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# Evaluation of the effect of a psychoeducational program on the burden in informal caregivers of patients with schizophrenia

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**Introduction.** Due to the change in the health care model for mental patients focused on the hospital to community care in recent decades, schizophrenic patients live with their families. This study aims to study the burden of family members or caregivers of schizophrenic patients before and after the application of a specific psychoeducational program for caregivers.

**Methods.** A psychoeducational program aimed at three groups was conducted: a) relatives of patients with schizophrenia who received educational program; b) parents or relatives on a previous educational program themselves, and c) control group (not including either parents or patients who received educational programs). The Zarit scale was used to rate burden in the three groups before and after completing the educational program.

**Results.** Application of the program was associated to a significant reduction of burden in the groups where it was provided compared with the control group that did not receive the program, independently of the treatment received for the patients.

**Conclusions.** Evidence suggests that these programs should be included in the therapeutical strategies for patients with schizophrenia.

**Key words:**  
Schizophrenia. Psychosis. Treatment. Rehabilitation. Psychoeducation. Caregivers. Family.

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## Valoración de la sobrecarga en cuidadores informales de pacientes con esquizofrenia antes y después de un programa psicoeducativo

**Introducción.** El cambio de modelo asistencial de los enfermos mentales centrado en el hospital a la atención comunitaria ha ayudado en las últimas décadas a los pacientes esquizofrénicos a convivir con sus familias. Los

objetivos de este trabajo son estudiar el nivel de sobrecarga de los familiares o cuidadores de pacientes con esquizofrenia y evaluar la eficacia del programa educativo.

**Métodos.** Se lleva a cabo un programa educativo dirigido a tres grupos: a) familiares de pacientes esquizofrénicos que recibían un programa educativo previo; b) padres o familiares de pacientes esquizofrénicos que estaban en programas educativos, y c) grupo control (ni los padres ni los hijos estaban adscritos a programas educativos). Se evaluó la sobrecarga de los familiares de los tres grupos utilizando la escala de Zarit antes y después de cumplimentar con el programa educativo.

**Resultados.** Los resultados muestran que la aplicación del programa educativo se asoció a una disminución significativa de la sobrecarga en los grupos que lo recibieron en comparación con aquellos que no lo recibieron, independientemente de los programas educativos recibidos por los pacientes.

**Conclusiones.** Las evidencias sugieren que los programas psicoeducativos de familiares deberían formar parte de los planteamientos terapéuticos para la esquizofrenia.

**Palabras clave:**  
Esquizofrenia. Psicosis. Tratamiento. Rehabilitación. Psicoeducación. Cuidadores. Familia.

## INTRODUCTION

After the psychiatric reform, professional care was substituted with informal care by the patient's relatives who did not have the knowledge, information and aptitudes to assume these functions in most of the cases. This situation has had consequences on the caregivers since providing care to chronic psychotic patients in the community causes a burden for the families, both because of subjective malaise caused by the patient's behavior and the absence of skills in their social relationships as due to the problems that are usually created in living together<sup>1</sup>.

In accordance to Trudley<sup>2</sup> «family burden» refers to the consequences for the relative due to close contact with severely disturbed patients. This has been classified into two

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types: «objective» and «subjective»<sup>3</sup>. Caregiver's burden is defined as a multidimensional concept that considers the tension existing in the emotional, physical, social and financial aspects of the life of the persons<sup>4</sup>.

Evaluation of the burden was first done in the works of Yarrow<sup>5</sup> and has been studied by Fadden<sup>6</sup> and Kuipers<sup>7</sup>, among others. The latter states how the patients return to the family protection in 60% of the cases after the first episode. This number decreases to 50% after successive episodes and admissions.

Many authors have developed scales to measure and distinguish between «objective» and «subjective» burden. Objective burden refers to the patient's symptoms of and sociodemographic characteristics, but also to the changes in their daily routine, family and social relationships, work, leisure activity, physical health, etc.<sup>8</sup>. Subjective burden would be the result of subjective malaise and health problems of the relatives. Boye<sup>9</sup> considers that female patients generate more stress and Dyck<sup>10</sup> that the younger patients have greater emotional burden, this coinciding with the data of Jungbauer<sup>11</sup> on the first episodes. The emotional alterations of the caregivers<sup>12</sup> and their psychological malaise<sup>13</sup> are a clear indicator of what their own need for care will be.

Several types of items have been studied in most of the questionnaires used<sup>14-17</sup>, going from those most linked to the appearance of symptoms (insomnia and frequent waking, crying, sadness, feeling of hopelessness, tiredness, exhaustion, physical health problems) to others that are related with total dedication to the patient's care (abandoning hobbies, problems to travel, vacations, social relationships, meetings at home, abandonment of other family members) with the feeling of being totally at the patient's disposition. The most well-known of these, such as SBAS (Social Behavior Scale), PFBS (Perceived familial burden scale) or ECI (Experience Caregiving Inventory) have not been used to evaluate psychoeducational programs, possibly due to lack of sensitivity to change.

In the present work, we have proposed the study of the burden of informal caregivers of schizophrenic patients and their response to a psychoeducational program, given its importance, above all in recent times, in the integral treatment of schizophrenia. The starting hypothesis is that the burden of the informal caregivers decreases after receiving psychoeducational program.

## MATERIAL AND METHODS

The informal caregivers of psychotic patients seen in a hospital Psychiatry Department were followed-up for 9 months with two evaluations, one at the beginning and one at the end of the psychoeducational program. As control groups, we evaluated the informal caregivers of the schizophrenic patients who followed a psychoeducational program and training in social skills and another group of care-

givers without program (nor the patients). The sociodemographic characteristics of the three groups were similar in regards to age, gender and social-educational level.

The three informal caregiver groups (90 in all) of schizophrenic patients were distributed as follows: group 01: made up of 30 informal caregivers, fundamentally parents of the schizophrenic patients whose children received a psychoeducational program and training in social skills (SH). Group 02: formed by 30 informal caregivers, fundamentally parents of schizophrenic patients who were, themselves, taking a psychoeducational program. The relatives and schizophrenic patients only underwent outpatient treatment. Group 03: formed by 30 informal caregivers, fundamentally parents, as control group, in which neither the patients nor the caregivers received any type of psychoeducational intervention.

Those who refused to participate or abandoned the sessions were excluded from groups 01 and 02.

The sample was selected in the following way: informal caregivers (principal) whose children were being treated for psychosis in the Psychiatry Department of the Hospital Clínico Universitario and mental health sites belonging to Area 4 and for whom the different area specialists had recommended inclusion in a psychoeducation program.

The inclusion criteria were:

- Having a relative diagnosed of psychosis.
- Being principal caregivers and
- Requesting the program voluntarily and agreeing to come.

The only exclusion criterion was refusal to participate or non-attendance to the sessions.

The program used with the informal caregivers, based on the Beller and Montero programs<sup>21</sup> and Liberman<sup>22</sup> on emotional expressiveness and skills, respectively, and on other psychoeducational programs, has been elaborated by Santolaya, and adapted to our needs and principally based on such important supports as communication, information on the disease, early detection of relapses and support.

The primary objective of our program was to provide up-dated, adequate and understandable information on the disease, its symptoms, cause and treatment and to teach the subjects coping strategies against the reactions and stress and how to detect changes in the patient to prevent relapses and/or rehospitalizations.

## Structure

The psychoeducational program is made up of a series of sessions previously established in the following way: dura-

tion, format, group composition, site, professionals and recruitment.

## Organization

The educational sessions included: information on disease, prognosis and treatment, management of problematic behavior, emotional support, promoting discussion and evaluation.

The program carried out with the patients is made up of three phases:

### *Educational*

The patients are given an explanation on the name of their disease, the symptoms they are suffering and the treatment to be followed.

### *Hierarchization of problems, deficits or needs*

Learning is initiated following the skills training model, which is made up of the following steps:

- Identification of the patient's problem by the trainer or therapist.
- Specification of objectives and task planning.
- Dramatizing the problem.
- Model and reinforcement

### *Practice in daily life of the skills learned*

The practice of these skills is performed in the patient's daily life and in his/her usual setting gradually.

Data and sociodemographic variables collection was made using a sheet created for the study with the patient's clinical data and the personal data of the caregivers and the sociodemographic variables.

The measurement instrument used was the ZARIT burden questionnaire, validated in our country by Manuel Martín<sup>23</sup>.

This work has been statistically analyzed using the ANOVA for quantitative variables and the Student's *t* test for independent groups. In regards to the qualitative variables, these were treated with Kruskal-Wallis statistical analysis (for more than two groups) and the Wilcoxon test for paired data before and after the program. The contrast tests were made with the Scheffe test.

The previously coded data obtained have been included in a SPSS database specifically created for this study. A des-

criptive analysis was made initially of each one of the variables of the patient and informal caregiver at two points in time of the evaluation: at the onset of the psychoeducational program and at the end of the program, using the mean and standard deviation of the groups.

The percentage of abandonments was not significant in groups 01 and 02. The losses after the first survey in group 03 were somewhat greater so that the number of caregivers surveyed had to be increased.

All of the caregivers who were surveyed in the three groups were asked for an informed consent for this study.

## RESULTS

The global sample was made up of 90 patients and their corresponding caregivers. All the patients were diagnosed of schizophrenic psychosis, following the usual diagnostic criteria (DSM IV). Mean age of the patients was  $34.20 \pm 7.96$  years (median: 33.5 years); the age of 45 patients was above the median (50%). The sample was made up of 26 women (28.9%) and 64 men (71.1%). The patients mainly lived in the urban area (86/90, 95.6%). An episode of hospital admission (last three years) was recorded in the clinical history of 36 patients (40%).

The characteristics of the patients in each one of the groups and the statistically significant differences between groups regarding each one of the variables are shown in table 1.

Table 2 presents the statistically significant differences among the three groups of caregivers. As can be observed, the only significant differences are found in that there are more subjects who have no partner in group 03 than in groups 01 and 02. Group 03 also has the poorest work situation, since only 10 out of the 30 subjects that make up the group are working. However, what stands out is that group 01 dedicates the least time to the patient. This is probably because it is the group that has the most men, although the differences between the groups regarding the amount of women are not statistically significant.

Table 3 shows the modifications on the burden scale (Zarit) after the application of the program. If we consider the cut-off at 47<sup>23</sup> in the three groups, there are elevated scores that show a clear burden in all the caregivers (table 3).

In the total group, the score decreased from 91% of the caregivers with clear burden to 72%. In group 01, the decrease was from 100 to 86.7%. In group 02, it went from 90% of the caregivers with burden to 73%. Finally, in group 03, there were hardly any differences, from 83% to 80%.

The variations between the baseline evaluation and the post-program evaluation, analyzed with the Student's *t* test

Table 1	Characteristics of the patients forming a part of each study group			
	Group 01	Group 02	Group 03	p
Age (mean $\pm$ SD)*	32.50 $\pm$ 5.54	32.73 $\pm$ 5.55	37.37 $\pm$ 10.84	0.027
Age (> median)	14 (46.7 %)	13 (43.3 %)	18 (60 %)	0.397
Gender (men)	19 (63.3 %)	23 (76.6 %)	22 (73.3 %)	0.499
Previous admission (yes)	10 (33.3 %)	8 (26.7 %)	18 (60 %)	0.021
Non-contributory pension (yes)	22 (73.3 %)	25 (83.3 %)	15 (50 %)	0.017

\* Statistical analysis by ANOVA. The remaining variables have been analyzed using the Kruskal-Wallis test.

for paired data, are significant in groups 01 ( $9.46 \pm 7.50$ ;  $p < 0.001$ ) and 02 ( $8.50 \pm 8.48$ ;  $p < 0.001$ ), but not in group 03 ( $-0.067 \pm 3.14$ ;  $p = 0.908$ ).

As can be seen in table 1, the differences are statistically significant in groups 01 and 02, that is, in those subjected to treatment while the number of subjects does not change in group 03, that did not receive any type of specialized psychological treatment.

In regards to the patient variables that had an influence on burden, younger ages (below the median) were associated to greater burden before and after the psychoeducational program ( $68.56 \pm 12.63$  vs.  $55.71 \pm 13.98$ , respectively;  $p < 0.001$ ). Neither gender of the patient nor background of hospital admissions had an influence on burden.

Table 2	Characteristics of the caregivers forming each study group			
	Group 01	Group 02	Group 03	p
Age (mean $\pm$ SD)*	60.80 $\pm$ 10.12	60.70 $\pm$ 7	60.80 $\pm$ 14.46	0.999
Age (> median)	14 (46.7 %)	10 (33.3 %)	13 (43.3 %)	0.554
Gender (women)	18 (60 %)	23 (76.7 %)	22 (73.3 %)	0.499
Partner (yes)	23 (76.7 %)	20 (66.7 %)	11 (36.7 %)	0.005
Social class (low)	5 (16.7 %)	10 (33.3 %)	10 (33.3 %)	0.254
Culture (basic)	12 (40 %)	13 (43.3 %)	13 (43.3 %)	0.956
Work situation (working)	20 (66.7 %)	23 (76.7 %)	10 (33.3 %)	< 0.001
Care time (> 10 h)	10 (33.3 %)	17 (56.7 %)	17 (56.7 %)	0.116
Dedication (> 10 h)	6 (20 %)	16 (53.3 %)	16 (53.3 %)	0.011

\* Statistical analysis by ANOVA. The remaining variables have been analyzed using the Kruskal-Wallis test

Table 3	Zarit. Distribution by cut-off (47 points) in the global group and in each one of the study groups	
	< 47 points	> 47 points
<b>Global group (n = 90)</b>		
Baseline survey	8 (8.9%)	82 (91.1 %)
Postprogram survey*	18 (20 %)	72 (80 %)
<b>Group 01 (n = 30)</b>		
Baseline survey	—	30 (100 %)
Postprogram survey**	4 (13.3 %)	26 (86.7 %)
<b>Group 02 (n = 30)</b>		
Baseline survey	3 (10 %)	27 (90 %)
Postprogram survey***	8 (26.7 %)	22 (73.3 %)
<b>Group 03 (n = 30)</b>		
Baseline survey	5 (16.7 %)	25 (83.3 %)
Postprogram survey****	6 (20 %)	24 (80 %)

Statistical analysis by Wilcoxon rank sum test: \*0.002; \*\*0.046; \*\*\*0.025; \*\*\*\*0.317

Among the variables of the caregivers, higher cultural level of them was associated to lower burden both before ( $64.87 \pm 14.98$  vs.  $72.53 \pm 13.13$ ;  $p = 0.013$ ) and after ( $58.87 \pm 15.25$  vs.  $66.61 \pm 12.89$ ;  $p = 0.013$ ) the psychoeducational program. Receiving a non-contributory pension by the patient was also associated to greater burden ( $70.90 \pm 14.07$  vs.  $61.89 \pm 14.06$ ;  $p = 0.006$ ,  $\gamma$   $64.73 \pm 14.54$  vs.  $56.39 \pm 13.72$ ;  $p = 0.012$ , before and after the program, respectively).

Among the caregivers, age, gender, social class, having a partner or time dedicated to the care of the patient did not influence in the levels of burden measured.

## DISCUSSION

The profile of the study patients is quite similar to those of other similar studies conducted in our country. For example, there is that of Castilla<sup>1</sup> that showed a group with a mean age of 38 years, 63% men, 57% of whom received a pension with a percentage of income of 56% (greater than that of our sample, presented in table 1). The latter data is more similar to the characteristics of our control group (group 03). In most of the works that include psychoeducational programs, the samples are not larger than ours: The work of Lauber<sup>29</sup> had 64 caregivers. There were 51 in that of Jungbauer<sup>11</sup>, 30 and 55 in that of Magliano<sup>31</sup>.

It is significant that those patients who had not received any type of educational intervention (neither them nor their caregivers) had greater clinical instability and exacerbations of the condition as is shown by the greater num-

ber of admissions during the same period with the same results as those of Hormung<sup>25</sup>.

The group 03 patients (control group) received fewer non-contributory pensions. This group may have a worse health care/social situation (non-inclusion in psychoeducational programs, fewer pensions, etc.). This is a group of caregivers recruited by different psychiatrists of our area who had not been included in any psychosocial intervention program in which we could not have controlled the reasons for this situation (prejudices of the psychiatrist?, refusal of the patients or their relatives?, the intervention is not considered necessary, etc.). This could mean a bias in this control group.

In regards to the caregivers, the profile of our group coincides with the data of the EUFAMI study<sup>26</sup>, with a mean age of 60 years, 72% caregivers and middle educational level. This predominance of women as caregivers is common in all the disorders, not only between the caregivers of schizophrenic patients. As Delicado<sup>27</sup> points out, this reaches 80% when all the mental disorders are included.

Contact time with the patients of more than 10 h in most of the caregivers is also consistent with the data found in the literature<sup>26,28</sup>. This time exceeded 39 h per week in Spain in the EUFAMI study.

In the evaluation of the burden, our study's finding of elevated levels of burden in the Zarit<sup>24</sup> with 91% of the caregivers above the cut-off is comparable with the results of the abundant literature on this aspect. Castilla reports 98% measured with the SBAS; Lauber<sup>29</sup> found 85% and there are similar values in the studies of Kuipers<sup>7</sup> and Keller<sup>32</sup>.

Among the factors that we have analyzed as determinants of the burden, we have found that the younger patients generate a greater burden. This coincides with the findings of Kuipers<sup>7</sup> and Lauber<sup>29</sup>. In the studies of Jungbauer<sup>30</sup> and Addington<sup>33</sup> this is even greater in the first episodes. On the contrary, Ostman<sup>34</sup> finds greater burden in the caregivers of elderly patients.

We found no differences in the burden based on the patient's gender on the contrary to the Thornicroft study<sup>35</sup> that found a greater burden in the caregivers of male patients. In regards to the relationship between burden and patient admissions, where we did not find a significant difference, this difference was significant in the studies of Mueser<sup>36</sup>, Jiska<sup>37</sup> and Martens<sup>18</sup>, but not in others such as Keller<sup>32</sup>.

Caregiver gender does not seem to have any influence on burden, this coinciding with Mueser<sup>36</sup> and Jiska<sup>37</sup>, nor does the caregiver's age. Cultural level of the caregivers does seem to condition lower burden, this also being found by Mueser<sup>36</sup> and Jiska<sup>37</sup>. It is possible that this better cultural

and educational level permits the caregivers to use better coping strategies in the care of the patient.

Greater burden is conditioned in the caregivers when they do not receive a non-contributory pension, this coinciding with the results obtained by Ohaeri<sup>38</sup>.

Surprisingly, there were no significant correlations in our sample between burden and care time and hours, one of the data most retorted in the literature<sup>19,36,39</sup>. It is difficult to explain the reason for this discrepancy, unless there is some mistake in the formulating of the survey or in the cut-off established (> 10 h), regarding the time of living together or dedication hours. It is also possible that the time the patient is in the family home in our setting does not contrast with that of other members of the family (brothers, for example).

### What impact does a program such as ours have on the aspects studied?

As we considered in the introduction, there are many publications on the good results of the psychoeducational programs in the course of the schizophrenic patients and in the positive influence on the relatives<sup>40-44</sup>. Almost all of them, as in our study, consider decrease of relapses and number of admissions as good result. Hornung<sup>25</sup> found 69% readmissions in the group without intervention versus 42% in the group included in a therapeutic program.

Some authors such as Brown<sup>46</sup> point out the persistence of family burden in the long-term follow-up. Something similar occurs in our Group 03 caregivers who were not included in any psychosocial intervention program.

As we have seen in table 3, the burden decreases globally and specifically in groups 01 and 02 significantly after the program is carried out. These results are similar to those obtained by Zhang<sup>47</sup>, Falloon<sup>48</sup>, Mc Farlane<sup>49</sup> and Raj<sup>50</sup>. This would imply that both the intervention on the patients and on the families improve the caregiver's burden and functioning, this being consistent with the findings of the BIOMED study (Magliano)<sup>51</sup>. In the recent study of Magliano et al.<sup>31</sup> of 55 families of schizophrenic patients, a clear improvement was found in the social functioning of the caregivers and also in their burden levels, with similar findings in different European countries.

### CONCLUSIONS

In the psychoeducational program described in this study, the caregiver's burden level decreases. This suggests that teaching informal caregivers how they should care for the mental patients considerably improves their quality of life and, by extension, the efficacy of their work in the patient's rehabilitation. Thus, the usefulness of this type of interventions could be reconsidered as part of the global treatment strategy of the schizophrenic patient.



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