequent illness is schizophrenia (53.1%), followed by bipolar disorder (20.1%), schizoaffective disorder (12.5%) and recurrent depressive disorder (8.5%).

Caregiver characteristics

Caregivers’ mean age is 57.80 (±12.22), and most are female (71%). Forty-one point one percent have completed primary education, 37.9% secondary education, 10.7% are educated to university level and 10.3% have no educational certificate. The majority of caregivers are married or in a stable relationship (55.8%), 10.3% are separated or divorced and 7.6% are widowed. In general, the caregiver is the mother or father (62.5%), followed by the partner (22.8%) and siblings (9.4%).

The majority of patients and caregivers (79.9%) live together in the same household.

Subjective and objective caregiver burden

Tools as FBIS allow to describe the differents aspects of care. Table 1 summarizes the data obtained for “care for daily activities” and “containment of behavioral disorders”. In care for daily activities, a greater presence is observed in assistance with schedules and times (55.8%), housework (55.4%) and administrative formalities (54%), but in the first two, moreover, the intervention is frequent and annoying. Regarding the containment of disturbed behaviors, it is the containment of suicide risk that requires the greatest presence of the caregiver (in 55.4% of cases) and which, in addition, generates a high level of discomfort (in 43.8% of cases).

Table 1. Data obtained from FBIS for "care for daily activities" and "containment of behavioral disturbances".

FBIS categories and items	Caregiver activity required		Frequency	
Care for daily activities	**NO**	**YES**	**None**	**<1 to 6 /week**
A1. Personal care	149 (66.%)	75 (33.5%)	150 (67%)	41 (18.3%)
A2. Medication	156 (69.6%)	68 (30.4%)	157 (70.1%)	28 (12.5%)
A3. Household chores	100 (44.6%)	124 (55.4%)	107(47.8%)	65 (29.02%)
A4. Shopping	127 (56.7%)	97 (43. %)	135 (60.3%)	59 (26.34)
A5. Family meal routine	175 (78.1%)	49 (21.9%)	183 (81.7%)	31 (13.84%)
A6. Journeys	185 (82.6%	39 (17.4%)	187 (83.5%)	23 (10.27%)
A7. Pocket money	122 (54.5%)	102 (45.5%)	126 (56.3%)	37 (16.52)
A8. Timetables and time	99 (44.2%)	125 (55.8%)	103 (46%)	71 (31.7%)
A9. Doctors and health services	138 (61.6%)	86 (38.4%)	140 (62.5%)	82 (36.61%)
A10. Administrative formalities	103 (46.0%)	121 (54.0%)	134 (59.8%)	87 (38.84%)
Containment behav. disturbances	**NO**	**YES**	**None**	**<1 to 6/week**
B1. Nuisance behavior	112 (50%)	112 (50%)	141 (62.9%)	70 (31.3%)
B2. Attention seeking	151 (67.4%)	73 (32.6%)	168 (75%)	51 (22.8%)
B3. Night time problems	180 (81.7%)	44 (18.3%)	189 (84.4%)	30 (13.4%)
B4. Insults, threats	154 (68.8%)	70 (31.3%)	194 (86.6%)	26 (11.6%)
B5. Suicide risk	100 (44.6%)	124 (55.4%)	184 (82.1%)	35 (15.6%)
B6. Alcohol	208 (92.9%)	16 (7.1%)	217 (4.5%)	6 (2.7%)
B7. Drugs	203 (90.6%)	21 (9.4%)	210 (93.8%)	10 (4.5%)

	Caregiver discomfort		Hours/week		
Every day	None/little	Much/ very much	0	<1-7	8->28
33 (14.7%)	174 (77.7%)	50 (22.3%)	150 (67%)	59 (26.3%)	15 (6.7%)
39 (17.4%)	187 (83.5%)	37 (16.5%)	156 (69.6%)	62 (27.7%)	6 (2.7)
52 (23.2%)	132 (58.9%)	92 (41.1%)	101 (45.1%)	81 (32.2%)	42 (18.8%)
30 (13.4%)	177 (79.0%)	47 (20.9%)	127 (56.7%)	66 (29.5%)	31 (13.8%)
10 (4.5%)	201 (89.7%)	23 (10.3%)	175 (78.1%)	40 (17.9%)	9 (4.0%)
14 (6.3%)	206 (92.0%)	18 (8.0%)	185 (82.6%)	23 (10.3%)	16 (7.1%)
61 (27.2%)	159 (80.0%)	65 (29.0%)	122 (54.5%)	85 (37.9%)	17 (7.6%)
50 (22.3%)	136 (60.7%)	88 (39.3%)	101 (45.1%)	84 (37.5%)	39 (17.4%)
2 (0.9%)	197 (87.9%)	27 (12.1%)	139 (62.1%)	72 (32.1%)	13 (5.8%)
3 (1.3%)	182 (81.2%)	42 (18.8%)	106 (47.3%)	108 (48.2%)	10 (4.5%)
Every day	**None/Low**	**High/very high**	**0**	**<1-7**	**8->28**
13 (5.8%)	135 (60.3%)	89 (39.7%)	40 (17.9%)	164 (73.2%)	20 (8.9%)
5 (2.2%)	177 (79.0%)	47 (21.0%)			
5 (2.2%)	196 (87.5%)	28 (12.5%)			
4 (1.8%)	174 (77.7%)	50 (22.3%)			
5 (2.2%)	126 (56.3%)	98 (43.8%)			
1 (0.4%)	214 (95.5%)	10 (4.5%)			
4 (1.8%)	206 (92.0%)	18 (8.0%)			

Other aspect obtained from FBIS is "financial burden", 47% of caregivers (106) report having incurred expenses pertaining to the patient, mainly for food (€52), housing (€34), educational or social activities (€28), tobacco (€26), pocket money (€17) and clothes (€14). The patient contributes an average of €437.19 per month to the family economy, generally in the form of a pension.

Respect "routines and life of the caregiver", 15.6% of caregivers have missed work in the preceding month as a result of caring for the patient and 26.4% of caregivers need to make permanent changes to three or more types of their routine activities.

Caregivers are frequently concerned about the patient: about his/her future (80.4%), social life (62.5%) and daily life (53.6%).

Fifty-eight percent of caregivers are able to receive help from other people which amounted, on average, to 9.4 hours of help per week.

Seventeen percent of caregivers require health care as a result of caregiving: 9.4% by their primary care physician and 11.2% by a psychologist or psychiatrist. This group of caregivers spends a mean of 0.8 days on medical leave.

Respect "overall impact on caregiver and family patient's interaction", 80.4% of caregivers think that the mental disorder has changed his/her personal relationship with the person with the disorder and 68.8% consider it to have changed the relationship of the whole family. This change is perceived as negative by 39.3% of caregivers, and for 29.5% it causes intense discomfort. In contrast, 52.7% of caregivers find positive effects on his/her personal relationship with the patient and 30% on the family relationship.

Explanatory models for the summary variables of the FBIS

The final explanatory models obtained for each of the summary variables using multiple or binomial logistic regression are shown in Tables 2 and 3.

Table 2. Explanatory multiple logistic regression models for “care for daily activities”, “containment of behavioral disturbances”, “routines and life of the carer” and “concerns” (FBIS II) and global perceived social support (Duke-UNC-11).

Model and variables	F (df)	R^2
Model-Frequency of care for daily activities	49.983 (2,221)	.311
Constant		
Frequency of concerns		
Total hours of care per week		
Model-Caregiver Discomfort by care for daily activities	35.655 (5,218)	.450
Constant		
Frequency of concerns		
Disruption caregiver routines (changes per week)		
Financial burden		
Frequency of containment of behavioral disturbances		
Total hours of care per week		
Model-Frequency of containment behavioral disturbances	66.615 (4,219)	.549
Constant		
Objective negative impact on family interaction		
Caregiver discomfort in containment behavioral disturbances		
Frequency of care for daily activities		
Disruption caregiver routines (changes per week)		

B: B coefficient for the constant, **df:** degrees of freedom (variables, cases), **S. Error:** standard error

ΔR²	B	S. Error	β	P	1- β	f²
.305				.001	1	.311
	-.876	.222		.001		
	.453	.050	.511	.001		
	.122	.029	.233	.001		
.437				.001	1	.818
	-.499	.159		,002		
	.243	.040	.347	.001		
	.031	.008	.228	.001		
	.242	.069	.193	.001		
	.223	.075	.162	.003		
	.040	.021	.097	.057		
.541				.001	1	1.217
	-.176	.047				
	.064	.019	.171	.001		
	.506	.042	.584	.001		
	.053	.020	.126	.010		
	.010	.005	.101	.042		

.../...

…/…

Model and variables	F (df)	R^2
Model-Caregiver Discomfort by containment behavioral disturbances	73.974 (3,216)	507
Constant		
Frequency of Containment behavioral disturbances		
Effects on caregiver health		
Quality of caregiver/patient relationship		
Model- Disruption caregiver routines (changes per week)	25.018 (4,215)	.322
Constant		
Total hours of care per week		
Perceived social support (Total Duke value)		
Financial Burden		
Effects on caregiver health		
Model-Frequency of worries	48.272 (3,214)	.404
Constant		
Caregiver Discomfort by care for daily activities		
Negative objective impact on patient interaction		
Negative subjective impact on patient interaction		
Model-Global perceived social support	13.288 (5,217)	.234
Constant		
Education caregiver level		
Frequency of concerns		
Help available		
Effects on caregiver health		
Positive impact on family interaction		

B: B coefficient for the constant, **df:** degrees of freedom (variables, cases), **S. Error**: standard error

ΔR²	B	S. Error	β	P	1- β	f²
.500				.001	1	1.028
	.598	.128				
	.703	.060	.609	.001		
	.212	.070	.152	.003		
	-.054	.024	-.114	.024		
.309				.001	.999	.475
	.735	.227		.001		
	.029	.005	.342	.001		
	-.016	.005	-.181	.003		
	.247	.095	.156	.010		
	.328	.126	.156	.010		
.395				.001	1	1.028
	1.609	.086				
	.536	.084	.383	.001		
	.128	.043	.208	.003		
	.127	.046	.191	.007		
.217				.001	.999	.305
	42.509	2.075		.001		
	1.725	.681	.152	.012		
	-2.493	.636	-.239	.001		
	-3.898	1.135	-.207	.001		
	-5.241	1.495	-.212	.001		
	.801	.405	.119	.049		

Thirty-one percent of the variance of the "Frequency of care for daily activities" is explained by worries about the patient and hours of care per week, while 45% of the "Discomfort by care for daily activities" is explained by concerns about the patient, changes to the caregiver's weekly routine, the financial burden incurred, the frequency in containment of behavioral disorders and hours of care per week.

Fifty-five percent of the variance of the "Frequency of containment of behavioral disorders" is associated with the frequency of negative interference in the family, the discomfort caused by this type of interventions, the frequency in care for daily activities and the changes to the caregiver's weekly routine. Fifty-one percent of the variance of the "Discomfort by containment of behavioral disorders" variable is explained directly by the frequency of this type of interventions and the impact on the caregiver's physical health, and inversely by the quality of the caregiver/patient relationship.

Table 3. Binary Logistic Regression Model for “Finan

Variables	Chi^2	R^2 (Nagelkerke)
Model-Financial burden	64.140	.332
Patient's age		
Frequency of concerns		
Constant		
Model-Help available for the caregiver	21.645	.124
Positive impact on caregiver/patient interaction (category H)		
Positive impact on caregiver's family interaction (category H)		
Patients studying		
Constant		
Model-Effects on caregiver health	38.178	.262
Discomfort by containment of behavioral disturbances		
Disruption caregiver routines (changes per week)		
Constant		

B: B coefficient for the constant, **St.Error:** Standard Error, **df:** degrees of freedom, **Sig:** Significance, **Exp (B):** exponentiation of the B coefficient (Odd Ratio), **CI:** Confidence Interval cial burden", "Help available for the caregiver" and "Effects on caregiver health".

B	St.Error	Wald	df	Sig	Exp (B)	95% CI
			2	.0001		
-.097	.018	28.622	1	.0001	.907	.875-.940
.900	.193	21.800	1	.0001	2.460	1.686-3.590
1.652	.824	4.025	1	.045	5.220	
			3	.0001		
.436	.122	12.711	1	.000	1.546	1.217-1.965
-.380	.126	9.128	1	.003	.684	.534-.875
1.107	.496	4.977	1	.026	3.025	1.144-7.997
-1.764	.541	10.611	1	.001	.171	
			2	.0001		
1.486	.371	16.084	1	.0001	4.420	2.138-9.137
.136	.038	12.493	1	.0001	1.145	1.062-1.235
-3.276	.413	62.949	1	.0001	.038	

Financial burden by caregiving are explained inversely by the patient's age and directly by concerns about the patient, both explaining 33% of the variance.

Thirty-two percent of the variance of the changes of the caregiver's weekly routine is explained directly by hours of care per week, financial burden, effects on caregiver health, and inversely by total perceived social support.

Concerns about the patient's future is explained (40% of the variance) by caregiver discomfort by care for daily activities and subjective and objective impact on caregiver-patient interaction.

Twelve percent of the variance in the availability of help avaible for the caregiver is explained directly by the perception of a positive impact on interaction with the patient and the patient's status as a student and inversely by the perception of a positive impact on caregiver’s family interaction.

Twenty-six percent of the variance in the effects on caregiver health is explained by caregiver discomfort by containment of behavioral disturbances and disruption caregiver routines (Tables 2 and 3).

Regarding overall impact on the caregiver and family, 32% of the negative objective impact on the caregiver is explained by the frequency of care for daily activities and by the changes to the caregiver's weekly routine, while 23% of the variance in objective and subjective impact on the family is explained by "frequency of containment of behavioral disorders and the discomfort caused by tasks of care for daily activities (Table 4).

Table 4. Explanatory regression models for overall impact on caregiver and family patient's interaction.

Variables Category H	F (df)	R^2
Negative objective impact on patient interaction	51.500 (2,215)	.324
Constant		
Frequency of care for daily activities		
Disruption caregiver routines (changes per week)		
Negative subjective impact on patient interaction	13.976 (3,220)	.160
Constant		
Frequency of concerns		
Total hours of care per week		
Disruption caregiver routines (changes per week)		
Positive impact on patient interaction	5.557 (2,221)	.047
Constant		
Level of caregiver education		
Frequency of help available for caregiver		
Negative objective impact on family interaction	30.995 (2,208)	.230
Constant		
Frequency of Containment behavioral disturbances		
Discomfort by care for daily activities		

B: B coefficient for the constant, **df:** degrees of freedom (variables, cases),
S. Error: standard error, **cat:** category

ΔR^2	B	S. Error	β	P	1- β	f^2
.318				.001	1	.479
	1.051	.129				
	.606	.113	.338	.001		
	.600	.115	.329	.001		
.149				.001	.999	.190
	1.244	.119		.001		
	.125	.029	.291	.001		
	.037	.016	.148	.018		
	.071	.033	.145	.031		
.038				.005	.849	.049
	1.582	.216		.000		
	.272	.115	.155	.019		
	.467	.191	.161	.015		
.222				.001	1	.299
	.682	.118				
	.783	.187	.275	.001		
	.633	.138	.302	.001		

…/…

…/…

Variables Category H	F (df)	R^2
Negative subjective impact on family interaction	33.588 (2,221)	.233
Constant		
Discomfort by care for daily activities		
Frequency of Containment behavioral disturbances		
Positive impact on family interaction	5.130 (1,222)	.023
Constant		
Frequency of help available for caregiver		

B: B coefficient for the constant, **df:** degrees of freedom (variables, cases),
S. Error: standard error, **cat:** category

ΔR^2	B	S. Error	β	P	1- β	f^2
.226				.001	1	.304
	.522	.106		.001		
	.471	.125	.240	.001		
	.910	.172	.338	.001		
.018				.001	.628	.023
	2.000	.125				
	.436	.193	.150	.024		

Social support perceived by the main caregiver

Perceived social support measured using the Duke-UNC-11 questionnaire (25) shows an average value for total support (37.6±9.3), which breaks down to 16.8±4.3 for the affective component and 20.8±5.9 for the confidential component. Sixty-four point seven percent of caregivers perceived the overall support they received as normal but 33% of caregivers considered it to be low.

Twenty-three point four percent of the variance in total perceived social support is explained directly by the caregiver's level of education and perceived positive impact to the family-patient interaction and inversely by concerns about the patient, help available to the caregiver and impact on the caregiver's health (Table 2).

Discussion

The role of the family in patient care is fundamental in most cultures and countries. The age of the patient and caregiver, the predominance of males as patients and females as caregivers, the level of education, marital status and other characteristics shown in the results section are similar to the majority of studies that assess the level of burden of caregivers of patients with severe mental disorders (9, 11,27-31). There are differences with respect to samples from countries with a predominantly young population, where patients and caregivers are younger and are separated by less of an age difference, the gender distribution of patients is more balanced and they have less formal education (11, 12, 17, 27, 28, 32-35). Data regarding the marital status of the caregiver, who is generally married or in a stable relationship, and the type of relationship he/she has with the patient, generally being the mother or father (62.5%), followed by the spouse or partner (22.8%) and siblings (9.4%), are similar to those of most studies.

The key role of the wife, mother, daughter or sister as primary caregiver is transversal in all samples except in the Eritrea study (34), where men are reported more often as the primary caregiver; it should be noted, however, that the definition of "primary caregiver" in Eritrea takes more into account responsibility for care than the practical execution of tasks.

There are no differences between the level of education of patients and caregivers, except in cases where no certificate is held, which apply to a higher percentage of caregivers (10.7% as opposed to 3.1%); this is consistent with Catalonian population data and intergenerational differences (36). The predominance among users of people who are single (52.7%) is higher than among the population of Catalonia as a whole (33%), while the predominance among caregivers (55.8%) of people who are married or in a stable relationship mirrors statistics for the Catalonian population in general (36).

Most patients and caregivers (79.9%) live together in the same home, and the average time spent together is 23.8±8.04 hours per week, which is similar to a sample from Italy (30) but much lower than Gater’s qualitative study (37) for the same mode of cohabitation.

People with greater dysfunction and disability generate a higher caregiving burden (1-2, 38-39) and this is true for dementia or intellectual disability, but should also be true for severe mental disorders, even though the tasks and emotions that explain this burden may be different. In this sense, tools such as the FBIS (40) the Zarit burden interview (41) or the Family Experiences Interview Schedule-FEIS (42) allow us to explore different aspects of caregiver burden and see which tasks, responsibilities and concerns generate the greatest burden.

Caregiver burden, refers to the strain endured by a person who cares for a chronically ill individual (4), could be summed up in a single value that many authors have related to different factors, such as individual characteristics of the caregiver, dynamics and type of family, socioeconomic status or type of illness (12-14,34). This point is important but it is also important to know the distribution of the objective and subjective burden among the different responsibilities and tasks. In our sample, as in other similar studies (7, 9-11,14-17, 24, 27-35, 37, 43, 44), it is assistance in keeping to schedules and times (55.8%) and household chores (55.4%) that require the most interventions and also cause the most discomfort. ADL's (Activities of Daily Living) are very important and, if they are not performed, are detrimental to the person's well-being and their life and social project (45). Thus, lack of personal hygiene has repercussions on group meetings or attendance at a training session, a choral session or a class, and has a negative impact on a job interview. In this way, concern for the patient's future goes some way to explaining the frequency with which these tasks associated with ADL's are performed (Table 2). In addition, these types of tasks have the greatest influence on the objective burden of care and the discomfort they cause, including changes to the caregiver's weekly routine, economic burden incurred (Table 3), and a perception of lower social support (total value on the Duke scale). In other words, concern gives rise to greater dedication, and this in turn generates greater discomfort and concern.

Containment of suicide risk and intervention for disruptive behaviors take up little time but generate concern and distress in the caregiver, have a detrimental effect on his or her health (Table 3) and have a negative impact on the family relationship, leading to further caregiver intervention (46, 47).

The majority of caregivers are permanently or frequently concern about the patient's future, social life and daily life (48). In this study, this concern is explained (40% of the variance) by the subjective discomfort felt by the caregiver in carrying out of care for daily activities and the objective interference of caregiving in the relationship with the patient (Table 2). The majority of caregivers consider the mental disorder to have a negative impact on the individual and family relationship with the person with the disorder, which generates a high level of discomfort in some caregivers (29.5%).

Care for daily activities may be the direct agent mediating between any factor and the impact on caregiver burden. In other words, carrying out tasks to cover basic needs and intervening in situations of suicide risk or behavioral disorders cause concern and discomfort for the caregiver, which results in a greater number of interventions, closing a vicious negative feedback cycle of concern>repetition of tasks>disturbance that overloads the circuit and results in exhaustion for the caregiver.

Bibliography

1. Lynch J. & Cahalan R. The impact of spinal cord injury on the quality of life of primary family caregivers: a literature review. Spinal Cord 2017 Nov;55(11):964-978. doi: 10.1038/sc.2017.56. Epub 2017 Jun 27.

2. Dauphinot V, Ravier A, Novais T, Delphin-Combe F, Mouchoux Ch, Krolak-Salmon P. Risk Factors of Caregiver Burden Evolution, for Patients with Subjective Cognitive Decline or Neurocognitive Disorders: A Longitudinal Analysis. J Am Med Dir Assoc (JAMDA) 2016 Nov 1;17(11):1037-1043. doi: 10.1016/j.jamda.2016.07.003. Epub 2016 Aug 26.

3. World Health Organization. (2019). The WHO special initiative for mental health (2019-2023): universal health coverage for mental health. World Health Organization. https://apps.who.int/iris/handle/10665/310981. Licencia: CC BY-NC-SA 3.0 IGO

4. Tamizi Z, Fallahi-Khoshknab M, Dalvandi A, Mohammadi-Shahboulaghi F, Mohammadi E, Bakhshi E. Defining the concept of family caregiver burden in patients with schizophrenia: a systematic review protocol. Syst Rev 8, 289 (2019). https://doi.org/10.1186/s13643-019-1182-6

5. Grad J, Sainsbur, P. Mental illness and the family. Lancet, 1(7280), 544–547 (1963).

6. Roth D, Fredman L, Haley W. Informal Caregiving and Its Impact on Health: A Reappraisal from Population-Based Studies. The Gerontologist. 2015;55(2):309-319.

7. Fekete C, Tough H, Siegrist J, Brinkhof M. Health impact of objective burden, subjective burden and positive aspects of caregiving: an observational study among caregivers in Switzerland. BMJ Open. 2017;7(12): e017369.

8. Ploeg J, Markle-Reid M, Valaitis R, McAiney C, Duggleby W, Bartholomew A, Sherifali D. Web-Based Interventions to Improve Mental Health, General Caregiving Outcomes, and General Health for Informal Caregivers of Adults with Chronic Conditions Living in the Community: Rapid Evidence. J Med Internet Res. 2017 Jul; 19(7): e263. doi: 10.2196/jmir.7564: 10.2196/jmir.7564

9. Yu Y, Liu ZW, Tang BW, Zhao M, Liu XG, Xiao SY. Reported family burden of schizophrenia patients in rural China. PLoS One 2017;12(6): e0179425. Available in: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5476254/

10. Akbari M, Alavi M, Irajpour A, Maghsoudi J. Challenges of family caregivers of patients with mental disorders in Iran: A narrative review. Iranian J Nursing Midwifery Res 2018; 23:329-37. doi: 10.4103/ijnmr.IJNMR_122_17

11. Yu Yu, Zi-Wei Liu, Tong-Xin Li, Yi-Lu Li, Shui-Yuan Xiao, Jacob Kraemer Tebes. Test of the stress process model of family caregivers of people living with schizophrenia in China. Social Science & Medicine 2020, Volume 259, 113113, ISSN 0277-9536. Available in: https://doi.org/10.1016/j.socscimed.2020.113113.

12. Clari R, Headley J, Egger J, Swai P, Lawala P, Minja A, Kaaya S, Baumgartner JN. Perceived burden and family functioning among informal caregivers of individuals living with schizophrenia in Tanzania: a cross-sectional study. BMC Psychiatry. 2022 Jan 4;22(1):10. doi: 10.1186/s12888-021-03560-0. PMID: 34983438; PMCID: PMC8728903.

13. Khatoon K, Dhamija S, Gupta N, Padhi D, Kiran M, Chaudhury S. Pattern of burden on the family of patients with schizophrenia and bipolar disorder: A comparative study. Ind Psychiatry J 2021; 30: S178-83.

14. Lasebikan VO, Ayinde OO. Family Burden in Caregivers of Schizophrenia Patients: Prevalence and Socio-demographic Correlates. Indian J Psychol Med [Internet]. 2013;35(1):60-66. Available in: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3701362/

15. Bastawrous M. Caregiver burden - A critical discussion. International Journal of Nursing Studies. 2013;50(3):431-441.

16. Zhang Z, Deng H, Chen Y, et al. Cross-sectional survey of the relationship of symptomatology, disability and family burden among patients with schizophrenia in Sichuan, China. Shanghai Arch Psychiatry [Internet]. 2014;26(1):22-29. Available in: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4117999/

17. Kenneth Ayuurebobi Ae-Ngibise, Victor Christian Korley Doku, Kwaku Poku Asante & Seth Owusu-Agyei. The experience of caregivers of people living with serious mental disorders: a study from rural Ghana, Global Health Action 2015, 8:1, 26957, DOI: 10.3402/gha.v8.26957

18. Grover S, Kate N, Chakrabarti S, Avasthi A. Positive Aspects of Caregiving and Its Correlates among Caregivers of Bipolar Affective Disorder. East Asian Arch Psychiatry [Internet] 2017 Dec [cited on 23 December 2020] 27(4):131-41. Available in: https://pubmed.ncbi.nlm.nih.gov/29259143/

19. Sanz J. Protocol de l'avaluació de l'efectivitat de l'itinerari assistencial ofert en el marc del programa "Activa't per la teva salut mental (http://activatperlasalutmental.org/)." Internal Report of Ivàlua, 83. 2015. Available in: https://www.ivalua.cat/sites/default/files/2020-01/Avaluacio_efectivitat_Activat_Salut_Mental_2017_final.pdf

20. Rojo Rodes E, San Pío Tendero MJ, Sanz Porras J. ACTIVA´T PER LA SALUT MENTAL: patients and caregivers as managers for integration of care and services in Mental Health. International Journal of Integrated Care. 2016;16(6): A323. DOI: http://doi.org/10.5334/ijic.2871

21. Cohen J. Statistical Power Analysis. Current Directions in Psychological Science. 1992;1(3):98-101. doi:10.1111/1467-8721.ep10768783

22. Boruch, R. F., Weisburd, D., Turner III, H. M., Karpyn, A. & Littell, J. Randomized controlled trials for evaluation and planning. In The SAGE handbook of applied social research methods (pp. 147-181). SAGE Publications, Inc. 2009. https://www.doi.org/10.4135/9781483348858

23. World Medical Association. Declaration of Helsinki Ethical Principles for Medical Research Involving Human Subjects. Amended by the 64th WMA General Assembly, Fortaleza, Brazil, October 2013. JAMA November 27, 2013 Volume 310, Number 20

24. Vilaplana, M., Ochoa, S., Martinez, A., Villalta, V., Martinez-Leal, R., Puigdollers, E., Salvador, L., Martorell, A., Muñoz, P. E., Haro, J. M., & PSICOST-RED RIRAG group. Validation in Spanish population of the family objective and subjective burden interview (ECFOS-II) for relatives of patients with schizophrenia. Actas Españolas de Psiquiatria, 2007, 35(6), 372–381.

25. Cuéllar-Flores I, Dresch V. Validation of the Duke-UNK-11 functional social support questionnaire in caregivers. Revista Iberoamericana de Diagnostico y Evaluacion Psicologica, 2012, Nº 34, Vol 1:89-101.

26. Faul F., Erdfelder E., Lang A.G., & Buchner A. G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. Behavior Research Methods, 2007, 39(2), 175-191

27. Chien W-T, Chan SWC & Morrissey J. The perceived burden among Chinese family caregivers of people with schizophrenia. Journal of Clinical Nursing 2007,16, 1151–1161.

28. Casanova-Rodas L., Rascón-Gasca M. L., Alcántara-Chabelas H., & SorianoRodríguez A. Apoyo social y funcionalidad familiar en personas con trastorno mental [Social support and family functionality in people with mental disorder]. Salud Mental 2014, 37(5), 443–448. https://doi.org/10.17711/SM.0185-3325.2014.052.

29. Mittendorfer-Rutz E, Rahman S, Tanskanen A, Majak M, MehtälÄ J, Hoti F, Jedenius E, Enkusson D, Leval A, Sermon J, Taipale E and Tiihonen J. Burden for Parents of Patients With Schizophrenia—A Nationwide Comparative Study of Parents of Offspring With Rheumatoid Arthritis, Multiple Sclerosis, Epilepsy, and Healthy Controls. Schizophrenia Bulletin vol. 45 no. 4 pp. 794–803, 2019. doi.org: 10.1093/schbul/sby130.

30. Di Lorenzo R, Girone A, Panzera N, Fiore G, Pinelli M, Venturi G, Magarini F and Ferris P. Empathy and perceived burden in caregivers of patients with schizophrenia spectrum disorders. BMC Health Services Research (2021) 21:250 https://doi.org/10.1186/s12913-021-06258-x.

31. Meng N, Chen J, Cao B, Wang F, Xie X, Li X. Focusing on quality of life in the family caregivers of patients with schizophrenia from the perspective of family functioning: a cross-sectional study. Medicine 2021;100:5 (e24270). http://dx.doi.org/10.1097/MD.0000000000024270.

32. Nasr T and Kausar R. Psychoeducation and the family burden in schizophrenia: a randomized controlled trial. Annals of General Psychiatry 2009, 8:17 doi:10.1186/1744-859X-8-17

33. Lasebikan VO. Validation of Yoruba Version of Family Burden Interview Schedu-

le (Y-FBIS) on Caregivers of Schizophrenia Patients. International Scholarly Research Network ISRN Psychiatry Volume 2012, Article ID 165179, 8 pages. doi:10.5402/2012/165179

34. Hidru TH, Osman MH, Lolokote S, et al. Extent and pattern of burden of care and its associated factors among Eritrean families of persons living with schizophrenia: a crosssectional study. BMJ Open 2016;6:e012127. doi:10.1136/bmjopen-2016-012127

35. Yu Y, Liu ZW, Li TX, Zhou W, Xi SJ, Xiao SY, Tebes JK. A comparison of psychometric properties of two common measures of caregiving burden: the family burden interview schedule (FBIS-24) and the Zarit caregiver burden interview (ZBI-22). Health Qual Life Outcomes 2020; 6;18:94. https://doi.org/10.1186/s12955-020-01335-x)

36. IDESCAT. Level of education of the population aged 16 years and over. By sex and age groups. Catalonia. Generalitat de Catalunya 2011.

37. Gater A, Rofail D, Tolley C, Marshall Ch, Abetz-Webb L, Zarit ZH and Berardo CG. "Sometimes It's Difficult to Have a Normal Life": Results from a Qualitative Study Exploring Caregiver Burden in Schizophrenia. Schizophrenia Research and Treatment. Volume 2014, Article ID 368215, 13 pages. http://dx.doi.org/10.1155/2014/368215

38. Irazábal M. The family burden of caregivers of young and adult people diagnosed with intellectual disability and mental disorders: A systematic review. Psiquiatría Biológica Volume 23, Issue 3, September–December 2016, Pages 93-102. Doi:10.1016/j.psiq.2016.08.004

39. Hayashi S, Terada S, Nagao S, Ikeda Ch, Shindo A, Oshima E, Yokota O and Uchitomi Y. Burden of caregivers for patients with mild cognitive impairment in Japan. International Psychogeriatrics (2013), 25:8, 1357–1363. doi:10.1017/S1041610213000537

40. 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.

41. Zarit SH ON, Zarit JM: The memory and behavior problems checklist, in Families under stress: Caring for the patient with Alzheimer's disease and related disorders. New York: University Pres; 1985.; 1985.

42. Tessler R and Gamache G. (1993). Evaluating Family Experiences with Severe Mental Illness To be used in conjunction with The Family Experiences Interview Schedule (FEIS). Toolkit for Evaluating Family Experiences with Severe Mental Illness. Evaluation Center@HSRI. Cambridge. Massachusetts.

43. Yu Y, Liu ZW, Zhou W, Zhao M, Tang BW, Xiao SY. Determining a cutoff score for the family burden interview schedule using three statistical methods. BMC Med Res Methodol 19, 93 (2019). https://doi-org.sire.ub.edu/10.1186/s12874-019-0734-8

44. Eloia SC, Oliveira EN, Lopes MVO, Parente JRF, Eloia SMC, Lima DDS. Family burden

among caregivers of people with mental disorders: an analysis of health services. Cien Saude Colet 23(9):3001-3011 (2018). https://www.scielosp.org/article/csc/2018.v23n9/3001-3011/en/

45. Mlinac M E, Feng M C. Assessment of Activities of Daily Living, Self-Care, and Independence. Archives of Clinical Neuropsychology 31 (2016) 506–516. doi:10.1093/arclin/acw049.

46. McDonell MG, Short RA, Berry CM, Dyck DG. Burden in schizophrenia caregivers: impact of family psychoeducation and awareness of patient suicidality. Fam Process. 2003 Spring;42(1):91-103. doi: 10.1111/j.1545-5300.2003.00091.x. Erratum in: Fam Process. 2004 Summer;42(2):184. PMID: 12698601.

47. Maple M, Wayland S, Sanford RL, Bhullar N. Predictors of Caregiver Burden Among Carers of Suicide Attempt Survivors. Crisis. 2021 Dec 17. doi: 10.1027/0227-5910/a000836. Epub ahead of print. PMID: 34915733.

48. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. JAMA. 2014 Mar 12;311(10):1052-60. doi: 10.1001/jama.2014.304. PMID: 24618967.