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ORIGINAL PAPER

Impact of psychosis on Portuguese caregivers: a cross-cultural exploration of burden, distress, positive aspects and clinical-functional correlates

Manuel Gonçalves-Pereira · Miguel Xavier · Bob van Wijngaarden · Ana L. Papoila · Aart H. Schene · José Miguel Caldas-de-Almeida

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Abstract

Purpose Further cross-cultural comparisons are needed on caregiving consequences of chronic psychotic disorders. The EPSILON study (European Psychiatric Services: Inputs Linked to Outcome Domains and Needs) involved five European countries, but not Portugal. We aimed to analyse the impact of severe mental illness in a Portuguese sample and to provide support to comparisons with some of the EPSILON results, focusing on the north-European Dutch centre.

Methods We studied 108 caregiver-patient dyads by a consecutive sampling of people with schizophrenia-spectrum disorders in psychiatric outpatient services. Relatives' assessments included the Involvement Evaluation Questionnaire, European version (IEQ), the 12-item General Health Questionnaire (GHQ-12); the loss, stigma and positive aspects' subscales of the Experience of Caregiving Inventory, and the Social Network and Family Coping Questionnaires. Patients were assessed regarding symptoms, disability and global functioning.

Results Caregiving rewards and negative consequences co-existed. On the IEQ, 49.1 % reported negative consequences and rank order of domain scores was *worrying* > *urging* > *tension* > *supervision*. More than one-third of caregivers were psychologically distressed according to GHQ screenings. Involvement Evaluation Questionnaire scores were correlated with caregivers' distress, stigma, loss, patient's involvement and other ways of coping, and patients' variables. Some of these failed to be included in a regression model.

Conclusions Many of these Portuguese caregivers were at risk regarding burden and psychological distress. In comparison with other European samples, caregiving arrangements and assessments were typical of Mediterranean countries, as Italy or Spain. All IEQ scores were significantly higher than those in the Netherlands. On account of small numbers, caution is needed in the interpretation of associations.

Keywords Schizophrenia · Family member · Caregiver · Cross-cultural psychiatry

Introduction

Schizophrenia and related psychotic disorders may impose a heavy burden on the life of patients and their families [1]. Conceptual models evolved from a narrow focus on burden alone to a wider interest in the dynamics of caregiving and its relations to clinical, social and cultural variables [2–5].

Psychosis has been found to affect caregivers in complex ways. Disability, impaired functioning and symptom severity are predictors of consequences for caregivers

M. Gonçalves-Pereira (✉) · M. Xavier ·
J. M. Caldas-de-Almeida
CEDOC, Departamento de Saúde Mental,
Faculdade de Ciências Médicas, Universidade Nova de Lisboa,
Campo dos Mártires da Pátria, 130, 1169-056 Lisbon, Portugal
e-mail: gpereira.sm@fcm.unl.pt

B. van Wijngaarden
Netherlands Institute of Mental Health and Addiction,
Utrecht, The Netherlands

A. L. Papoila
Department of Biostatistics and Informatics,
Faculdade de Ciências Médicas, Universidade Nova
de Lisboa and CEAUL, Lisbon, Portugal

A. H. Schene
Department of Psychiatry, Academic Medical Center,
University of Amsterdam, Amsterdam, The Netherlands

[6, 7]. Moreover, the characteristics of caregivers themselves, and of their relationship to patients, are important determinants [5]. For instance, caregiver's age, being a parent, or the number of hours spent in caregiving may be related to higher burden [8]. Good social support and adaptive coping may be protective (e.g., problem-solving seems more effective than avoidance or other emotional coping strategies) [1, 3]. Finally, regarding the well-known association between caregiver burden and distress, the direction of causality remains a matter of debate [3, 5, 8].

International comparisons have also been conducted in the field of caregiving [3–5, 9]. A need remains, however, to improve the description of caregiving arrangements in countries where research has not been extensive so that cross-national and cross-cultural comparisons may be facilitated.

In Portugal, mental health services remain insufficient, in terms of accessibility, equity and quality of care. Inpatient care continues to eat up the majority of resources (83 % of the total national mental health budget), while community services are still underdeveloped [10]. A reform of mental health services is under implementation since the launching of a new Mental Health Plan in 2007, aiming to promote a modern community model of organization and delivery of care [10]. At a national level, the family still represents a major resource for the severe mentally ill, although a sociological trend now emerges towards the weakening of some family ties. Early explorations of caregiver strain in relatives of chronic psychotic outpatients suggested levels of need which were not met by the current standards of community care. This first Portuguese study on the consequences of caregiving replicated some international findings, namely that patients' disability and caregivers' distress were associated to the burden of care [11].

Within this national context, a Portuguese centre took part in the BIOMED I-financed European prospective study on the relations of family burden and coping with social and clinical factors in schizophrenia [3, 4, 12]. In that study, burden was measured with the Family Problems Questionnaire (FPQ) [3]. In all the centres, higher levels of burden were related to less adaptive coping and to lower levels of social support [3].

A second European study was the EPSILON study (European Psychiatric Services: Inputs Linked to Outcome Domains and Needs). This study involved three countries from the North (England, the Netherlands and Denmark) and two from the South of Europe (Italy and Spain) [13]. The Involvement Evaluation Questionnaire-European version (IEQ-EU) [14, 15] was chosen to evaluate caregiver issues. The IEQ had been appointed at an ENMESH (European Network for Mental Health Services Evaluation) conference in 1994 as the most favoured instrument to be used in Europe, due to known psychometric properties. The IEQ proved to be a valid and reliable instrument in all five countries [14] and highlighted differences between countries on the caregiver domains of interpersonal tension, worrying, urging and supervision [15]. For the moment it is the most widespread instrument regarding caregiving assessments in severe mental illness [16].

In this paper we present the results of a study on family burden that was based, for the sake of comparability, on the methodology used in the EPSILON surveys (including the IEQ-EU). To ensure a more comprehensive approach, we added detailed evaluations of caregivers' social and personal resources and patients' assessments including both clinical symptoms and disability, as in the previous international study including a Portuguese sample [3].

The aims of our study were (1) to comprehensively analyse the impact of severe mental illness in a Portuguese sample, conducting cross-sectional analyses of associations of the aforementioned caregiving-related variables; (2) to compare Portuguese IEQ-EU findings with those in other European countries, in particular with those in the Netherlands, a typical northern country and origin of the IEQ. We hypothesised that our results would differ from those previously found in the Netherlands, by evidencing closer caregiving relationships and higher levels of IEQ-EU negative consequences.

Methods

Design and participants

This is a study of the baseline sample of the "FAmilies of people with PSychotic disorders" (FAPS) survey [17], in a cross-sectional analysis.

The sample was drawn from a total of 115 patients with ICD-10 Diagnostic Criteria for Research (DCR) of schizophrenia (F20), schizo-affective (F25) or delusional disorder with atypical schizophreniform characteristics (F22.8). These were outpatients who contacted one of three mental health facilities, during a 6-month period. There were two mental health services, the Department of Psychiatry and Mental Health of *Hospital S. Francisco Xavier* (a community oriented service in a low-middle class suburban area near occidental Lisbon, with a population of 250,000) and *Clínica Psiquiátrica de S. José* (a non-profit psychiatric facility attending low-middle class people, with no defined catchment area, in central Lisbon). Some patients were on professional rehabilitation programmes at ARIA, *Associação de Reabilitação e Integração Ajuda* (a non-profit associative organization). Exclusion criteria were coexisting learning disability, organic disorders and inpatient treatment episodes in the 2 months previous to assessments, as required for using the IEQ-EU and other caregiving measures in community settings. Diagnoses were made by experienced psychiatrists in each service, on the basis of chart review and, if indicated, consensus discussion. All these clinicians had been trained to provide valid and reliable ICD-10 DCR diagnoses.

Primary caregivers, all of them family of the patient, were approached. Refusals to participate came from four patients and from three caregivers. So the final sample was composed of 108 patient-caregiver dyads (63 from *Hospital S. Francisco Xavier*, 28 from *Clínica de S. José* and 17 from ARIA). Caregivers could choose between appointments either at the mental health facilities or at home.

Measures

Caregivers were comprehensively assessed on caregiving consequences, psychological distress, social network and coping. The time frame was the previous 4 weeks.

The IEQ-EU [14, 15] was used to measure caregiving impact. It is an 81-item questionnaire (full version), in which 31 core items related to caregiving consequences are scored for research use on Likert scales from 0 (= never) to 4 (= always or almost always). Twenty-seven of these core items may be summarised in four subscales, based on factor analysis (two items load on two subscales): worrying (6 items), urging (8 items), tension (9 items) and supervision (6 items). A 27-item total score can also be computed [15]. The full modular version which was used additionally provides data on demographics and clinical aspects, on the impact of illness on finances, on general health and on consequences for children.

A first version of the IEQ had been translated into Portuguese and tested, including for construct validity [11]. Later, the psychometric properties of the IEQ-EU Portuguese translation were documented, including ecological, face and content validity issues and factorial validation. As for internal consistency, Cronbach's alphas ranged from 0.71 to 0.87 in the IEQ-EU scales (total score and the four domains). Test–retest reliability was above 0.80 concerning the same scores [18].

In summary, the IEQ-EU is the most widely validated and used questionnaire in this field [16]. This allows for extensive international comparisons regarding the levels of family burden. Also the Portuguese version of the IEQ-EU was proved to be valid and reliable [18].

The IEQ-EU includes, as one of its modules, the 12-item version of the General Health Questionnaire (GHQ-12), for general psychological distress [19]. The GHQ-12 may be scored in different ways. Summing the number of items on which the respondent negatively deviates from his/her usual self, the GHQ standard score is obtained (total range 0–12). However, other methods may be used, as the 'Likert GHQ', obtained by scoring each item response from 0 to 3 (total range 0–36). Regardless of the method, higher scores mean higher distress.

The GHQ can also be used as a screening test for psychiatric morbidity in non-psychiatric clinical settings, adopting cut-offs to define "GHQ caseness". We followed a usual case-definition for culturally similar populations (≤ 2 = no case; ≥ 3 = case, using the GHQ standard 0–12 score) [20]. However, reports of mean GHQ-12 standard scorings higher than 2.7 in a similar Portuguese sample [21] led us to also to use the 3/4 cut-off (≤ 3 = no case; ≥ 4 = case) as an alternative, following the GHQ Manual suggestion [19]. A GHQ-12 Portuguese translation is available from the publisher [19].

Relatives were also assessed with another popular instrument measuring caregiving experiences, the *Experience of Caregiving Inventory* (ECI) [22]. The ECI is a 66-item questionnaire, providing information on negative (ten subscales) and positive aspects of caregiving (two subscales, namely positive personal experiences and good aspects of relationship). The ECI was chosen as a second instrument for the assessment of caregiving because of the fact that positive aspects could be also assessed, along with stigma and loss. These are not covered by the IEQ. We report results of the stigma (5 items) and loss (7 items) negative subscales, and of the positive aspects subscales (which may be summed in a 14-item total positive score). Items are scored on 5-point Likert scales, from 0 (= never) to 4 = [(nearly) always]. The Portuguese ECI version was developed by the first author of this paper, according to a standard translation-back translation procedure. Its acceptability and construct validity were reported [23, 24].

Caregivers' social network was assessed with the *Social Network Questionnaire* (SNQ) [3], with 15 items including information on social contacts, practical and emotional support. Coping was measured with the *Family Coping Questionnaire* (FCQ) [3], with 34 items evaluating different forms of coping in caregiving: seeking disease-related information; positive communication with the patient; maintenance of own social interests; use of coercive, avoidance or resignation strategies; stimulating patient's social involvement; use of alcohol; collusion; searching spiritual relief; and talking with friends. Both SNQ and FCQ are scored on 4-point Likert scales, higher scores meaning higher levels of social support, or frequency of use of the corresponding coping strategy. Validity and reliability of the corresponding Portuguese translations are good [12].

Patients' symptoms were assessed with the extended (24 item) *Brief Psychiatric Rating Scale* (BPRS) [25–27]. The WHO *Disability Assessment Schedule* II (DAS) [28] and the *Global Assessment of Functioning Scale* (GAF) [29] were also used. The assessments were made by research assistants, all of them mental health professionals who were trained in the use of these instruments. The BPRS is a widely used measure for severe psychopathology. Global Assessment of Functioning Scale total scores reflect overall psychosocial functioning, with clinical and social functioning determinants. Brief Psychiatric Rating Scale and GAF had been used in the EPSILON studies. Regarding DAS assessments, we only report on the single-item global evaluation section.

Finally, additional information on clinical or social data was collected in interviews (e.g., Graffar social class, with five categories from low (V) to high (I) [30]).

Ethical issues

The protocol was approved by ethical committees at the three aforementioned mental health facilities. Informed consent was obtained from participants (caregivers and patients).

Statistical analysis

Descriptive statistics and nonparametric tests were used as required. Patient and caregiver characteristics are presented as frequencies and percentages for categorical data, and as mean or median, standard deviation (SD), range and minimum/maximum values for continuous variables.

When a linear association was present between ordinal variables, correlations were assessed with Spearman's coefficients.

Generally IEQ scale scores are skewed. Only in relatively few cases caregiver consequences happen regularly, often or always. For this reason, the original authors [5] constructed dichotomised scores, assuming that if an event happens never, or sometimes, there are no consequences (≤ 1 = non-event), but when an event happens regularly, often or (almost) always, there are consequences (≥ 2 = event).

To study the influence of the known caregiving-related variables, logistic regression analyses were carried out using the IEQ-EU total score as dependent variable, applying a similar dichotomisation to the mean total score of each participant (≤ 1 = non-event vs. >1 = event, or presence of caregiving consequences) [31]. We preferred this approach to multiple regression analyses on the IEQ-EU ordinal scores, as normality of the data could not be assumed here and because dichotomisation was more clinically sound. Our use of regression procedures does not imply the search for a causal model, but only the possibility of controlling for confounders. Covariates were selected from patients' clinical characteristics (BPRS, DAS and GAF scores); caregivers' demographic and clinical characteristics (gender, age, civil status, relationship between patient and caregiver); objective burden characteristics (hours and days of contact between patient and caregiver, cohabitation); loss, stigma or positive ECI subscales; caregivers' social network (SNQ scores); coping (FCQ scores); and psychological distress (GHQ standard method scores). Covariates were entered in the regression model using a stepwise procedure, and odds-ratios (OR), 95 % CI and p values (Wald) were calculated.

The significance level of $\alpha = 5$ % was chosen. All data were entered and analysed using the Statistical Package for the Social Science for Windows 15.0 (SPSS, Inc.).

Results

The results of patients' and caregivers' assessments are presented in Tables 1 and 2, along with data on demographics and caregiving arrangements.

General description of the sample and patients' assessments

Regarding the 108 index patients (Table 1), most were males, white Europeans, single or divorced and had no active occupation. There was a distribution along social categories with Graffar middle-classes II and III overrepresented in the sample (65.7 %). Diagnosis was schizophrenia in the majority of cases (88.9 %), mainly paranoid type, F20.0 (76.9 %). Three patients had delusional disorders, F22.8 (2.8 %) and nine had schizo-affective disorders, F25 (8.3 %). Most of these patients were young adults (mean age 21.6; SD 6.2 years) at the beginning of their chronic illness, while their current age was mean 35.9 (SD = 10.0) years. At the moment of evaluation, they had a median number of two previous admissions, a minority of which had been involuntary. The large majority was living in the community for a considerable length of time. These patients had a non-negligible level of symptoms, as readable from BPRS assessments, especially positive and depression/anxiety symptoms. DAS ratings were of poor adjustment, or lower, for 51.9 % of the sample. Global Assessment of Functioning Scale scores accordingly reflect some heterogeneity in clinical and functional characteristics of patients, along with a proportion of severe cases in the sample.

In the corresponding 108 caregivers (Table 2), mean age was 60.1 (SD 12.1) years. Most were females, married, parent of the patient, and living with him/her with a substantial personal contact (e.g., 74.3 % with a mean weekly contact of >32 h). Only 2.8 % of caregivers lived alone. More than half reported somatic illness (mainly cardiovascular conditions) and almost one-third reported previous psychiatric illness (depression or anxiety). A large majority

Table 1 Patients' demographics and clinical-functional assessments

Demographics	
Age (years)	
Mean (SD)	35.9 (10.0)
Range	20–65
Gender, *n* (%)	
Male	83 (76.9 %)
Female	25 (23.1 %)
Occupation, *n* (%)	
Employed/student	24 (22.2 %)
Sheltered work	20 (18.5 %)
Unemployed/pension	64 (59.3 %)
Social class (Graffar)	
I	6 (5.6 %)
II	31 (28.7 %)
III	40 (37.0 %)
IV	20 (18.5 %)
V	11 (10.2 %)
Ethnicity	
White European	100 (92.6 %)
Other	8 (7.4 %)
Marital status	
Married	10 (9.3 %);
Single	89 (82.4 %)
Divorced	9 (8.3 %)
Age at beginning of illness (years)	
Mean (SD)	21.6 (6.2)
Range	11–45
Time since diagnosis (years)	
Mean (SD)	14.3 (9.4)
Median	11.0
No of inpatient admissions	
Mean (SD)	2.3 (2.4)
Median	2.0
Range	0–16
Involuntary admissions, median (range)	0 (0–4)
Time living in community since discharge (months), median (min–max); *n* = 92	24.0 (2–302)
Clinical-functional assessments	
BPRS mean scores	
Total	1.8 (0.5); 1.7
Positive symptoms	2.0 (1.0); 1.8
Negative symptoms	1.6 (0.6); 1.4
Maniac excitement	1.4 (0.5); 1.3
Depression/anxiety	1.9 (0.7); 1.8
DAS global evaluation (total score)	2.5 (0.9); 3.0
DAS global evaluation (categories)	
(0) Very good adjustment	1 (0.9 %)
(1) Good adjustment	13 (12.0 %)
(2) Fair adjustment	38 (35.2 %)
(3) Poor adjustment	44 (40.7 %)
(4) Very poor adjustment	11 (10.2 %)
(5) Severe maladjustment	1 (0.9 %)
GAF score	52.6 (13.8); 51.0

N = 108, unless stated otherwise; Graffar class: I (high), II (medium/high), III (medium), IV (medium/low), V (low); for all questionnaire scores, "mean (SD); median", are presented, while *mean scores* represent raw totals per number of items; BPRS items are coded into seven categories (1 = no symptoms, to 7 = extremely severe) [25, 26], and DAS global evaluation in six categories (0 = very good adjustment, to 5 = severe maladjustment) [28]; GAF scores are 0–100, higher scores meaning better functioning [29]

SD standard deviation, *BPRS* Brief Psychiatric Rating Scale, *DAS* Disability Assessment Schedule II, *GAF* Global Assessment of Functioning

(82.1 %) completed the self-assessment questionnaires, and 13.9 % were interviewed on account of limited literacy. No questionnaires had to be discarded from analysis.

Caregiver assessments

On the IEQ-EU, 53 (49.1 %) participants reported caregiving consequences (IEQ mean total score >1). Scores were higher in the *worrying* domain. Almost half of these caregivers (45.4 %) reported they had to spend more than 75 euros a month on account of their patient's illness. Ten patients (9.3 %) had children less than 16 years of age. Few consequences were reported for these children: for instance, having to stay with other relatives or friends was reported in two cases, while there was no mention of having to miss school on account of the parents' illness.

Psychiatric morbidity in caregivers [GHQ-caseness or GHQ(+)] was found in 47 cases (43.5 %), using the 2/3 cut-off GHQ(+) for the conventional method. The adoption of the alternative 3/4 cut-off would lower this figure to 40 GHQ(+) caregivers (37.0 %). Regarding these symptoms of distress, 36 participants (33.3 %) reported being helped by general practitioners and 13 (12.0 %) by mental health professionals.

Results on ECI, SNQ and FCQ assessments are presented in Table 2. Social Network Questionnaire and FCQ results were higher regarding affective support, and coping through spirituality, positive communication and social involvement (patient or own's).

Bi and multivariable analysis

Correlations between IEQ-EU scores and other caregivers' scores (GHQ, ECI, SNQ, and FCQ) and patients' assessments (BPRS, DAS, and GAF) are shown in Table 3 for coefficients with absolute value higher than 0.2. Focusing on associations

Table 2 Caregivers' demographics and clinical-functional assessments

Demographics	
Age (years)	
Mean (SD)	60.1 (12.1)
Range	25–86
Gender	
Male	15 (13.9 %)
Female	93 (86.1 %)
Occupation	
Employed/housewife	65 (60.2 %)
Retired/pension	43 (39.8 %)
Monthly net income, mean (SD)	4.0 (1.5)
Marital status	
Married	64 (59.3 %)
Single	7 (6.5 %)
Divorced	17 (15.7 %)
Widowed	20 (18.5 %)
Living situation	
With spouse/children	95 (87.9 %)
With others	10 (9.3 %)
Alone	3 (2.8 %)
Relationship to patient	
Mother/father	83 (76.9 %)
Sibling	9 (8.3 %)
Partner	6 (5.6 %)
Other relative	10 (9.3 %)
Lives with patient?	
Yes	94 (87.0 %)
Relationship characteristics	
Mean weekly contact > 32 h	52 (74.3 %)
Hours of personal contact, mean (SD)	5.4 (1.3)
No. days lived together	
Mean (SD)	23.3 (10.1)
Median	28.0
Reported somatic illness?	
Yes	60 (55.6 %)
Reported psychiatric illness?	
Yes	33 (30.6 %)
Clinical-functional assessments	
IEQ-EU mean scores	
Tension	0.9 (0.6); 0.7
Supervision	0.4 (0.6); 0.2
Worrying	2.2 (0.9); 2.2
Urging	1.0 (0.8); 0.9
Sumscore	1.1 (0.6); 1.0
GHQ-12 scores	
Conventional GHQ method	3.3 (3.7); 2.0
Likert method	14.0 (6.5); 12.5
ECI scores	
Stigma	4.7 (3.9); 4.0
Loss	10.9 (4.1); 11.0
Positive personal experiences	16.9 (7.0); 18.0
Good aspects of relationship	13.7 (3.8); 14.0
Total positive score	30.7 (8.8); 32.0
SNQ mean scores	
Social contact	2.2 (0.7); 2.0
Practical support	3.0 (1.0); 2.0
Emotional support	3.1 (0.8); 3.2
FCQ mean scores	
Information	2.1 (1.0); 2.0
Positive communication	3.0 (0.7); 3.0 ($n = 106$)
Maintenance of social interests	2.6 (0.8); 3.0
Coercion	1.8 (0.7); 1.6
Avoidance	1.3 (0.6); 1.0
Resignation	2.4 (0.8); 2.3
Patient's social involvement	2.8 (1.0); 3.0
Use of alcohol	1.3 (0.7); 1.0
Collusion	1.9 (1.0); 1.7 ($n = 82$)
Spiritual help	3.1 (1.1); 4.0 ($n = 100$)
Talking with friends	1.9 (0.1); 2.0

$N = 108$, unless stated otherwise; monthly net income is coded into six range scores in item 14 of the IEQ-EU (1, minimum, to 6, maximum); hours of personal contact are coded into six range scores (1 = less than 1 h a week, to 6 = more than 32 h a week); for all questionnaire scores, "mean (SD); median", are presented, while *mean scores* (IEQ-EU, SNQ, FCQ) represent raw totals per number of items

SD standard deviation, *IEQ-EU* Involvement Evaluation Questionnaire, European version, *GHQ* General Health Questionnaire, *ECI* Experience of Caregiving Inventory, *SNQ* Social Network Questionnaire, *FCQ* Family Coping Questionnaire

of moderate or higher strength, IEQ total, and tension and worrying subscale scores were positively related to the GHQ conventional or Likert scores ($r_s \geq 0.45$, $p < 0.001$, for all corresponding correlations). IEQ total score and tension score were slightly less associated with ECI stigma and loss (r_s ranging from 0.35 to 0.38, $p < 0.001$, for all corresponding correlations). Moderate positive correlations (r_s ranging 0.42 to 0.51, $p < 0.001$) were obtained between some IEQ scores and some coping strategies of the non-adaptive kind: IEQ total and FCQ coercion, or resignation; IEQ tension and FCQ coercion, avoidance, or resignation. But correlations of the same level were also found between IEQ total, or urging, and FCQ patient's social involvement. There was no evidence of association between IEQ scores and the positive aspects of caregiving. There was an association between IEQ total score and BPRS total ($r_s = 0.43, p < 0.001$) and positive symptom ($r_s = 0.41$, $p < 0.001$) scores, and an inverse association of

Table 3 Correlations between IEQ scores and other caregivers and patients assessments

Scores	Tension	Supervision	Worrying	Urging	IEQ sumscore
GHQ standard	**0.55*****	0.27**	**0.47*****	0.32**	**0.51*****
GHQ Likert	**0.56*****	0.31***	**0.45*****	0.32**	**0.49*****
ECI stigma	**0.38*****	0.29**	0.27**	0.33**	**0.38*****
ECI loss	**0.37*****		0.31**	0.23*	0.35***
FCQ coercion	**0.51*****	**0.38*****	0.32**	0.32**	**0.46*****
FCQ avoidance	**0.47*****	0.31**	0.33***	0.23*	**0.38*****
FCQ resignation	**0.49*****	0.31**	**0.36*****	0.32**	**0.45*****
FCQ patient's social involvement	0.24*		**0.36*****	**0.47*****	**0.42*****
FCQ use of alcohol	0.26**		**0.36*****	0.29**	0.35***
FCQ collusion	0.24*				
FCQ talking with friends	0.23*		0.32**	0.25**	0.34***
BPRS total	**0.38*****	0.28**	**0.35*****	**0.37*****	**0.43*****
BPRS positive symptoms	**0.36*****	0.27**	0.32**	0.34***	**0.41*****
BPRS manic excitement	0.34***	0.25*	0.28**	0.31**	**0.37*****
DAS global	0.34***		0.29**	0.24*	0.32*
GAF	**−0.46*****	−0.28**	**−0.36*****	**−0.36*****	**−0.46*****

BPRS Brief Psychiatric Rating Scale, *DAS* Disability Assessment Schedule II, *GAF* Global Assessment of Functioning, *GHQ* General Health Questionnaire, *ECI* Experience of Caregiving Inventory, *SNQ* Social Network Questionnaire, *FCQ* Family Coping Questionnaire

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; bold type indicates correlations >0.35; correlations are indicated by Spearman's coefficients

the IEQ total, and tension, with GAF scores ($r_s = -0.46$, $p < 0.001$, in both cases).

The logistic regression analysis was conducted on dichotomised IEQ total scores using the above covariates from bivariable analysis (among other independent variables, selected from univariate findings as described in Methods). Seven variables could be fitted in the final regression model (Table 4): patients' disability (DAS > 2—"poor" adjustment or higher disability level); caregivers' civil status (non-married); stigma (ECI); social network contacts and lower emotional support (SNQ); and coping (FCQ) by means of patient's social involvement or coercion. However, the impact of some co-variables is not likely to be stable because of the relatively small sample size.

Comparison to a Dutch sample

Regarding our second aim of providing support to comparisons with results on the IEQ-EU use in other countries, we undertook a comparison with the Amsterdam centre results in EPSILON ($n = 36$) [15].

This Lisbon patient sample ($n = 108$) included a higher proportion of male (76.9 vs. 66.7 %; $p = 0.014$) and single (82.4 vs. 63.9 %; $p < 0.001$) patients, all of them living in domestic accommodations (vs. 75 % in Amsterdam; $p < 0.001$). In Lisbon, the number of prior inpatient admissions were lower (mean 2.3 SD 2.4 vs. mean 3.6 SD 2.8; $p = 0.007$). Brief Psychiatric Rating Scale and GAF scores were similar (mean 1.8 SD 0.5 vs. mean 1.6 SD 0.4

Table 4 Logistic regression on IEQ-EU dichotomised total scores

Covariates	OR	CI 95 %	Wald	*df*	*p* (Wald)
Disability, DAS	5.60	1.55–20.19	6.92	1	0.009
Caregiver's civil status	3.81	1.13–12.89	4.64	1	0.031
ECI stigma	1.28	1.08–1.51	8.18	1	0.004
SNQ social contact	3.25	1.22–8.66	5.56	1	0.018
SNQ affective support	0.29	0.11–0.81	5.56	1	0.018
FCQ coercion	2.88	1.23–6.75	11.32	1	0.015
FCQ patient's social involvement	4.60	1.89–11.19	5.92	1	0.001

$n = 108$; number of events (IEQ-EU > 1) = 53 (49.1 %); regarding categorical independent variables, reference categories were 'DAS $\leq$ 2' (fair adjustment or higher levels) and 'married'

df degrees of freedom

for mean BPRS totals, $p = 0.278$; and mean 52.6 SD 13.8 vs. mean 56.3 SD 12.3 for GAF, $p = 0.135$).

The caregivers in the Lisbon sample had a higher age (mean 60.1 SD 12.1 vs. mean 50.9 SD 12.4; $p < 0.001$) and monthly net income (mean 4.0 SD 1.5 vs. mean 3.2 SD 1.4; $p = 0.004$). We also found a higher proportion of women caregivers (86.1 vs. 63.9 %; $p < 0.001$); more were married (59.3 vs. 47.2 %; $p = 0.106$), more lived with spouse or children (87.9 vs. 66.7 %; $p < 0.001$), and more were mother or father of the patient (76.9 vs. 44.4 %; $p < 0.001$). A much higher proportion of caregivers were living with their relative with psychosis compared with the Amsterdam ones (87 vs. 27.8 %; $p < 0.001$). This trend was reflected, for the month previous to assessments, in a higher number of days lived together (mean 23.3 SD 1.3 vs. mean 8.4 SD 12.9; $p < 0.001$), and hours of personal contact according to the IEQ range scores from 1 (= less than 1 h a week) to 6 (= more than 32 h a week) (mean 5.4 SD 1.3 vs. mean 3.2 SD 2.0; $p < 0.001$).

On the IEQ-EU, mean (SD) scores were higher in the Lisbon sample. This regarded the total score: 28.85 (15.20) versus 14.81 (12.90), and domain scores: *worrying* 13.30 (5.36) versus 5.75 (4.82), *urging* 7.93 (6.10) versus 5.00 (5.78), *tension* 7.61 (5.65) versus 3.54 (3.31), and *supervision* 2.38 (3.57) versus 1.11 (2.23). All these differences regarding the IEQ-EU results were highly significant ($p < 0.001$).

Discussion

Main findings in a Portuguese population of caregivers

The aims of this study were twofold: (1) to analyse the impact of severe mental illness on Portuguese caregivers and (2) to compare Portuguese and Dutch results on the IEQ-EU.

Regarding the first aim, our study allows for a grasp of caregiving experiences in chronic psychosis, within the context of public or non profit south-European mental health services. This is the first study to comprehensively describe a Portuguese sample of more than one hundred of such patient-caregiver dyads (through the assessment of patients' clinical and functional variables, and of the corresponding caregivers' burden, distress, positive aspects of caregiving, social network and coping strategies).

Patients' BPRS, DAS and GAF scores reveal the existence of a low-moderate level of symptoms and of a more severe level of disability and ill-functioning ability. Most caregivers and patients shared the same household, and high levels of personal contact were reported, which is the usual situation in Portugal. In summary, considering demographics, clinical characteristics and caregiving arrangements, our sample may well be representative of Portuguese populations [3, 11, 12, 24].

Caregiver burden was evidenced in IEQ-EU findings (almost half of the sample reporting consequences in the total scale), as well as from the ECI assessments on stigma and loss. These ECI negative scale assessments, together with those on positive experiences were similar to those previously found in Portuguese samples [23, 24]. Psychological distress was readable from GHQ scores and caseness proportion. Standard and Likert GHQ scores were slightly lower than those reported in Portuguese dementia caregivers [21], but at least 37 % of caregivers in our sample were screened as "cases". As for caregivers' coping, FCQ assessments were also similar to other Portuguese findings, with emphasis on spiritual coping and social strategies (positive communication, patient's social involvement) [12].

We were also able to document associations of IEQ-EU consequences with other variables. In the correlational study, the IEQ total score correlated with patients' symptoms (mainly positive and manic excitement), disability and lower functioning, as well as with caregivers's psychological distress and coping (frequently of non-adaptive type). At a minor level, IEQ scores also directly correlated with stigma and loss. This association between perceived burden and stigma, for instance, had been reported in other studies, either in mental illness in general [32] or in schizophrenia [33]. There was no association of the IEQ total score with caregiving rewards, suggesting that both may co-exist. Furthermore, at this level of analysis, the existence of burden did not preclude the acknowledgment of coping that may be adaptive, as involving the patient in social activities or talking with friends.

While controlling for possible confounders, IEQ-EU total caregiving consequences were associated with patient's disability, caregiver status (being non-married) and caregiver's lack of emotional support, sense of stigma, and coping by patient's social involvement and coercion (but also, somehow unexpectedly, to the presence of social contacts). This direct relation between the acknowledgement of social contacts and IEQ consequences merits further exploration. Perhaps a higher level of IEQ consequences led to more contact seeking in these participants. We should also wonder why distress (GHQ) or patient's functioning (GAF) was not important at predicting IEQ consequences, contrary to usual findings in the literature [5–7]. Anyway, the interpretation of our multivariable model calls for prudence, on account of small numbers.

On the whole, these analyses additionally confirmed the construct validity of the Portuguese IEQ-EU. This represents further evidence of the validity of the IEQ-EU, confirming that a comparison with other European countries can be made, as we aimed in the second place.

Comparisons with other studies regarding IEQ-EU assessments

The rank order of the four IEQ-EU domains was the same as in the EPSILON results (*worrying*, *urging*, interpersonal *tension* and *supervision*) [14, 15] or other recent works [8].

In the EPSILON study, higher levels of IEQ consequences were found in Mediterranean centres, especially Verona, than in northern centres (Amsterdam, Copenhagen or London) and this was outlined by the authors as a robust conclusion, independently of score adjustments [14]. Patterns of impact which we now assessed in Lisbon caregivers are closer to findings from those Mediterranean samples (Santander, Verona), albeit not entirely coincident (e.g., even higher IEQ worrying).

Considering sample composition, demographics and caregiving arrangements of the EPSILON centres, the Lisbon sample would be closer to the Santander and Verona samples. In our direct comparison with the Amsterdam centre, the Lisbon sample included a greater proportion of male single patients who were living at their family's home, but clinical and functional assessments did not differ that much. Lisbon caregivers were older, typically a mother to the patient, more often sharing the same household and reporting a much closer contact. Caregivers also more frequently reported the existence of a close family network. Perhaps surprisingly for a less developed south European country, they stated a higher monthly net income. This last discrepancy might be due to non-randomization, to real differences in the two sampling areas or to a misfit of categories in the corresponding IEQ item, regardless of all care put in the cross-cultural adaptation of income ranks. The concordant distribution of Graffar class index in our sample would favour the second possibility.

Still the "North–South" axis?

On the whole, this study corroborates previously reported differences between northern and southern European countries [3].

There have been discussions around possible reasons for discrepancies regarding caregiving assessments in international comparisons, including real differences in caregiving consequences (e.g., low-quality of mental health services implying a more negative caregiving impact), differences in sample composition, in participants' reactions to burdensome situations, or in cultural characteristics, or even a cultural bias [3, 15]. Having discarded this last possibility [11, 18], the remaining three must be kept in consideration while interpreting our results.

We lack enough data to fully characterize mental health care provision to our participants, as was the case in EPSILON, and this precludes related comparisons. At the best, ours would be a low-quality service provision pattern, implying that caregivers would be pushed to more negative caregiving consequences.

Anyway, we replicated previously reported associations between IEQ consequences and several patient and caregiver characteristics and aspects of their relationship [15, 34], so at least a part of the explanation for different scoring patterns in our sample could reside in sample composition, which seems typical of caregiving arrangements in Portugal. However, in the EPSILON study, intercountry discrepancies in IEQ scores could not be attributed to differences in samples' characteristics regarding patients, caregivers, their relationships or number of inpatient beds. Social support and coping play a part in IEQ scorings, as would be expected from previous studies using family burden questionnaires[4, 12], but they do not explain everything, as our multivariable model suggests.

Perhaps real intercultural differences do play a part. Quoting van Wijngaarden et al. [15] on caregiving consequences, "while the concept is stable across cultures, differences are found". Although the EPSILON study itself did not provide clear-cut results on the argument upon a "north–south axis" regarding the experience of caregiving [3, 12, 15], the heavier burden of care related to worrying issues in these Portuguese participants suggests a cultural appraisal of caregiving in "warm-blooded" Mediterraneans, especially in accordance with a Portuguese fatalistic stereotype, as opposed to the "cold-blooded" northerners. Our study seems to strengthen the view that Mediterranean centres usually provide different sociodemographic sample characteristics and patterns of caregiving assessments.

This is in accordance with our findings regarding ECI assessments. Stigma and loss tended to be similar to those of an Italian sample, and higher than those in UK samples [9, 35]. However, caregiving rewards seemed more deeply acknowledged in ours than in those Italian caregivers, now closer to the UK findings [9].

Strengths and limitations of the study

This study replicates a major part of the EPSILON study methodology, with a sample size which clearly outnumbered any of the EPSILON centre samples. Furthermore, we used comprehensive assessments of caregiving in severe mental illness. Although we did not thoroughly document service provision, a common limitation to the EPSILON study, we did evaluate, by contrast, subjective and positive dimensions of caregiving, social support and coping. These assessments allowed us to document some new associations between variables and to replicate some previous findings in the literature.

Brief Psychiatric Rating Scale, DAS and GAF assessments, and general demographic and clinical data, were typical of a population of this kind in Portuguese mental health services. However, this was a non-randomised sample and may well be not entirely representative: it is arguably skewed towards more favoured social and educational levels.

We did not use a semi structured psychiatric diagnosis for patients, nor did we assess their level of cognitive dysfunction, which has been lately identified as a determinant of caregiver burden [7]. Caregivers' personality or personal coping-determining variables were not assessed: for instance, sense of coherence evaluations, although a part of parallel FAPS protocols, were not studied here. Although the GHQ-12 is a widely used measure for distress, it does not allow for a comprehensive assessment of psychological morbidity as other questionnaires may do (e.g., the SCL-90) [36]. GHQ case proportion interpretations call for prudence since Portuguese cut-offs are postulated. Regarding associations between variables, this was a cross-sectional study involving a limited number of participants, so results must be cautiously interpreted and causality may not be inferred.

Implications

A great proportion of these caregivers were at risk regarding burden and psychological distress, albeit not in direct contact with mental health services. Their needs should be recognised and screened. We did not provide direct evidence on the clinical usefulness of the IEQ-EU for everyday practice in Portugal. However, our results suggest that IEQ-EU assessments should be further explored as a screening and monitoring measure.

At the baseline of the FAPS study, burden was associated with forms of emotional coping and, among patient's variables, mostly to disability. The prospective survey will allow for a more conclusive analysis of associations of caregiving-related variables. In accordance with previous research, negative consequences of caregiving did not prevent participants from experiencing some degree of caregiving rewards. This could be highlighted as a focus for family interventions.

A question remains on whether unexplained international differences in caregiving consequences should be attributed to cultural factors or to other issues, such as differences in mental health care.

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Conflict of interest None.

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