

## Predictors of expressed emotion, burden and quality of life in relatives of Mexican patients with psychosis

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### **Abstract:**

Expressed emotion, burden and quality of life of relatives received attention because of the increasing interest in predicting and preventing relapse in psychotic patients; but they have subsequently acquired interest of their own as important aspects of families' psychological well-being. The study explores whether the psychological distress and illness perception of a sample of relatives of Mexican patients with psychosis can predict their levels of expressed emotion, burden and quality of life above patients' clinical and functional status. Sixty-five patient–relative dyads were interviewed. Relatives self-reported on expressed emotion, burden, quality of life, psychological distress and illness perception. Patients' clinical and functional status was rated by an interviewer. Pearson correlations and hierarchical multiple linear regressions were used for statistical analyses. Patients' functional status and relatives' psychological distress were significantly associated with expressed emotion, burden and quality of life. Patients' clinical status and relatives' illness perception were most strongly related to expressed emotion and burden. Relatives' psychological distress and illness perception dimensions predicted both burden and quality of life, over and above patients' clinical and functional status. Results underscore the relatives' need of support to overcome their own distress and concerns about the illness, for the psychological well-being of both patients and relatives.

**Keywords:** burden | expressed emotion | illness perception | psychological distress | psychosis | quality of life

### **Article:**

#### **Introduction**

As deinstitutionalization of patients with psychotic illnesses has been promoted, the active involvement of families in the care of their relatives has increased. Families play an important role in the recovery of patients from the first episode of psychosis through remission and

relapses. Without support from and an alliance with clinical professionals, family members may experience worry, shame, stigma, guilt and even depression when facing the challenge of having a relative with a brief or chronic mental disorder (Barrowclough *et al.* 1996, Szmukler 1996, Schene *et al.* 1998, Barrowclough & Hooley 2003, Ferriter & Huband 2003, Addington *et al.* 2005, Ewertzon *et al.* 2010). Expressed emotion (EE), burden and quality of life (QoL) of relatives are three concepts that emerged as part of the increasing interest in predicting and preventing relapse in psychotic patients, but have subsequently acquired recognition of their own as important aspects of families' psychological well-being.

EE refers to critical, hostile or emotionally overinvolved attitudes and interactions of family members towards a relative with a disorder or impairment (Barrowclough & Hooley 2003). High EE is a predictor of relapse not only in schizophrenia (Bland 1989, Butzlaff & Hooley 1998, Miklowitz 2004), but also across a range of psychiatric conditions (Butzlaff & Hooley 1998, Hooley 2007). Consequently, family intervention programmes have been developed to reduce relatives' EE levels (Hahlweg & Wiedemann 1999, Barbato & D'Avanzo 2000). The evidence suggests that high EE families benefit more from family interventions (Kuipers *et al.* 1999, Askey *et al.* 2007), but caution must be taken in families with low EE, as it may increase the levels of EE (Askey *et al.* 2007). Also, the effect of high EE on relapse has not been replicated globally (e.g. Mexican-Americans) suggesting that cultural factors might play an important role (Kopelowicz *et al.* 2002, Kealey 2005, Kymalainen & Weisman de Mamani 2008).

A parallel line of research has shifted the focus towards the consequences of severe mental illness for patients' caregivers. Family burden refers to a psychological state produced by the combination of physical work, emotional pressure, social restrictions and financial difficulties arising from taking care of an ill relative (Caqueo-Urizar *et al.* 2009). It involves shame, embarrassment and feelings of self-blame and guilt (Awad & Voruganti 2008). Results indicate that relatives might suffer burden in different life domains, such as reduction of subjective health, restrictions in leisure time, daily routine and social contacts, occupational problems, and coping with the patients' symptoms and emotional problems (Möller-Leimkühler 2005). Effective family interventions have been developed to treat burden in families (Campbell 2004, Nasr & Kausar 2009, Lowenstein *et al.* 2010), although not all findings concur (McDonnell *et al.* 2003, González-Blanch *et al.* 2010).

A closely related and increasingly studied concept is QoL, defined as the 'individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (The WHOQOL Group 1998). Although the QoL of patients with schizophrenia has been widely studied, recent efforts have also focused on relatives' QoL (Fischer *et al.* 2004, Foldemo *et al.* 2005). Caregiving relatives of patients with schizophrenia exhibit significantly lower QoL than the general population, resulting from fear of discrimination, concern about the care of the patient in later life and feeling a lack of security because of the patient (Fischer *et al.* 2004).

Support for relatives has focused on improving their knowledge about psychotic illnesses and reducing EE. Nevertheless, as the main providers of informal care for patients, the recognition and support for other equally relevant concerns (e.g. guilt, economic restraints, patient's autonomy and risk for relapse) and unfulfilled needs (e.g. social support and satisfactory family relationships) that might affect relatives' QoL and put them at risk of psychopathology are necessary (Bloch *et al.* 1995, Caqueo-Úrizar *et al.* 2009).

Patients' poor functioning and high symptom severity have generally been associated with increased EE (Rascón *et al.* 2008) and burden (Foldemo *et al.* 2005, Koukia & Madianos 2005, Parabiaghi *et al.* 2007, Roick *et al.* 2007, Van *et al.* 2007), and poorer QoL in relatives (Angermeyer *et al.* 2006). Nevertheless, not all findings concur (Sczufca & Kuipers 1996, Miklowitz 2004, Möller-Leimkühler 2005). Some studies suggest that burden is rather stable, and that symptom severity is not necessarily associated with relatives' burden (Brown & Birtwistle 1998).

The ongoing psychological distress experienced by relatives is also an important factor to be taken into account, as those with high levels of distress are likely to experience high EE (Barrowclough & Parle 1997, Shimodera *et al.* 2000) and burden (Boye *et al.* 2001, Provencheret *et al.* 2003, Hanzawa *et al.* 2008). A causal relationship cannot be concluded in either direction; however, psychological distress implies mild symptoms that might be due to other factors apart from the probable stress of having an ill relative (e.g. health, work or economic problems of their own). Hence, it seems appropriate to consider the relatives' psychological distress as a suitable predictor of other related factors such as EE, burden and QoL.

Underlying perceptions of illness by relatives are important in explaining their reactions to illness (Miklowitz 2004, Van *et al.* 2007, Lowenstein *et al.* 2010), and have implications both for identifying those at risk for poor adaptation and for designing strategies that might improve their well-being (Barrowclough & Parle 1997). Nevertheless, some specific dimensions of relatives' illness perception might be more influential than others. Caregivers' well-being seems to be related mainly to perceptions of the magnitude of the illness consequences for themselves, whereas their EE levels seem to be related to beliefs about their own (Barrowclough *et al.* 2001) or the patient's control (McNab *et al.* 2007) over the illness. Although some studies have found no association between illness perception and EE (Lobban *et al.* 2005), caregivers who rate patients as having little control have shown significantly poorer self-esteem and more stress and depression (Kuipers *et al.* 2007).

EE, burden and QoL are closely related concepts (Foldemo *et al.* 2005, Möller-Leimkühler 2005, Caqueo-Úrizar *et al.* 2009); however, they do not overlap completely. Hence, it is useful to explore all three in relation to previously related predictors in the same study. Learning about the specific and common underlying factors affecting EE, burden and QoL should enhance family interventions, thereby improving the outcomes of both patients and relatives. This should be of special importance in the first years of illness, when patients' relatives are most motivated for

learning skills and the illness course is more malleable (Birchwood 2000). Thus, the purpose of the study was to explore whether relatives' psychological distress and illness perception are stronger predictors of EE, burden and QoL than patients' clinical and functional status. If relatives' (mal)adjustment is related to specific factors, such as psychological distress and illness perception, above patients' clinical and functional status, this would print out to the critical usefulness of devoting therapeutic efforts tailored at this population. It was hypothesized that: (1) patients' poor clinical and functional status would relate to high EE and burden and to poor QoL in relatives; (2) relatives' high psychological distress and negative illness perception would relate to high EE and burden and to poor QoL; and (3) relatives' psychological distress and negative illness perception would predict EE, burden and QoL better than patients' clinical and functional status.

## **Methods**

This was a cross-sectional study focusing on the relatives of patients who received mental health care in the adult service of the Hospital Psiquiátrico Yucatán (HPY). The HPY is a public institution located in the city of Merida, Mexico that offers inpatient and outpatient care to all patients in need. The HPY has a broad catchment that includes patients from neighbouring states (e.g. Campeche, Quintana Roo); however, for this study, sampling was restricted to the inhabitants of the city of Merida. The study design, consent forms and measures were approved by the Hospital's Ethical Committee; ethical principles of privacy, confidentiality and voluntary participation were guaranteed.

Clinical files from the Yucatan Psychiatric Hospital (Mexico) were reviewed in search of patients who fulfilled the following criteria: (1) a primary Diagnostic and Statistical Manual of Mental Disorders, 4th edition text revision (DSM-IV-TR) [American Psychiatric Association (APA) 2000] diagnosis of schizophrenia or other related psychotic disorder; (2) occurrence of a first episode of psychosis between 1999 and 2005; (3) age at onset 15–45 years; (4) psychosis not of affective, organic or toxic type; (5) no report of an evident intellectual disorder; and (6) accurate current contact information. The search resulted in 108 potential cases who, by phone calls or home visits, were contacted: 37 declined to participate, 3 had passed away, 2 were out of town and 1 agreed to collaborate but the main caregiver was not available at the time. A relative, identified by each patient as his/her main caregiver/support, was invited to participate. The final sample included 65 patient–relative dyads; all participants signed a consent form describing the objective of the study, outline of the content of the interview, confidentiality agreement, understanding that participation is voluntary (with no economic compensation involved), and that they were free to withdraw at any time. Interviews were conducted from December 2008 to October 2009. No pilot study was performed given that the number of participants made it unfeasible.

## **Participants**

At the time of the assessment, none of patients was hospitalized. In terms of current DSM-IV-TR diagnoses, 44 patients had schizophrenia (16 paranoid, 3 disorganized, 1 catatonic and 24 residual) and 21 patients had other types of psychoses (9 schizoaffective, 7 delusional, 2 schizophreniform, 2 brief, and 1 not otherwise specified). Mean illness course was 6.9 years [standard deviation (SD) = 2.1]. Patients' current mean age was 36.2 years (SD = 9.9) and mean age at onset was 29.3 years (SD = 9.7). There were no significant sex differences for either current ( $t_{(63)} = -0.80$ ) or onset ( $t_{(63)} = -0.68$ ) age. For all patients, between 3 and 10 years had passed since their first psychotic episode. This range of time allows the inclusion of patients who have not been ill for a long time but have passed through the 'critical period' of psychosis (Birchwood 2000) when most significant decline occurs.

Forty-eight (73.8%) relatives were females. All relatives reported having contact with the patient at least once a week, and 58 (89.2%) lived with the patient. Relatives included 30 (46.2%) parents, 17 (26.2%) spouses, 7 (10.8%) siblings, 6 (9.2%) offspring and 5 (7.7%) other relatives (grandmother, aunt, nephew, mother-in-law and sister-in-law). Two of the relatives (3.1%) were illiterate, 38 (58.5%) had secondary or lower education (up to 9th grade), and the remaining 25 (38.5%) had partial/complete medium or higher education. Mean age of relatives was 48.7 years (SD = 16.5) and did not differ significantly by sex ( $t_{(63)} = -1.10$ ). Relatives' sex, age and educational level were not significantly related to any of the outcome measures.

## Measures

### Relatives' outcome

1. EE was measured with the Family Questionnaire (FQ) (Wiedemann *et al.* 2002, González-Blanch *et al.* 2010), a 20-item self-report instrument for measuring the EE status of relatives of patients with schizophrenia.
2. Burden was measured with the Caregiver Burden Interview (Zaritz *et al.* 1980, Alpuche-Ramírez *et al.* 2008). Although originally designed for caregivers of people with dementia, it is used with relatives of patients with schizophrenia (Hanzawa *et al.* 2008, Yusuf *et al.* 2009). It includes 22 items enquiring about relatives' relationships with the patient, physical and psychological well-being, finances, social life and expectations.
3. QoL was measured with the World Health Organization Quality of Life-BREF scale (WHOQOL-BREF) (Lucas 1998, The WHOQOL Group 1998, Skevington *et al.* 2004), a 26-item instrument applicable cross-culturally to assess four main domains of subjective QoL: physical health, psychological well-being, social relationships and satisfaction with the conditions of the immediate environment.

### Patient predictor factors

1. Patients' current clinical status was rated with the Positive and Negative Syndrome Scale (PANSS) (Kay *et al.* 1987, Peralta & Cuesta 1994, Fortune *et al.* 2005), widely used for the assessment of positive and negative symptoms, and general psychopathology.
2. Patients' current functional status was rated with the Global Assessment of Functioning (GAF) Scale (APA 2000), which rates overall functioning from 0 to 100.

### **Relative predictor factors**

1. Psychological distress was measured with the 28-item General Health Questionnaire (GHQ-28) (Goldberg & Hillier 1979, Lobo *et al.* 1986). This instrument assesses somatic symptoms, anxiety-insomnia, social dysfunction and depressive symptoms.
2. Illness perception was measured with the Illness Perception Questionnaire – Schizophrenia Carers Version (IPQ-SCV) (Barrowclough *et al.* 2001). Through 23-items relatives report on illness severity, its negative impact on psychological, social and economic functioning, its amenability to cure or control, and how chronic and/or fluctuating the illness is perceived to be. There are six subscales: consequences of illness for the patient, consequences of illness for the relative, control/cure of illness by patient and/or treatment, control/cure of illness by relative, chronic nature of illness and episodic nature of illness.

The FQ and GHQ-28 use a four-point scale, whereas the Caregiver Burden Interview, WHOQOL-BREF and IPQ-SCV use a five-point scale. From the initial review of clinical files, it was found that most patients and their relatives had a low educational level; this might have made it difficult for participants to respond self-report Likert-type scales, particularly if they were presented in different formats (i.e. four- and five-point scales). Therefore, in order to facilitate the interview to the participants, all scales were presented on a four-point scale, and items were read aloud by the interviewer with participants requested to respond by pointing at one of four drawn squares, from the smallest ('not at all' = 1) to the largest ('definitely yes' = 4).

### **Statistical analyses**

First, Pearson correlations were used to analyse the associations between each of the predictor and outcome variables. Next, a series of hierarchical regressions were computed to predict EE, burden and QoL using patient and relative factors. The primary goal of the regression analyses was to examine whether relatives' psychological distress and illness perception accounted for variance in the dependent variables over-and-above patient factors (symptom severity and functioning). The following steps were entered in all regression analyses. The PANSS total score was entered at step 1 to examine the variance accounted for by patient symptom severity. Patients' GAF score was entered at step 2 to examine variance accounted for by patient functioning. Relatives' total GHQ-28 was entered at step 3 to examine variance accounted for by relatives' psychological distress. The six IPQ-SCV subscales were entered as a block at step 4 to

examine the variance accounted for by relatives' perception of the patient's illness. The individual scale scores, rather than the total score, were used to test specific relations of the subscales with the dependent variables.

## Results

Descriptive data are presented in Table 1. EE and burden scores were generally low, as 83.1% and 93.8% of sample, respectively, scored below the 2.5 mid-point. QoL showed overall satisfactory levels, as only 7.7% of sample scored below the mid-point. EE was significantly related to both QoL ( $r = -0.27, P < 0.05$ ) and burden ( $r = 0.72, P < 0.001$ ), and these two were also significantly related to each other ( $r = -0.33, P < 0.01$ ).

**Table 1. Descriptive statistics for relatives ( $n = 65$ ) and patients ( $n = 65$ )**

Variable	Scale	Mean (SD)	Range	Cronbach's alpha
Relatives' outcome				
Expressed emotion	Family Questionnaire	1.9 (0.5)	1.2–3.0	0.84
Burden	Caregiver Burden Interview	1.8 (0.4)	1.1–3.0	0.82
Quality of life	WHOQOL-BREF	3.3 (0.5)	2.1–4.0	0.92
Patient predictor factors				
	PANSS	49.3 (16.0)	30–93	0.89
Clinical status	Positive symptoms	10.6 (4.1)	7–25	0.68
	Negative symptoms	12.5 (5.9)	7–30	0.83
	General psychopathology	26.2 (7.9)	16–48	0.76
Functional status	GAF	72.5	30–	–

<b>Variable</b>	<b>Scale</b>	<b>Mean (SD)</b>	<b>Range</b>	<b>Cronbach's alpha</b>
		(18.4)	100	
Relative predictor factors				
	GHQ-28	1.6 (0.5)	1.0–3.2	0.92
	Somatic symptoms	1.7 (0.7)	1.0–3.7	0.80
Psychological distress	Anxiety-insomnia	1.6 (0.7)	1.0–3.9	0.85
	Social dysfunction	1.9 (0.7)	1.0–3.6	0.85
	Depression	1.2 (0.6)	1.0–3.7	0.94
	IPQ-SCV	2.6 (0.4)	1.8–3.4	0.61
	Consequences-patient	2.6 (0.5)	1.0–3.4	0.31
Illness perception	Consequences-relative	2.3 (0.6)	1.0–3.8	0.38
	Control-cure of illness	3.0 (0.5)	2.0–4.0	0.15
	Control-cure by relative	2.7 (0.9)	1.0–4.0	0.39



Variable	Scale	Mean (SD)	Range	Cronbach's alpha
	Timeline-chronic	2.7 (1.1)	1.0–4.0	0.78
	Timeline-episodic	2.6 (0.9)	1.0–4.0	0.65

*PANSS, Positive and Negative Syndrome Scale; GAF, Global Assessment of Functioning; GHQ-28, 28-item General Health Questionnaire; IPQ-SCV, Illness Perception Questionnaire – Schizophrenia Carers Version.*

Predictor and outcome variables showed low to moderate correlations, although most of them were significant (Table 2). Patients' functional status was significantly associated to EE, burden and QoL, whereas patients' clinical status was significantly associated only to the first two. Relatives' psychological distress was the factor most consistently related to relatives' EE, burden and QoL across all dimensions. Negative illness perception dimensions were mostly related to EE and burden. From all illness perception dimensions, only the relatives' view of negative consequences of the illness for themselves was related to all three outcomes.

**Table 2. Pearson correlations between predictors (patient and relative factors) and relatives' outcome variables ( $n = 65$ )**

	Expressed emotion	Burden	Quality of life
Patient factors			
Patient clinical status			
PANSS	<b>0.47***</b>	<b>0.36**</b>	-0.17
Positive symptoms	<b>0.37**</b>	<b>0.24*</b>	-0.10
Negative symptoms	<b>0.40***</b>	<b>0.38**</b>	-0.17
General psychopathology	<b>0.45***</b>	<b>0.32**</b>	-0.18
Patient functional status			

	Expressed emotion	Burden	Quality of life
GAF	<i><b>-0.50***</b></i>	<i><b>-0.44***</b></i>	<i><b>0.30**</b></i>
Relative factors			
Psychological distress			
GHQ-28	<i><b>0.46***</b></i>	<i><b>0.46***</b></i>	<i><b>-0.74***</b></i>
Somatic symptoms	<i><b>0.45***</b></i>	<i><b>0.36**</b></i>	<i><b>-0.64***</b></i>
Anxiety-insomnia	<i><b>0.46***</b></i>	<i><b>0.41***</b></i>	<i><b>-0.54***</b></i>
Social dysfunction	0.21	<i><b>0.34**</b></i>	<i><b>-0.58***</b></i>
Depression	<i><b>0.31**</b></i>	<i><b>0.30**</b></i>	<i><b>-0.52***</b></i>
Illness perception			
IPQ-SCV	<i><b>0.38**</b></i>	<i><b>0.51***</b></i>	-0.11
Consequences-patient	0.24*	<i><b>0.32**</b></i>	-0.00
Consequences-relative	<i><b>0.35**</b></i>	<i><b>0.45***</b></i>	<i><b>-0.35**</b></i>
Control-cure of illness	-0.06	-0.11	0.28*
Control-cure by relative	0.25*	<i><b>0.30*</b></i>	0.02
Timeline-chronic	0.27*	<i><b>0.45***</b></i>	-0.19
Timeline-episodic	0.13	0.19	-0.05

1. \* $P \leq 0.05$ ; \*\* $P \leq 0.01$ ; \*\*\* $P \leq 0.001$

2. Medium effect sizes ( $r \geq 0.30$ ) in bold, large effect sizes ( $r \geq 0.50$ ) in bold and italics.

3. *PANSS, Positive and Negative Syndrome Scale; GAF, Global Assessment of Functioning; GHQ-28, 28-item General Health Questionnaire; IPQ-SCV, Illness Perception Questionnaire – Schizophrenia Carers Version.*

Note that for the hierarchical regressions the total PANSS and GHQ-28 scores were used because (1) specific hypotheses were not offered about the impact of each PANSS or GHQ-28 dimensions; (2) positive intercorrelations were found among the PANSS symptom dimensions (.54 to .73) and the GHQ-28 subscales (.21 to .75); and (3) each PANSS and GHQ-28 dimensions were similarly related to outcome variables (Table 1). Given the differential associations between illness perception dimensions and the outcome variables, all subscales were entered in the analysis.

Hierarchical regression for EE (Table 3) revealed that patients' clinical status and relatives' psychological distress significantly accounted for variance in EE. Neither patients' functional status nor any of the relatives' illness perception measures accounted for significant variance in the model.

**Table 3. Hierarchical regression for expressed emotion in relatives of patients with psychosis ( $n = 65$ )**

Step	Predictors	$\beta$	$\Delta R^2$	$P$
1	Patients' clinical status (PANSS total score)		0.216	<0.001
2	Patients' functional status (GAF)		0.041	0.069
3	Relatives' psychological distress (GHQ-28 Total score)		0.128	<0.001
	Relatives' illness perception (IPQ-SCV)		0.045	0.632
	Consequences-patient	0.061		0.620
	Consequences-relative	0.071		0.597
4	Control-cure of illness	-0.014		0.906
	Control-cure by relative	0.181		0.108
	Timeline-chronic	0.081		0.504

Step	Predictors	$\beta$	$\Delta R^2$	$P$
	Timeline-episodic	-0.047		0.672
	Total R <sup>2</sup>		0.430	<0.001

*PANSS, Positive and Negative Syndrome Scale; GAF, Global Assessment of Functioning; GHQ-28, 28-item General Health Questionnaire; IPQ-SCV, Illness Perception Questionnaire – Schizophrenia Carers Version.*

In terms of burden (Table 4), each of the four steps accounted for a significant increment in variance. Among the illness perception subscales, perception of controllability of illness by relative and chronicity accounted for variance over and above the other variables in the model.

**Table 4. Hierarchical regression for burden in relatives of patients with psychosis ( $n = 65$ )**

Step	Predictors	$\beta$	$\Delta R^2$	$P$
1	Patients' clinical status (PANSS total score)		0.132	0.003
2	Patients' functional status (GAF)		0.057	0.040
3	Relatives' psychological distress (GHQ-28 total score)		0.128	0.001
	Relatives' illness perception (IPQ-SCV)		0.190	0.005
	Consequences-patient	0.063		0.582
	Consequences-relative	0.232		0.066
	Control-cure of illness	-0.122		0.259
4	Control-cure by relative	0.265		0.013
	Timeline-chronic	0.272		0.018
	Timeline-episodic	0.003		0.977
	Total R <sup>2</sup>		0.507	<0.001

*PANSS, Positive and Negative Syndrome Scale; GAF, Global Assessment of Functioning; GHQ-28, 28-item General Health Questionnaire; IPQ-SCV, Illness Perception Questionnaire – Schizophrenia Carers Version.*

Patient functioning, relatives' psychological distress and relatives' illness perception accounted for significant increments in QoL variance (Table 5). Among relatives' illness perception subscales, both illness consequences for patients and relatives, as well as controllability of illness by patients/treatment accounted for significant variance.

**Table 5. Hierarchical regression for quality of life in relatives of patients with psychosis (n = 65)**

Step	Predictors	$\beta$	$\Delta R^2$	P
1	Patients' clinical status (PANSS total score)		0.030	0.165
2	Patients' functional status (GAF)		0.088	0.015
3	Relatives' psychological distress (GHQ-28 total score)		0.443	<0.001
	Relatives' illness perception (IPQ-SCV)		0.129	0.003
	Consequences-patient	0.188		0.041
	Consequences-relative	-0.259		0.011
	Control-cure of illness	0.247		0.005
4	Control-cure by relative	0.160		0.055
	Timeline-chronic	0.023		0.796
	Timeline-episodic	0.005		0.951
	Total R <sup>2</sup>		0.690	<0.001

*PANSS, Positive and Negative Syndrome Scale; GAF, Global Assessment of Functioning; GHQ-28, 28-item General Health Questionnaire; IPQ-SCV, Illness Perception Questionnaire – Schizophrenia Carers Version.*

Finally, note that the combination of the patient and relative predictors accounted for 43% to 69% of the total variance in the dependent variables.

## **Discussion**

In line with our third hypothesis, our most important finding was that relatives' psychological distress accounted for variance over-and-above patient variables in the prediction of EE, burden and QoL and that relatives' illness perception accounted for significant variance for perceived burden and poor QoL, over-and-above all of the predictors in the model. Relatives' burden was predicted by their perception of illness as chronic and the belief that the relative himself can influence the patient's illness. Relatives' perception of the consequences of illness for patients and themselves, and of the controllability of illness by the patient and/or treatment, predicted poor QoL.

Relatives' perception of illness as being under the control of the patient and/or treatment rather than under their own control reduces burden and favours QoL. This suggests that attribution of control to external factors is an important aspect when coping with having an ill relative, reducing self-blame and the weight of responsibility. Furthermore, it has been suggested that beliefs about the capacity of patient and treatment to control illness should ideally be considered as independent factors. Fortune *et al.* (2005) found that caregivers holding a strong belief that their relative could exert personal control over the psychosis tended to report more distress, while stronger beliefs in control by means of treatment was associated with less self-reported distress. Even though our sample included patients with no more than 10 years of illness, results showed that relatives' perception of illness as chronic predicted higher burden. Caregivers can be more pessimistic than patients regarding illness persistence, particularly those who are stressed (Kuipers *et al.* 2007). Results also showed that the QoL of caregivers is disrupted by their perception of illness as affecting their own lives as well as patients'. This underscores the involvement and empathy of caregivers towards their ill relative. Psychosis affects to a greater or lesser degree the lives of patients and also of their close ones. Families have an important role in patients' illness but, undeniably, they find themselves also in need of support.

Consistent with some previous studies, our first hypothesis was partly confirmed: overall patients' clinical and functional status was related to relatives' EE (Rascón *et al.* 2008) and burden (Parabiagli *et al.* 2007), but not to QoL (Möller-Leimkühler 2005). Initial research on EE viewed criticism and overinvolvement attitudes in families as threatens to a vulnerable patient, who in consequence relapsed. Alternatively, EE can be seen as a reflection of disturbances in the transactional patterns of the entire family system. The patient might have shown early temperamental, cognitive or behavioural disturbances as signs of liability to psychiatric disorders. In turn, other family members, due to their own personality and psychological features, could be prone to react with frustration, anxiety, criticism or overprotective guilt. The patient is influenced by these attitudes, and his/her own behaviour feeds back on the family. Thus, a tense family dynamic is established, what is likely to trigger relapse (Miklowitz 2004). It

is remarkable that even though on average patients showed a relatively low level of psychopathology, clinical and functional status were still related to their relatives' burden. A relative might feel particularly overwhelmed, confused or distressed by patient's (even) mild residual symptoms and poor functioning, wondering if the patient is really getting better, and how much longer it will take to recover. The associations of burden with the relatives' perception of illness as chronic and with the magnitude of the consequences of the illness for themselves and for the patients support this interpretation, suggesting that relatives might suffer from a constant state of alarm, which extends beyond symptom stabilization in the patient.

Results also confirmed, to some extent, our second hypothesis, that relatives' psychological distress and negative illness perception would relate to high EE and burden and to poor QoL. Even though relatives' psychological distress was strongly related to their EE, burden and QoL levels, a causal relationship cannot be concluded in either direction. Relatives might react negatively because of their own temperamental disturbances, enhanced by the strain of taking care of an ill relative (Miklowitz 2004). Psychological distress might well reflect a vulnerability to psychopathology shared among parents, siblings and offspring. Signs of disturbance under the clinical threshold in relatives should be addressed in order to prevent a transition to psychopathology and to enhance a more stable family environment for the patient. Overall negative illness perception was related to EE and burden, but not to QoL. Unlike EE and burden, QoL involves relatives' life dimensions beyond their relationship with the patient, and that might be reflected in a less consistent association with dimensions of illness perception. Interestingly, the perception of the magnitude of the illness consequences for the relative was related to high EE and burden, and to low QoL. Families cannot be seen exclusively as a causal factor of illness to be controlled; illness of a family member affects the other members as well, particularly the one who assumes the role of main caregiver.

Overall, this sample of relatives of patients with psychosis did not show high levels of EE and burden, or severely affected QoL. Studies with similar results have proposed that one explanation for this could be that relatives, in some way, can become habituated to their situation (Foldemo *et al.* 2005). However, the inclusion in our sample of relatives of both patients who still suffer severe or subtle symptoms as well as patients who have improved and/or never relapsed (i.e. residual schizophrenia, schizophreniform and brief psychotic disorders) might account for these favourable results. Moreover, the cultural background of our sample is an important fact to take into consideration. Research has found that families of patients with schizophrenia with a Mexican background are less critical of their ill relatives than Caucasians (Kopelowicz *et al.* 2002) and exhibit low EE levels (Kopelowicz *et al.* 2006, Dorian *et al.* 2008). Mexican-American caregivers seem particularly accepting of their relative's illness, showing non-blaming and low aversive responses to patient's behaviour (Dorian *et al.* 2008). Which underlying mechanisms facilitate tolerance and acceptance of illness in Mexican families and which might affect their psychological well-being, are worth exploring, for further

implementation or emphasis in support programmes and interventions designed for this population living at home or abroad.

The present study contributed to our understanding of psychological well-being in relatives of Mexican patients with psychosis. Relatives' psychological distress and illness perception dimensions stood over patients' clinical and functional status as significant predictors of both burden and QoL. This is an important aspect to take into account not only for professionals of this country but also for those working with immigrant populations of Mexican (and other culturally similar) origin. Furthermore, our results underscore the relatives' need of support to overcome their own distress and concerns about the illness, which could benefit the psychological well-being of both patients and relatives. Given that nurses and other front-line health-care providers who frequently interact with patients and their caregivers are in a unique position to identify needs and guide interventions, these findings might be particularly relevant to their professional practice.

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### **Declaration of interest**

None.

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