

# Primary caregivers of schizophrenia outpatients: Burden and predictor variables

Pamela Grandón<sup>a,b,1,2</sup>, Cristina Jenaro<sup>c,\*</sup>, Serafín Lemos<sup>d,3</sup>

<sup>a</sup> *Facultad de Psicología Universidad del Desarrollo Ainavillo 456, Concepción, Chile*

<sup>b</sup> *The Psychiatry and Mental Health Unit, Hospital las Higueras Alto Horno 777, Higueras, Talcahuano, Chile*

<sup>c</sup> *Facultad de Psicología, Universidad de Salamanca Avda. de la Merced, 109-131. 37005-Salamanca, Spain*

<sup>d</sup> *Facultad de Psicología, Universidad de Oviedo Plaza Feijóo, s/n. 33003 Oviedo, Spain*

Received 8 September 2005; received in revised form 12 December 2006; accepted 13 December 2006

## Abstract

This article explores family burden in relation to relatives' coping strategies and social networks, as well as in relation to the patients' severity of positive and negative symptoms. Data on the severity of symptoms (Positive and Negative Syndrome Scale for Schizophrenia [PANSS]), social functioning (Social Functioning Scale [SFS]), caregivers burden (Interview on Objective and Subjective Family Burden or Entrevista de Carga Familiar Objetiva y Subjetiva [ECFOS]), coping skills (Family Coping Questionnaire [FCQ]), and social support (Social Network Questionnaire [SNQ]) were gathered from a randomized sample of 101 Chilean outpatients and their primary caregivers, mostly mothers. Low levels of burden were typically found, with the exception of moderate levels on general concerns for the ill relative. A hierarchical regression analysis with four blocks showed that clinical characteristics, such as higher frequency of relapses, more positive symptoms and lower independence-performance, together with lower self-control attributed to the patient, decrease in social interests, and less affective support, predict burden. The results support the relevance of psychoeducational interventions where families' needs are addressed.

© 2007 Elsevier Ireland Ltd. All rights reserved.

**Keywords:** Schizophrenia; Burden; Families; Caregivers; Predictor variables; Assessment

## 1. Introduction

Care activities for schizophrenia patients affect on the general and mental health of caregivers (Reinhard, 1994; Reinhard and Horwitz, 1995; Schene et al., 1998;

Grandón and Jenaro, 2002b). Burden refers to the negative impact of the individual's mental disorder on the entire family (Schene, 1990; Biegel and Schultz, 1999; Grandón and Jenaro, 2002a). It is possible to distinguish between objective burden, negative consequences on family routines, and subjective burden that relates to emotional disturbances experienced by the caregiver (Reinhard et al., 1994; Schene et al., 1994; Provencher and Mueser, 1997). Yet, subjective burden and stress have been incorrectly considered as equivalent, resulting in inappropriate assessments (Stull et al., 1994; St-Onge and Lavoie, 1997; Reine et al., 2003).

\* Corresponding author. Tel.: +34 923 294 617; fax: +34 923 29 46 85.

E-mail addresses: [pamegrandon@udd.cl](mailto:pamegrandon@udd.cl) (P. Grandón), [crisje@usal.es](mailto:crisje@usal.es) (C. Jenaro), [slemos@correo.uniovi.es](mailto:slemos@correo.uniovi.es) (S. Lemos).

<sup>1</sup> Tel.: +56 41 268602.

<sup>2</sup> Tel.: +56 41 501 513.

<sup>3</sup> Tel.: +34 985 103 254.

Other studies overlap variables from objective burden and from social functioning (Szmukler, 1996).

Research on family burden has been increasingly focused on identifying relations between physical, psychological and emotional health of caregivers (e.g. Gutierrez-Maldonado et al., 2005), and patient's symptoms (e.g. Provencher and Mueser, 1997; Lauber et al., 2003). Patient predictors of burden are typically related to clinical characteristics (suicidal ideation, behavioral disturbances, negative symptoms, etc.) (Provencher and Mueser, 1997; Dyck et al., 1999; Wolthaus et al., 2002; Kopelowicz et al., 2003; McDonnell et al., 2003; Reine et al., 2003; Saunders, 2003; Madianos et al., 2004; Koukia and Madianos, 2005). However, more research efforts need to be made in order to identify the impact of the patient's sociodemographic variables on burden (Cook and Pickett, 1988; Winefield and Harvey, 1993; Castilla et al., 1998), and on clinical variables, to determine whether they have equivalent effects on burden (Provencher and Mueser, 1997; Schene et al., 1998; Webb et al., 1998; Martínez et al., 2000), or rather have a differentiated effect (Dyck et al., 1999; Wolthaus et al., 2002).

Caregiver predictors of burden have been found to be related to sociodemographic and personality variables such as attributions, coping strategies (Karanci, 1995; Dyck et al., 1999; Ohaeri, 2001; Laidlaw et al., 2002; Lauber et al., 2003; Reine et al., 2003; Saunders, 2003), or expressed emotion (King et al., 2003; Bachmann et al., 2002, 2006). Nevertheless, one of the questions still to be answered is which types of coping strategies have more impact on burden (Magliano et al., 1998a,b; Webb et al., 1998; Hinrichsen and Lieberman, 1999; Scazufca and Kuipers, 1999). In addition, there is a scarcity of studies that assess caregivers' appraisal of the level of control of the patient regarding his or her disease, and those studies that exist offer contradictory results (Greenberg et al., 1997; Provencher and Mueser, 1997; Scazufca and Kuipers, 1999). In addition, most studies, with some exceptions (e.g. Shibre et al., 2003; Gutierrez-Maldonado et al., 2005; Kealey, 2005), have taken place in developed countries while sociocultural context seems to affect not only perceived burden, but also cultural construction and ways of coping with mental disease, in addition to social and family networks and supports (Horwitz and Reinhard, 1995; Guarnaccia and Parra, 1996; Jenkins and Schumacher, 1999). Finally, the empirical literature on family burden predictors requires more efforts to identify how socio-demographic, clinical, and personality variables from patients and their relatives may combine to predict higher levels of burden.

This study aims to help better understand family burden in schizophrenia outpatients from South America, and its etic (universal) and emic (culture-bound) properties (Berry et al., 1992; Jenaro et al., 2005). More specifically, the aims of this study are to (i) examine the levels of burnout experienced by primary caregivers of outpatients with schizophrenia in a regional area of a medium income country in South America; (ii) assess predictors of burden on primary caregivers of outpatients with schizophrenia; (iii) identify the impact of positive and negative symptoms on burden of those caregivers; (iv) specify which type of coping strategies has more impact on burden. The following hypothesis was tested: Sociodemographic and personality characteristics of the caregiver, together with clinical characteristics of the patient (i.e. frequency of relapses, positive and negative symptoms, social functioning), will predict burden.

## 2. Method

### 2.1. Sample

The study was carried out in Chile from January to February 2001. A randomized sample of 106 patients with schizophrenia who were attending a public mental health outpatient service from the Psychiatry and Mental Health Unit of the Hospital "Las Higueras" was selected. This Unit belongs to the Health Service Talcahuano from the Eighth region of Chile. Information was gathered from outpatients and their primary caregivers. Inclusion criteria were as follows: (1) The primary caregiver was defined as the member of the family who was most involved with the care of the outpatient; (2) All patients had a DSM-IV diagnosis of schizophrenia made by his or her psychiatrist; (3) The duration of illness encompassed at least 6 months before the present study; (4) Both patient and caregiver were older than 18. Potential participants were selected from the register of the clinic for neuroleptics, where they go once a month to obtain their prescriptions, as the psychiatric service of this hospital has no inpatient services. This system acts as an additional follow-up for adherence to pharmacological treatment. (5) Patients who had a dual diagnosis consisting of drug and alcohol abuse, intellectual handicap, or organicity were excluded from the study. Four out of 106 patients and one relative declined to participate, stating a lack of time. No obvious differences (gender, age, socioeconomic status, educational background, occupational status) were found when compared to the remaining participants. Thus, 101 patients and their respective key caregivers

were interviewed after informed consent had been obtained.

## 2.2. Instruments

Sociodemographic and clinical characteristics of the patient and caregiver were collected in an *ad hoc* survey. Six groups of additional variables were measured. First, positive and negative symptoms were measured by the Spanish version (Peralta and Cuesta, 1994) of the Positive and Negative Syndrome Scale for Schizophrenia (PANSS) (Kay et al., 1987). Reliability indexes of the Spanish version were  $\alpha=0.62$  for the PANSS-P,  $\alpha=0.92$  for the PANSS-N, and  $\alpha=0.55$  for the general scale. Second, social functioning was measured by the Spanish version (Vázquez and Jiménez, 2000) of the Social Functioning Scale (SFS) (Birchwood et al., 1990). Moderate–high levels of internal consistency were obtained for the different subscales (between  $\alpha=0.66$  and  $\alpha=0.90$ ), with the exception of the interpersonal communication domain ( $\alpha=0.45$ ). Test–retest reliability ranged from 0.66 to 0.88 for the different subscales (Vázquez and Jiménez, 2000).

Third, caregivers' burden was measured by the Spanish version (ECFOS) (Martínez et al., 2000) of the Family Burden Interview Schedule—Short Form (FBIS/FS) (Tessler and Gamache, 1996). Reliability indexes were similar to those from the original measure (between  $\alpha=0.68$  and  $\alpha=0.85$ ). Fourth, coping skills were measured by a Spanish translation of the Family Coping Questionnaire (FCQ) (Magliano et al., 1996, 1998a,b). The measure showed medium–high levels of internal consistency for the different subscales (between  $\alpha=0.52$  and  $\alpha=0.81$ ), and moderate levels for the total scale ( $\alpha=0.65$ ).

Fifth, social support was measured by a Spanish translation of the Social Network Questionnaire (SNQ) (Magliano et al., 1998a,b). Seven questions were added to assess the support received from mental health services during the last year. Confirmatory factor analyses supported the adequacy of reliability and validity properties. Factors included in the measure were: i) health support ( $\alpha=0.91$ ), ii) practical support ( $\alpha=0.61$ ), iii) social contacts ( $\alpha=0.75$ ), and iv) affective support ( $\alpha=0.67$ ). Finally, caregivers' sense of control over behavioral problems of the patient was measured by the Spanish translation (Vallina et al., 1998) of The Family Questionnaire (FQ) (Barrowclough and Tarrier, 1995). For the present study, an additional question was added to the measure — What level of control do you think your relative has over these behaviors? Both the original and the Spanish version have shown appropriate

psychometric properties (Quinn et al., 2003; Vallina et al., 1998). Reliability index on frequency of problems was  $\alpha=0.90$  for the present study.

## 2.3. Procedure

Two types of interviews were conducted during a 2-month period: one with the outpatient and one with the primary caregiver. Separate schedules for each informant were established in order to ensure confidentiality. First, outpatient interviews were performed. The average time for interviews with outpatients was 30 min, and the main researcher conducted all of these interviews. Second, the main researcher or one of three experienced research clinicians from the Mental Health Unit interviewed caregivers. Several training sessions, as well as follow-up sessions, were established to ensure the guarantee the adequacy of the process. The average time for the interviews with caregivers was 2 h and 30 min.

Written protocols were distributed to the interviewers to ensure the standardization of the assessment and the data collection. Protocols included general instructions for each of the measures, and specific instructions related to frequently asked questions for potentially conflicting items. Sociodemographic and clinical information was collected in a structured survey with close-ended questions developed *ad hoc* for this study. It comprises three sections: (1) demographic information of the relative, with 11 questions; (2) demographic and clinical information of the patient, composed of 14 questions; (3) information on the composition of the family unit, with two questions. All the clinical files were also reviewed to ensure the adequacy of the information provided by the informants.

## 2.4. Data analysis

Completed interviews were returned to the author/contact person for compilation and analysis. Upon receipt, each interview form was verified for completeness, and the data were entered into an SPSS spreadsheet. All analyses used the SPSS® v.10 for Windows (SPSS Inc., 1999). Data analyses required the following steps: First, routine exploratory analysis, using descriptive statistics to check for normality, outliers, linearity, and variance homogeneity, was performed in order to guarantee the adequacy of parametric tests. Second, bivariate (analysis of variance and Pearson correlations) and multivariate (a hierarchic regression analysis with blocks) tests were used to contrast the hypothesis. An alpha level of 0.05 was selected for all the analyses.

### 3. Results

#### 3.1. Sociodemographic and clinical characteristics

Most of patients were male, with a mean age of 40.7 (S.D.=11.9). A high percentage (91.1%,  $N=92$ ) live with their families. The population under study is basically composed of chronic patients, with a mean length of the disturbance of 18.3 years (S.D. = 10.5), and ranging from 3 to 48 years. Relapses average 7.2 per person (S.D.=8.2), with a mean of 2.5 hospitalizations (S.D.=3.7) per patient, and an average of 3.5 days (S.D.=1.6) of duration of the hospitalization. The majority receives both oral and depot neuroleptics (52.2%,  $N=53$ ); 17.8% receive oral or depot medication ( $N=18$  each), and 11.9% receive atypical medication ( $N=12$ ). They only receive outpatient mental health consulting (79.2%,  $N=80$ ), combined in some instances ( $N=16$ ) with a day center (15.8%), or with attendance at a social club (5%;  $N=5$ ).

Typical primary caregivers were females, with a mean age of 56.32 (S.D. = 14.12). Their relationship with the patient is mother (54.5%,  $N=55$ ) followed by sister (10.9%,  $N=11$ ). Regarding education, mean years are 7.75 (S.D. = 4.56). A majority of the caregivers evaluate the quality of their relationship with the patient as very good/good (70.3%,  $N=71$ ), although 16.8% ( $N=17$ ) evaluate it as poor/bad. Finally, the mean number of family members living at home is 4.95 (S.D. = 2.38), and ranges from 2 to 14 individuals. Table 1 summarizes additional sociodemographic data from patients and relatives.

#### 3.2. Burden levels

Means and standard deviations for each of the areas of burden, as assessed with the ECFOS, were calculated. The overall mean was 43.57 (S.D. = 25.1) and, since the scale ranges from 0 to 169, it can be said that the participants in the study have low levels of burden. The same pattern can be seen for all the areas: help in daily activities (objective) (mean=8.66, S.D.=7.58, range 0–40); help in daily activities (subjective) (mean=7.41, S.D.=7.40, range 0–30); control of behavioral problems (objective) (mean=1.99, S.D.=2.75, range 0–28); control of behavioral problems (subjective) (mean=3.51, S.D.=3.77, range 0–21); disturbances in caregiver routines (mean=1.79, S.D.=3.19, range 0–16), loss of opportunities (mean=1.40, S.D.=1.75, range 0–6). The only exception is the dimension of general concerns that shows moderate levels of burden (mean=18.8, S.D.=0.52, range 0–28).

Table 1

Clinical and sociodemographic characteristics of the outpatients and their relatives

	Outpatients		Relatives	
	Frequency	Percentage	Frequency	Percentage
Gender				
Male	57	56.4	20	19.8
Female	44	43.6	81	80.2
Age				
20–35 years	36	35.6	12	11.9
36–51 years	46	45.5	22	21.8
52–67 years	16	15.8	42	41.6
>67 years	3	3.0	25	24.8
Civil status				
Married/partner	10	9.9	57	56.3
Single	76	75.2	15	14.9
Widow	9	8.9	25	24.8
Divorced	6	5.9	4	4.0
Educational background				
No studies/primary education	36	35.6	61	60.4
Secondary education	50	49.5	24	23.8
Higher education or more	15	14.9	16	15.8
Occupational status				
Housekeeper	13	12.9	63	62.4
Non-qualified job	12	11.9	14	13.8
Unemployed	76	75.2	2	2.0
Qualified job			7	6.9
Professional			5	5.0
Retired			10	9.9

#### 3.3. Predictors of burden

A hierarchic regression analysis with blocks was made to establish the variables that predict burden after verifying (Kerlinger and Pedhazur, 1973; Cohen and Cohen, 1983; Tabachnick and Fidell, 2001): (i) the lack of multicollinearity among explanatory variables, by using the tolerance coefficient and the Variance Inflation Factor (VIF); (ii) linearity of relations, by a visual inspection of scattergrams between burden and correlated independent variables; (iii) normality of the errors distribution, by a visual inspection of residuals through histogram and P–P normal graphic; (iv) the independence of the errors, with the Durbin–Watson test; (v) the homoscedasticity of the errors, with a visual inspection of residuals. Outliers were also identified to check their possible impact on the regression.

Bivariate correlations between burden and 25 independent variables were first calculated. Variables that did

Table 2  
Summary of the hierarchic regression of burden

Predictor	Block 1	Block 2	Block 3	Block 4
	Beta	Beta	Beta	Beta
Sociodemographic characteristics				
Patient education	-0.253*	-0.068	-0.099	-0.062
Clinical characteristics				
Frequency of relapses		0.132*	0.168**	0.127*
Positive symptoms		0.192**	0.177**	0.168**
Negative symptoms		0.062	0.073	0.000
Communication		0.067	0.136	0.125
Prosocial activities		-0.039	0.050	0.050
Independence-performance		-0.622**	-0.602**	-0.486**
Employment		-0.009	-0.029	-0.080
Social support				
Social contacts			-0.167*	-0.067
Affective support			-0.173*	-0.147**
Predictor	Block 1	Block 2	Block 3	Block 4
Personality characteristics				
Attributed patient self-control				-0.305**
Resignation				-0.074
Avoidance				0.095
Maintenance of social interests				-0.183**
Positive communication				-0.021
<i>R</i>	0.253	0.794	0.828	0.898
<i>R</i> <sup>2</sup>	0.064*	0.630***	0.686***	0.807***
Corrected <i>R</i> <sup>2</sup>	0.055	0.598	0.651	0.773

\* $P < 0.05$ , \*\* $P < 0.01$  and \*\*\* $P < 0.001$ .

not significantly correlate to burden and those with high intercorrelations were removed to prevent collinearity. Finally, four blocks were included in the analysis. The first block (sociodemographic information) included years of education; the second (clinical characteristics) included frequency of relapses, positive and negative symptoms, and four social functioning subscales; the third (social support) included social contacts and affective support subscales; the fourth block (personality characteristics) included the item on the caregiver judgments of the patient's self-control over his or her behaviors, and four subscales of coping: resignation, avoidance, maintenance of social interests, and positive communication. In all, 15 variables grouped into four blocks were considered in the analysis.

Table 2 summarizes the hierarchic regression. As can be seen, the first block explains 5% of total variance. When the second block is included, the corrected determination coefficient reaches 59.8%, meaning that frequency of relapses, positive symptoms and independence-performance, controlling for years of education, explain 54.3% of variance. When the third block is aggregated, the percentage reaches 65.1%, meaning that social contact and affective support, controlled for the

other variables, explain 5.3% of variance. Finally, when the fourth block was included, the explanatory percentage of variance is 77.3%, meaning that personality characteristics explain 12.2% of total variance, controlled for the rest of the variables included. The final model includes as predictors, in order of importance: lower independence-performance, lower self-control attributed to the patient, decrease in social interests, more positive symptoms and less affective support, together with higher frequency of relapses.

The significance of the Model was tested to contrast the null hypothesis "omnibus" by using the *F* test of the last block in the regression. The final model was composed of six variables and it was significant ( $F = 23.662$ ,  $df = 15, 85$ ,  $P < 0.0001$ ). In summary, three out of four factors – with the exception of sociodemographic characteristics – predict burden.

#### 4. Discussion

The present study confirms the relevance of clinical, personality variables, and social support on family burden. Clinical characteristics that help predict burden such as frequency of relapses and severity of positive

symptoms have been found in previous studies as well (Pickett et al., 1995; Webb et al., 1998; Ricard et al., 1999). In addition, low independence-performance in social situations contributed to explain burden, which agrees with previous studies where functional limitations or disturbed behavior was a greater determinant of severity of burden than psychiatric diagnosis (Chakrabarti and Kulhara, 1999; Martínez et al., 2000; Ohaeri, 2001). Social support, and more specifically affective support, emerges as a significant variable in the current study and this agrees with previous research (Reinhard and Horwitz, 1995; Solomon and Draine, 1995a). The only coping skill that, controlled for the other variables, contributes to the prediction of burden is the maintenance of social interests, which is social in nature. The relevance of social variables in caregivers leaves the door open for community-based interventions. Ensuring a social support network has proven efficacy in alleviating burden in caregivers (Ohaeri, 2001; Saunders, 2003).

Responsibility attribution for behavioral disorders is one of the variables that most helps explain burden, and those caregivers who attributed lower levels of self-control to the patient experience higher levels of burden. This result contrasts with some previous studies (Greenley, 1986; Hooley, 1987; Terkelson, 1987), but supports Provencher and Mueser (1997), who concluded that there might be disadvantages for caregivers who assume that patients have no control over their negative symptom behaviors. In other words, according to attributional models of expressed emotion, emotional overinvolvement and its associated burden may result when symptoms are attributed to factors outside the patient's control (King et al., 2003). Also, in accordance with Scazufca and Kuipers (1999), burden of care seems to be more dependent on relatives' appraisal of the patient's condition than on patients' actual deficits. This result offers additional support for the relevance of interventions based on the reduction of expressed emotion and on the increase in relatives' knowledge about schizophrenia. These types of psychoeducational programs have demonstrated their usefulness in reducing burden, relapses, and increasing social functioning of patients and relatives (Zhao et al., 1999; Muela and Godoy, 2002; Koukia and Madianos, 2005). Paradoxically, although these intervention strategies have demonstrated their effectiveness, they are not fully used in health services nor have they become the standards of care in the community (Biegel and Schultz, 1999; Vallina and Lemos, 2000). More attention to specific components of these programs, and better matches between the patient's clinical characteristics and the sociodemographic and personality character-

istics from families may help increase their effectiveness as well (Montero et al., 2005).

The general low levels of burden in the studied sample are quite surprising. Possible explanations could be related, in the first place, to the characteristics of the sample. Since participants are chronic outpatients who have already been discharged from the hospital, rather than being in an acute episode of schizophrenia, the frequency or intensity of support during the last 30 days might not be the main source of burden (Winefield and Harvey, 1993). Additional tentative explanations relate to culturally bound differences. As Jenkins (1988) stated, Hispanic families may conceive the mental disease as a "nervios" problem, which leads them to a greater acceptance of behavioral disorders. In fact, some cross-cultural studies have shown that in developing countries attitudes toward mental illness are more tolerant (Lefley, 1990; Kealey, 2005). Culturally bound differences may be based on the prototypical traditional family, with more extensive and close networks than in modern families, and with normative roles as caregivers assumed mostly by the mother, as "the right thing to do" (Guarnaccia and Parra, 1996). From a cross-cultural perspective, and as in other work fields, further studies need to be conducted in order to test if such differences are better explained as cultural differences that need to be respected, or as disadvantaged situations that need to be prevented (Jenaro et al., 2005).

Contrary to expectations, negative symptoms did not help predict burden. Therefore, it is necessary to analyze if their effects on burden act through other variables. For example, several studies indicate that as negative symptoms increase, social functioning decreases (Fenton and McGlashan, 1991; Tandon et al., 1995). Something similar might happen with social contacts, which lose influence on burden when the fourth block (personality characteristics) is included in the regression. Maybe their effects on burden are indirect through variables included in the just mentioned fourth block of the equation; specifically the maintenance of social interests could be a mediator on this relation. This could help explain why when both variables are in the equation, one of them becomes redundant. Nevertheless, more studies exploring this hypothesis are needed.

The lack of predictive value of coping skills such as resignation and avoidance was also unexpected. It seems that passive oriented or emotion-focused coping strategies (resignation, avoidance) have less impact on burden than active oriented or problem-focused strategies. Thus, in some instances, repetitive efforts focused on coping may exacerbate feelings of burden instead of reduce it, similar to what happens in other work fields

(Jenaro et al., 2007). While existing literature on schizophrenia indicates that caregivers tend to use more emotion-focused strategies (Chakrabarti and Gill, 2002; Nehra et al., 2005), studies also recognize the impact of caregiver's knowledge or appraisal on coping styles (Chakrabarti and Gill, 2002; Reine et al., 2003) and, in some instances, higher levels of burden are associated with the use of problem-focused oriented coping strategies (Webb et al., 1998). As Nehra et al. (2005) stated, more culturally relevant investigations are required to fully understand the cultural construction of schizophrenia and its implications on attributions of personal control and on burden.

It is important to note some limitations of this study. First, participants come from a region of quite low social status in a South American country, so results should not be generalized to other regions and services. Second, information from families came exclusively from the primary caregiver and, thus, it is not possible to ascertain that the whole family agrees with his or her opinions; results from different perspectives are only comparable to a limited extent (Bachmann et al., 2006). Third, although for the current study, burden was treated as a unidimensional variable, further work analyzing predictors separately for objective and subjective burden should be done. Finally, additional analyses should be performed to evaluate the mediator role of variables such as social support, coping skills, and attributed patient self-control in the general well-being of the primary caregiver (Solomon and Draine, 1995a,b; Szmukler, 1996; Magliano et al., 1998a,b, 1999; Schene et al., 1998; Webb et al., 1998).

## 5. Conclusions

To conclude, this study has obtained data that support our hypothesis: burden results from a combination of clinical characteristics of the patient, plus personality characteristics of caregivers, plus forms of social support. In our study 77.3% of burden is explained by a mixture of the above-mentioned variables. Given the preeminence of clinical characteristics related to behavioral problems (positive symptoms and poor independence-performance) on the onset of burden (more than 50%), the implementation of comprehensive cognitive-behavioral interventions (based on self-regulation, empowerment, and skills training) after discharge from hospital treatment may help significantly reduce burden. The results regarding personality characteristics, explaining more than 12% of burden, and more specifically by attributions and a reduction in social interests, suggest that additional benefits can be derived from

interventions designed to increase the patient's self-awareness and control of his/her own illness. Respite opportunities, together with the use of cognitive interventions such as reattribution techniques when required, could be effective ways to reduce burden. Finally, the fact that 5% of burden is explained by a lack of support from family and friends (affective support) shows the relevance of providing respite opportunities for caregivers so that they have time to create, extend and maintain informal, self-help or even structured help networks and relationships. All these interventions may potentially benefit the quality of life of both patients and caregivers.

## References

- Bachmann, S., Bottmer, C., Jacob, S., Kronmüller, K.-T., Backenstrass, M., Mundt, C., Renneberg, B., Fiedler, P., Schröder, J., 2002. Expressed emotion in relatives of first-episode and chronic patients with schizophrenia and major depressive disorder—a comparison. *Psychiatry Research* 112 (3), 239–250.
- Bachmann, S., Bottmer, C., Jacob, S., Schröder, J., 2006. Perceived criticism in schizophrenia: a comparison of instruments for the assessment of the patient's perspective and its relation to relatives' expressed emotion. *Psychiatry Research* 142 (2–3), 167–175.
- Barrowclough, C., Tarrier, N., 1995. *Families of Schizophrenic Patients: Cognitive Behavioral Intervention*. Chapman-Hall, London.
- Berry, J.W., Poortinga, Y.H., Segall, M.H., Dasen, P.R., 1992. *Cross-Cultural Psychology: Research and Applications*. Cambridge University Press, Cambridge.
- Biegel, D., Schultz, R., 1999. Caregiving and caregiver interventions in aging and mental illness. *Family Relations* 48, 345–355.
- Birchwood, M.J., Smith, J., Cochrane, R., Wetton, S., Copestake, S., 1990. The Social Functioning Scale: the development and validation of a scale of social adjustment for use in family intervention programmes with schizophrenic patients. *British Journal of Psychiatry* 157, 853–859.
- Castilla, A., López, M., Chavarria, V., Sanjuán, M., Canut, P., Martínez, M., Martínez, J.M., Cáceres, J., 1998. La carga familiar en una muestra de pacientes esquizofrénicos en tratamiento ambulatorio. *Revista de la Asociación Española de Neuropsiquiatría* XVIII, 621–642.
- Chakrabarti, S., Gill, S., 2002. Coping and its correlates among caregivers of patients with bipolar disorder: a preliminary study. *Bipolar Disorders* 4 (1), 50–60.
- Chakrabarti, S., Kulhara, P., 1999. Family burden of caring for people with mental illness. *British Journal of Psychiatry* 174, 463.
- Cohen, J., Cohen, P., 1983. *Applied Multiple Regression/Correlation Analysis for the Behavioral Sciences*, 2nd ed. Lawrence Erlbaum, Hillsdale, NJ.
- Cook, J.A., Pickett, S.A., 1988. Feelings of burden and criticalness among parents residing with chronically mentally ill offspring. *Journal of Applied Social Sciences* 12, 79–107.
- Dyck, D.G., Short, R., Vitaliano, P.P., 1999. Predictors of burden and infectious illness in schizophrenia caregivers. *Psychosomatic Medicine* 61 (4), 411–419.
- Fenton, W., McGlashan, T., 1991. Natural history of schizophrenia subtypes II. Positive and negative symptoms and long-term course. *Archives General of Psychiatry* 11, 978–986.

- Grandón, P., Jenaro, C., 2002a. El concepto de carga en familias de personas con trastornos mentales graves (The concept of burden in families of people with severe mental disorders). *Psiquiatría y Salud Mental* XIX, 75–81.
- Grandón, P., Jenaro, C., 2002b. Descripción de la carga en una muestra de familias de personas con esquizofrenia (Description of burden in a sample of families of people with schizophrenia). *Psiquiatría y Salud Mental* XIX, 82–92.
- Greenberg, J.S., Kim, H.W., Greenley, J.R., 1997. Factors associated with subjective burden in siblings of adults with severe mental illness. *American Journal of Orthopsychiatry* 67 (2), 231–241.
- Greenley, J., 1986. Social control and expressed emotion. *Journal of Mental Disorders* 174, 24–30.
- Guarnaccia, P., Parra, P., 1996. Ethnicity, social status, and families' experiences of caring for a mentally ill family member. *Community Mental Health Journal* 32 (3), 243–260.
- Gutierrez-Maldonado, J., Caqueo-Urizar, A., Kavanagh, D.J., 2005. Burden of care and general health in families of patients with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology* 40 (11), 899–904.
- Hinrichsen, G.A., Lieberman, J.A., 1999. Family attributions and coping in the prediction of emotional adjustment in family members of patients with first-episode schizophrenia. *Acta Psychiatrica Scandinavica* 100, 359–366.
- Hooley, J.M., 1987. The nature and origins of expressed emotion. In: Hahlweg, H., Goldstein, M.J. (Eds.), *Understanding Major Mental Disorder: The Contribution of Family Interaction Research*. Family Process Press, New York, NY, pp. 176–194.
- Horwitz, A.V., Reinhard, S.C., 1995. Ethnic differences in caregiving duties and burdens among parents and siblings of persons with severe mental illnesses. *Journal of Health and Social Behavior* 36 (2), 138–150.
- Jenaro, C., Verdugo, M.A., Caballo, C., Balboni, G., Lachapelle, Y., Otrebski, W., Schalock, R.L., 2005. Cross-cultural study of person-centred quality of life domains and indicators: a replication. *Journal of Intellectual Disability Research* 49, 734–739.
- Jenaro, C., Flores, N., Arias, B., 2007. Burnout and coping in human service practitioners. *Professional Psychology: Research and Practice* 38 (1), 80–87.
- Jenkins, J., 1988. Ethnopsychiatric conceptions of schizophrenia illness: the problem of nervios within Mexican-American families. *Culture, Medicine and Psychiatry* 12 (3), 303–330.
- Jenkins, J., Schumacher, J., 1999. Family burden of schizophrenia and depressive illness: specifying the effects of ethnicity, gender and social ecology. *British Journal of Psychiatry* 174, 31–38.
- Karanci, A.N., 1995. Caregivers of Turkish schizophrenic patients: causal attributions, burdens and attitudes to help from the health professionals. *Social Psychiatry and Psychiatric Epidemiology* 30 (6), 261–268.
- Kay, S.R., Fiszbein, A., Opler, L.A., 1987. The Positive and Negative Syndrome Scale (PANSS) for schizophrenia. *Schizophrenia Bulletin* 13, 261–276.
- Kealey, E.M., 2005. Variations in the experience of schizophrenia: a cross-cultural review. *Journal of Social Work Research and Evaluation* 6 (1), 47–56.
- Kerlinger, F.N., Pedhazur, E.J., 1973. *Multiple Regression in Behavioral Research*. Holt, Rinehart and Winston, Inc., New York.
- King, S., Ricard, N., Rochon, V., Steiger, H., Nelis, S., 2003. Determinants of expressed emotion in mothers of schizophrenia patients. *Psychiatry Research* 117 (3), 211–222.
- Kopelowicz, A., Zarate, R., Gonzalez-Smith, V., Mintz, J., Liberman, R.P., 2003. Disease management in Latinos with schizophrenia: a family assisted, skills training approach. *Schizophrenia Bulletin* 29 (2), 211–227.
- Koukia, E., Madianos, M.G., 2005. Is psychosocial rehabilitation of schizophrenic patients preventing family burden? A comparative study. *Journal of Psychiatric and Mental Health Nursing* 12 (4), 415–422.
- Laidlaw, T.M., Coverdale, J.H., Falloon, I.R., Kydd, R.R., 2002. Caregivers' stresses when living together or apart from patients with chronic schizophrenia. *Community Mental Health Journal* 38 (4), 303–310.
- Lauber, C., Eichenberger, A., Luginbuhl, P., Keller, C., Rossler, W., 2003. Determinants of burden in caregivers of patients with exacerbating schizophrenia. *European Psychiatry* 18 (6), 285–289.
- Lefley, H., 1990. Culture and chronic mental illness. *Hospital & Community Psychiatry* 41 (3), 277–284.
- Madianos, M., Economou, M., Dafni, O., Koukia, E., Palli, A., Rogakou, E., 2004. Family disruption, economic hardship and psychological distress in schizophrenia: can they be measured? *European Psychiatry* 19 (7), 408–414.
- Magliano, L., Guarneri, M., Marasco, C., Tosini, P., Morosini, P., Maj, M., 1996. A new questionnaire assessing coping strategies in relatives of patients with schizophrenia: development and factor analysis. *Acta Psychiatrica Scandinavica* 94, 224–228.
- Magliano, L., Fadden, G., Economou, M., Xavier, M., Held, T., Guarneri, M., Marasco, C., Tosini, P., Maj, M., 1998a. Social and clinical factors influencing the choice of coping strategies in relatives of patients with schizophrenia: results of the BIOMED I study. *Social Psychiatry and Psychiatric Epidemiology* 33, 413–419.
- Magliano, L., Fadden, G., Madianos, M., Caldas de Almeida, J., Held, T., Guarneri, M., Marasco, C., Tosini, P., Maj, M., 1998b. Burden on the families of patients with schizophrenia: results of the BIOMED I study. *Social Psychiatry and Psychiatric Epidemiology* 33, 405–412.
- Magliano, L., Fadden, G., Fiorillo, A., Malangone, C., Sorrentino, D., Robinson, A., Maj, M., 1999. Family burden and coping strategies in schizophrenia: are key relatives really different to other relatives? *Acta Psychiatrica Scandinavica* 99 (1), 10–15.
- Martínez, A., Nadal, S., Beperet, M., Mendióroz, P., Grupo Psicost, 2000. Sobrecarga de los cuidadores familiares de pacientes con esquizofrenia: Factores determinantes (Burden upon family caregivers of patients with schizophrenia: determining factors). *Anales Sis San Navarra* 23, 101–110.
- Montero, I., Hernandez, I., Asencio, A., Bellver, F., LaCruz, M., Masanet, M.J., 2005. Do all people with schizophrenia receive the same benefit from different family intervention programs? *Psychiatry Research* 133, 187–195.
- McDonnell, M.G., Short, R.A., Berry, C.M., Dyck, D.G., 2003. Burden in schizophrenia caregivers: impact of family psychoeducation and awareness of patient suicidality. *Family Process* 42 (1), 91–103.
- Muela, J.A., Godoy, J.F., 2002. Family intervention programme in schizophrenia: two-year follow-up of the Andalusia study. *Psychology in Spain* 6, 56–60.
- Nehra, R., Chakrabarti, S., Kulhara, P., Sharma, R., 2005. Caregiver—coping in bipolar disorder and schizophrenia A re-examination. *Social Psychiatry and Psychiatric Epidemiology* 40 (4), 329–336.
- Ohaeri, J.U., 2001. Caregiver burden and psychotic patients' perception of social support in a Nigerian setting. *Social Psychiatry and Psychiatric Epidemiology* 36 (2), 86–93.
- Peralta, V., Cuesta, M., 1994. Validación de la Escala de los Síndromes Positivo y Negativo (PANSS) en una muestra de esquizofrénicos españoles (Validation of The Positive and Negative Syndrome



- Scale (PANSS) in a schizophrenia Spanish sample). *Actas Luso Espanolas de Neurologia y Psiquiatria* 22, 171–177.
- Pickett, S.A., Greenley, J.R., Greenberg, J.S., 1995. Off-tiredness as a contributor to subjective burden for parents of offspring with severe mental illness. *Family Relations* 44, 195–202.
- Provencher, H., Mueser, K., 1997. Positive and negative symptom behaviors and caregiver burden in the relatives of persons with schizophrenia. *Schizophrenia Research* 26, 71–80.
- Quinn, J., Barrowclough, C., Tarrier, N., 2003. The Family Questionnaire (FQ): a scale for measuring symptom appraisal in relatives of schizophrenic patients. *Acta Psychiatrica Scandinavica* 108 (4), 290–296.
- Reine, G., Lancon, C., Simeoni, M.C., Duplan, S., Auquier, P., 2003. La charge des aidants naturels de patients schizophrènes: revue critique des instruments d'évaluation (Caregiver burden in relatives of persons with schizophrenia: an overview of measure instruments). *Encephale* 29 (2), 137–147.
- Reinhard, S.C., 1994. Perspectives on the family's caregiving experience in mental illness. *Journal of Nursing Scholarship* 26, 70–74.
- Reinhard, S.C., Horwitz, A.V., 1995. Caregiver burden: differentiating the content and consequences of family caregiving. *Journal of Marriage and the Family* 57, 741–750.
- Reinhard, S.C., Gubman, G., Horwitz, A.V., Minsky, S., 1994. Burden assessment scale for families of the seriously mentally ill. *Evaluation and Program Planning* 17, 261–269.
- Ricard, N., Bonin, J.P., Ezer, H., 1999. Factors associated with burden in primary caregivers of mentally ill patients. *International Journal of Nursing Studies* 36, 73–83.
- Saunders, J.C., 2003. Families living with severe mental illness: a literature review. *Issues in Mental Health Nursing* 24 (2), 175–198.
- Scazufo, M., Kuipers, E., 1999. Coping strategies in relatives of people with schizophrenia before and after psychiatric admission. *British Journal of Psychiatry* 174, 154–158.
- Schene, A.H., 1990. Objective and subjective dimensions of family burden. Toward an integrative framework for research. *Social Psychiatry and Psychiatric Epidemiology* 25, 289–297.
- Schene, A.H., Tessler, R.C., Gamache, G.M., 1994. Instruments measuring family or caregiver burden in severe mental illness. *Social Psychiatry and Psychiatric Epidemiology* 29, 228–240.
- Schene, A.H., Van Wijngaarden, B., Koeter, M., 1998. Family caregiving in schizophrenia: domains and distress. *Schizophrenia Bulletin* 24, 609–618.
- Shibre, T., Kebede, D., Alem, A., Negash, A., Deyassa, N., Fekadu, A., Fekadu, D., Jacobsson, L., Kullgren, G., 2003. Schizophrenia: illness impact on family members in a traditional society rural Ethiopia. *Social Psychiatry and Psychiatric Epidemiology* 38 (1), 27–34.
- Solomon, P., Draine, J., 1995a. Subjective burden among family members of mentally ill adults: relation to stress, coping, and adaptation. *American Journal of Orthopsychiatry* 65, 419–427.
- Solomon, P., Draine, J., 1995b. Adaptive coping among family members of persons with serious mental illness. *Psychiatric Services* 46, 1156–1160.
- SPSS Inc., 1999. SPSS Base 10.0 for Windows User's Guide. SPSS Inc., Chicago IL.
- St-Onge, M., Lavoie, F., 1997. The experience of care-giving among mothers of adults suffering from psychotic disorders: factors associated with their psychological distress. *American Journal of Community Psychology* 25, 73–94.
- Stull, D., Kosloski, K., Kercher, K., 1994. Caregiver burden and generic well-being: opposite sides of the same coin? *The Gerontologist* 34, 88–94.
- Szmukler, G., 1996. From family "burden" to caregiving. *Psychiatric Bulletin* 20, 449–451.
- Tabachnick, B.G., Fidell, L.S., 2001. *Using Multivariate Statistics*, Fourth Edition. Allyn and Bacon, Boston.
- Tandon, R., Jibson, M., Taylor, S., DeQuardo, J., 1995. Conceptual models of the relationship between positive and negative symptoms. In: Shrikki, C., Nasrallah, H. (Eds.), *Contemporary Issues in the Treatment of Schizophrenia*. American Psychiatric Press, Washington D.C., pp. 109–124.
- Terkelson, K.G., 1987. The evolution of family responses to mental illness through time. In: Hatfield, A.B., Lefley, H.P. (Eds.), *Families of the Mentally Ill: Coping and Adaptation*. Guilford Press, New York, pp. 151–166.
- Tessler, R.C., Gamache, G.M., 1996. The family burden interview schedule—short form. In: Sederer, L.L., Dickey, B. (Eds.), *Outcome Assessment in Clinical Practice*. Williams & Wilkins, Baltimore, pp. 110–112.
- Vallina, O., Lemos, S., 2000. Dos décadas de intervenciones familiares en la esquizofrenia (Two decades of family interventions in schizophrenia). *Psicothema* 12, 671–681.
- Vallina, O., Lemos, S., García, A., Otero, A., Alonso, M., Gutiérrez, A.M., 1998. Tratamiento psicológico integrado de pacientes esquizofrénicos (Comprehensive psychological treatment of schizophrenia patients). *Psicothema* 10, 459–474.
- Vázquez, A., Jiménez, R., 2000. Social functioning scale (SFS): new contributions concerning its psychometric characteristics in a Spanish adaptation. *Psychiatry Research* 93, 247–256.
- Webb, C., Pfeiffer, M., Mueser, K., Gladis, M., Mensch, E., DeGirolamo, J., Levinson, D., 1998. Burden and well-being of caregivers for severely mentally ill: the role of coping style and social support. *Schizophrenia Research* 34, 169–180.
- Winefield, H., Harvey, E., 1993. Determinants of psychological distress in relatives of people with chronic schizophrenia. *Schizophrenia Bulletin* 19 (3), 619–625.
- Wolthaus, J.E., Dingemans, P.M., Schene, A.H., Linszen, D.H., Wiersma, D., Van Den Bosch, R.J., Cahn, W., Hijman, R., 2002. Caregiver burden in recent onset schizophrenia and spectrum disorders: the influence of symptoms and personality traits. *Journal of Nervous and Mental Disease* 190 (4), 241–247.
- Zhao, B., Shen, J., Shi, Y., 1999. A comparative study on family intervention on schizophrenics in community. *Chinese Mental Health Journal* 13 (6), 323–324.