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Family intervention in schizophrenia: long-term effect on main caregivers

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Introduction. The bulk of research on Family Interventions concentrates on assessing its efficacy in reducing psychotic relapses, there being very little research into its ability to reduce the morbidity of the main caregiver over the course of time.

Method. Follow-up study at five years of a cohort of informal caregivers of persons with schizophrenia who had taken part in an empirical trial with two therapeutic approaches assigned at random.

Results. 87.7 % of main caregivers are women and they tend to care for more chronic and inactive patients than men ($p < 0.041$). More than 55% of main caregivers had high General Health Questionnaire (GHQ) scores, with women suffering more emotional repercussions than men. Morbidity gradually declines over time (GHQ scores: 8.1 before intervention; 6.9 at the end of intervention and 4.6 five years later) although statistical significance was only achieved when taking the entire period into account, i.e., from beginning to the end of follow-up.

Conclusions. Family intervention over a limited period followed by a support group gradually reduces morbidity of the caregiver to a significant level at five years, although this reduction is not associated with the type of setting or the absence or presence of the patient. Clinical implications are discussed and likewise the need for a more equitable distribution of responsibilities and risk.

Key words:
Informal carer. Stress. Gender. Family intervention. Schizophrenia.

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Intervención familiar en la esquizofrenia: efecto a largo plazo en los cuidadores principales

Introducción. El grueso de la investigación sobre intervenciones familiares se centra en la evaluación de su eficacia para reducir las recaídas psicóticas, siendo muy escasos los trabajos donde se analiza su capacidad para reducir la morbilidad del cuidador principal a lo largo del tiempo.

Método. Estudio de seguimiento a 5 años de una cohorte de cuidadores informales de personas diagnosticas de esquizofrenia que en su día participaron en un ensayo empírico con asignación aleatoria a dos abordajes terapéuticos.

Resultados. El 87,7 % de los cuidadores principales son mujeres y tienden a hacerse cargo de pacientes más crónicos e inactivos que los hombres ($p < 0{,}041$). Más del 55 % de los cuidadores principales obtuvieron puntuaciones elevadas en el Cuestionario General de Salud (GHQ), siendo las mujeres las que presentaron una mayor repercusión emocional en comparación con los hombres. La reducción de la morbilidad fue progresiva a lo largo del tiempo (medias en el GHQ: 8,1 antes de la intervención, 6,9 al finalizar la misma y 4,6 a los 5 años), aunque sólo llegó a alcanzar significación estadística al considerar todo el período, es decir, desde el inicio hasta el final del seguimiento.

Conclusiones. Una intervención familiar de duración limitada seguida de un grupo de apoyo reduce la morbilidad del cuidador de forma progresiva, llegando a ser significativa a los 5 años, sin que esta reducción esté asociada al tipo de encuadre o a la presencia o ausencia del paciente. Se discuten las implicaciones clínicas, así como la necesidad de un reparto más equitativo de la carga y de los riesgos.

Palabras clave:
Cuidador informal. Estrés. Género. Intervención familiar. Esquizofrenia.

INTRODUCTION

Caring for a family member with a serious mental disorder, whether of long evolution or more recent onset, entails increased pressure on the family, giving rise to quite a few conflicts and ambivalences. It is difficult for the families to understand and manage the behavior and symptoms, they must face their own beliefs on the disease, evolution and outcome and on the treatment efficacy. And other more

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specific problems such as quilt, grief work, stigmatization or isolation are added to the common problems of other chronic and dependent patient's caregivers[1].

In turn, the families are unsatisfied regarding the quality of care given in the services: lack of community resources, difficulty of access to the professionals, lack of information and participation as they do not feel involved in the treatment planning are some of the complaints[2].

It has been well established that caring for persons with a mental disorder has an impact on the caregiver's health, social relationships and family economy[3]. Thus, identifying families who have a greater risk continues to be an integral part of the investigation of the community psychiatric services[4].

When theory and need were converged around the 1980's, a series of studies on efficacy of therapeutic interventions aimed at reducing environmental stress and acquiring the necessary skills to face the stressing situations entailed in living with a person diagnosed of schizophrenia more effectively appeared. The results are consistent, and their capacity to reduce both psychotic relapses and use of hospital resources can be stated[5,6]. On the contrary, it has been less established if these types of interventions reduce, and to what degree, the load and morbidity of those family members responsible for the patient's care[7]. Furthermore, there is limited information on their longer term effects, the duration of them being a fundamental aspect when planning the services and assigning resources.

An intervention study previously conducted by our group offers us the opportunity to assess if the reduction of the emotional impact of the family detected after the therapeutic intervention is maintained or lost over time and to determine if the classification and presence or absence of the patient contribute to a long term differentiated response.

METHOD

Five year follow-up study of a cohort of family members of schizophrenic patients who had participated in an empiric trial with random assignment to two intervention groups.

Study subjects

The sample is made up of principal caregivers of 87 patients diagnosed of schizophrenia (DSM III-R) who participated in the previous intervention study[8]. Principal caregiver was identified as that family member who spent more time with the patient and was responsible for most of the patient's cares. The patients were sent to the program according to the criteria of the psychiatrist responsible for his/her treatment, after giving his/her informed consent. However, no case was excluded based on clinical seriousness, dysfunction degree, level of familial expressed emotion or presence of co-morbidity, except for patients who presented physical dependence on substances in the initial evaluation.

The initial sample is similar to that described in most of the family intervention studies: they are patients with a mean age around 27 years and with more than five years evolution, with predominance of men, single persons, occupationally inactive, where 52.9 % live in a family setting made up of more than three members, who present active symptoms, who globally comply with the medication prescribed, two thirds (69.5 %) presenting important deficits and social maladaptations.

The profile of the main caregiver also corresponds to that of most the main caregivers of patients having other conditions, these mostly being women (87.8 %), mothers of the patients (82 %), with a mean age of 56 years (11.7) and more than half without paid work (66.7 %). The level of expressed emotion was assessed as critical, hostile or with excessive emotional overinvolvement in 59.6 % of the cases, the direct face-to-face contact between the patient and caregiver being very elevated for more than half of them (66.7 %).

Assignement

After having completed the initial evaluation, they were assigned according to the random numbers table to the groups of: *a)* behavioral familial intervention or, and *b)* familial group. The difference between both approaches is found in the patient that in the group assigned to the first format actively participated in all the sessions, this occurring in his/her home, while in the group format, these were carried out in the clinical setting and in absence of the patient. Up to now, there is no evidence of greater efficacy in terms of reduction of psychotic relapses, based on whether these strategies are applied in a group or centered format in the familial unit[9].

The comparative analysis of the characteristics of the patients and their family members did not detect significant differences, the groups thus being very similar.

Therapeutic intervention

The program was offered within the public care and out-patient clinic level and was given by an interdisciplinary team that had been previously trained and with regulated supervisions. The strategies applied over twelve months included psychopharmacological treatment with training in the development of strategies that increase compliance and adherence to the maintenance regime, prevention and minimization of side effects, information and education on schizophrenia, training of the patient and informal caregivers in the management of stressing situations and early detection and intervention in crisis, making it possible for these to be resolved as quickly and effectively as possible[10].

After finishing the structured intervention period, all the family members were invited to participate in a support group.

Follow-up

It was decided to make an evaluation identical to the previous two in 87 cases assigned with independence of the number of sessions they had attended. Given that entry into the therapeutic program occurred over a five year period, and in order to homogenize the follow-up period, the evaluation was done successively during a similar period.

One or two independent raters of the therapeutic team were trained until reaching an adequate level of reliability (ICC > 0.90), in the management and evaluation of a battery of measurements and instruments.

Morbidity of the caregiver has been measured with the General Health Questionnaire (GHQ-28)[11]. The total score, taken as continuous variable, has been considered for this study. In regards to a cut-off, it is taken as a dichotomic variable, it being considered positive if a score over 5 is obtained. The measurement of the knowledge the key family member has on different aspects of schizophrenia has been estimated based on the responses collected in the Spanish version of the interview —Knowledge About Schizophrenia Inventory (Kasi)[12]— and finally, the family members have been classified as having high or low expressed emotion after assessment in the Camberwell Family Interview following the classical classification criteria[13].

Losses were considered to be those cases that rejected the new evaluation, those others which, after three attempts, could not be located, and those cases in which the main caregiver died or did not have the necessary physical or psychic conditions to be able to participate in the evaluation.

Data analysis

The descriptive analysis has been conducted by numerical summaries (means and standard deviations for the continuous variables and frequency tables for the quantitative ones).

Changes in morbidity of the main caregiver, level of knowledge acquired on the disease and its management and family level of expressed emotion between the end of the intervention and follow-up (or between its onset and follow-up) were analyzed with the Wilcoxon sign rank test in the categorical variables, the McNemar test in the dichotomic variables and the Student's *t* test for paired data in continuous variables.

Comparison between the two therapeutic approaches in the expressed emotion was analyzed with the chi squared test, Mann-Whitney U test and *t* test for independent samples, according to the characteristics of the variables.

RESULTS

A total of 16 out of the 87 cases initially assigned were lost in the follow-up period, that is 18.4%, this percentage being comparable to the three other long term follow-up studies of intervened cohorts[14-16]. When the profile of the family members lost were compared with those for whom complete data are available, significant differences are only detected regarding the proportion of the cases which had previously dropped out of the intervention: 81.2 % of the losses correspond to cases of drop-out versus 31 % that continued until the end ($p < 0.0001$).

The cohort follow-up is characterized by being the main caregivers of patients having more than 11 years of disease evolution, with a predominance of men, single persons, occupationally inactive, with little presence of active psychotic symptoms and without serious social maladjustments, where more than half of them had good compliance to drug treatment, live with their origin family surrounded by a not very adverse emotional setting.

The characteristics of the caregivers did not significantly vary over time, that is, it is still women and mothers of the patients who continue to be mostly in charge of their care in spite of the passage of time. Women tend to take charge of the more chronic and inactive patients than the men ($p < 0.041$) regardless of the degree of relationship with the patient, while men tend to give care to more adapted patients and when it is their partners ($p < 0.043$).

Caregivers as a whole presented elevated scores on the GHQ, the mean being at 8.1 (SD: 6.1), that is, above the established cut-off. Differences were detected in the percentage of psychiatric morbidity based on the caregiver's gender (women, 59 %, vs men, 33 %; $p < 0.095$). However this difference does not reach statistical significance, probably due to the small proportion of male caregivers in our sample.

The form of approaching the problems seems to be different between men and women caregivers. Women are more emotionally and affectively involved with the daily problems, while men act more instrumentally, which may generate less tension or malaise in them[17]. On the other hand, we cannot rule out the fact that women tend to take charge of more dependent and inactive patients that may explain the differences in overload as has been detected in other studies[18].

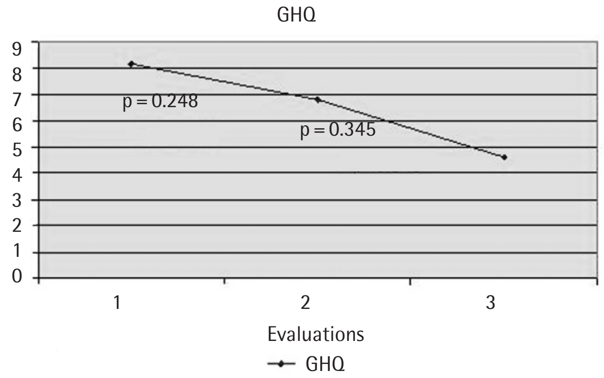
The fact of being the mother or father of the patient is significantly associated to greater distress ($p < 0.043$) and, on the contrary to that expected, a greater number of family members living in the same home is also associated to greater morbidity ($p < 0.020$). This situation may cause women to feel more overloaded as they have to assume a greater number of roles instead of giving rise to a more equal distribution of the load. Three other variables are associated to the caregiver's morbidity, without reaching statistical significance: high scores in expressed emotion (EE) ($p < 0.060$), elevated expectations ($p < 0.082$) and the fact of not recognizing the negative symptoms as part of the disease ($p < 0.061$). According to Barrowcloungh[19] the cognitive representation of the disease has important implications, not only in the evolution of schizophrenia but also in the caregiver's morbidity.

The repercussion that the fact of caring for a family member with schizophrenia has on the psychic health condition of the family member decreases with time (measurements on GHQ in three measurements: 8.1, 6.9 and 4.6), although the change is only significant when the entire period is considered, from the onset of the intervention. Thus, it is a slow process. Over time, grief work is elaborated, the disease and the resources to handle it that do not seem to respond to the patient's clinical condition, the number of relapses or re-hospitalizations are better known (fig. 1).

Even though the intervention seems to be associated to the changes in EE, most of the study are not conclusive in this regards, as it cannot be ruled out if the reduction of the EE level decreases over time due to getting used to it or acceptance of the situation[20], which remains stable in non-intervened families[21,22]. In our study, the change in family EE level is only significant in the cases that were intervened, maintaining the same level as at the end of the intervention (High family EE: 56.3 % at onset, 25 % after the intervention and 26.3 % in the follow-up). In those that dropped out of the intervention, a change occurred only in one case (of high EE to low EE), which leads us to think that the intervention plays a role in the change and not only in the mere passage of time. Hostility appears as the most stable component, the loss of affection standing out over time in most of the family members ($p < 0,015$). Face-to-face contact time between the patient and his/her family remains high in an elevated percentage of cases, no significant changes being detected.

One of the hypothesis that have been formulated regarding efficacy of family based psychological interventions refers to their ability to increase antipsychotic treatment compliance on promoting knowledge regarding the disease and its management and promoting changes in the family's emotional setting. This occurs in such a way that it would make them capable of managing behaviors aimed at reinforcing compliance more effectively, on avoiding confrontation and excessive control on the patient[23].

The fact that the family's level of knowledge has been maintained or even increased during the period in regards to the importance of the «medication» has not been sufficient to control the increase of non-compliers, that went from 14 % at the end of the intervention to 37 % in the follow-up ($p < 0.000$). This indicates that the fact that although the family knows the importance of the maintenance drug, this does not necessarily imply that the patient's compliance with it can be assured (fig. 2). Once the dependence on the medication and its importance is accepted, it does not seem that passing of time changes what has been learned, but rather the experience of new relapses related with changes and drop-outs of medication reinforces this knowledge[24,25].



Wilcoxon sign rank test; p = 0.005.

Figure 1 | *Scores in GHQ in the three evaluation times (1: onset; 2: final intervention; 3: 5 years after the end).*

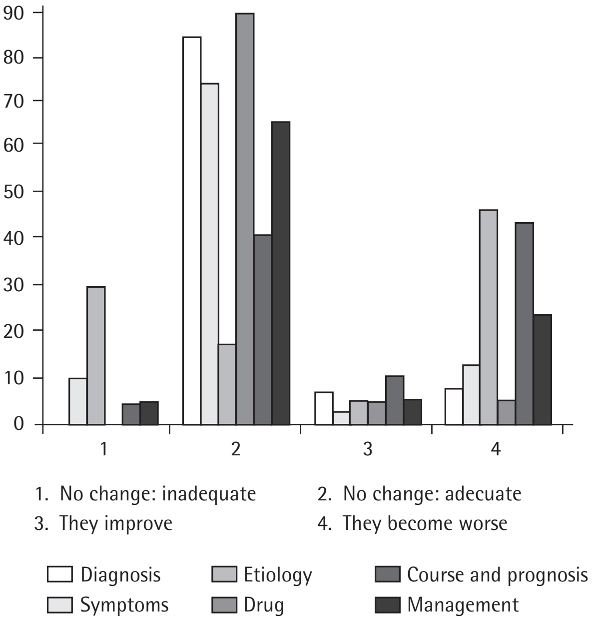


Figure 2 | *Changes in knowledge levels on the disease and its management after finishing the intervention and follow-up.*

It can be stated that both therapeutic strategies have a similar impact in the long run, although the group of caregivers assigned to the group format tends to obtain the most favorable results over time in the detailed analysis of change according to the specific strategy of the intervention conducted (table 1). This same tendency was already observed in a previous study[26]. However, we cannot rule out the possible contribution of the support group offered after finishing the intervention, where the number of participants from the family group has been three times greater than that of those from the intervention focused on the family unit.

We can conclude that the data of our study, as a whole, orients towards the fact that a 12 month long family intervention followed by a support group, aimed at reducing the stress derived from providing care to a person with a serious mental health disorder progressively reduces the caregiver's morbidity, reaching significance at five years, and that this reduction is not associated to the presence or absence of the patient.

LIMITATIONS

However, different factors may have influenced the results obtained. The fact that the study was not designed to evaluate specifically the impact on the psychic health of the main caretaker takes has left variables involved in the process, such as social support and confrontation style, outside of the analysis. On the other hand, the fact that the analysis has been conducted by intention to treat, so that family members who did not receive the complete intervention were included, could have given rise to poorer results in some results. As compensation, this method assures a greater internal validity and moves us closer to the clinical reality.

Table 1 **Family member variables at end of follow-up according to theraputic intervention group**

	Single family member	Group of family members	p
EE (n = 49) low EE	18 (69.2 %)	17 (73.9 %)	0.717
Health repercussion (n = 33)	4.9	4.1	0.530*
Deficient knowledge n = 48)			
Diagnosis	4 (14.8 %)	1 (4.8 %)	0.369
Symptoms	7 (25.9 %)	4 (19 %)	0.733
Etiology	23 (85.2 %)	15 (71.4 %)	0.297
Drug	2 (7.4 %)	1 (4,8 %)	1.000
Course/prognosis	13 (48.1 %)	14 (66.7 %)	0.199
Management	7 (28 %)	8 (38.1 %)	0.467

Chi squared test. * Mann-Whitney U test.

Even though significant differences have not been detected between the lost cases and the final sample, the fact that most of the losses correspond to cases which had previously abandoned the therapeutic intervention does not allow us to know if family members of greater or lesser risk have been left out of the study.

In regards to the generalization of the results, it must be remembered that our findings provide information on the long term effects of a family intervention in those who were once sent to the program and accepted to participate. In spite of the efforts made to be able to have a cohort that was representative of patients diagnosed of schizophrenia who live with their family members and who are seen in the mental health services, it is not possible to rule out biases associated to referral criteria of the clinicians responsible for these patients. Specifically, there were few cases that showed a rapid recovery after a psychotic decompensation episode and first episodes. Perhaps the changes observed over time could have different regarding those detected in this study if the main caregivers of the patients have been better represented with a more favorable profile.

Thus new long term follow-up studies with large samples and repeated measurements at regular intervals that overcome these methodological limitations and make it possible to validate the results of the present study must be designed.

CLINICAL IMPLICATIONS

The fact that it was family distress progressively decreases suggests the need to initiate the interventions in the first phases of the disease and extend them over time and to promote the support groups, above all for those caregivers who have patients with greater evolution time to take care of.

Psychological impact derived from providing cares to persons with serious mental disorders is associated to negative cognitive assessment and to a not very effective confrontation style, the therapeutic methods should not use either didactic approaches with standard content or instruction. They should use interactive approaches that examine the meaning, and, in its case, they should help make a cognitive reconstruction and analyze the confrontation strategies used, reinforcing those that have been most useful.

The effects derived from the fact of taking care of others is a very important issue for women. This requires a strong institutional decision that permits the implementation of strategies and effective interventions in the reduction of psychiatric morbidity risk and the search for new alternatives and of a more balanced distribution of the load and the risks between men and women.

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