

Links Between Expressed Emotion and Burden of Care in Relatives of Patients with Schizophrenia

MARCIA SCAZUFCA and ELIZABETH KUIPERS

Background. Findings that the EE level of a relative may change over time support the idea that EE may represent the circumstances of the relationship between patient and caregiver. The present study examines to what extent EE levels in relatives are related to relatives' burden of care and their perceptions of patients' deficits in social role performance.

Method. Fifty patients recently admitted to hospital with DSM–III–R diagnoses of schizophrenia or schizophreniform disorder were assessed for positive and negative symptoms. Fifty relatives who were living or were in close contact with these patients were interviewed for the assessment of EE and burden of care, and to provide information about patients' social role performance and social and behaviour problems.

Results. High-EE relatives had considerably higher mean scores for burden of care than low-EE relatives (12.5 v. 6.8, respectively, $P=0.002$), and perceived more deficits in patients' social functioning than low-EE relatives (means: 16.2 v. 6.9, respectively, $P=0.004$). The employment status of relatives was the only socio-demographic characteristic of relatives and patients associated with EE levels, those who were working being less likely to be high EE. Patients' psychopathology was not associated with EE levels and burden of care.

Conclusions. This study shows that EE and the burden of care are related. EE and burden both measure aspects of the relationship between relatives and patients. These findings suggest that EE and burden of care are more dependent on relatives' appraisal of the patient condition than on patients' actual deficits.

The policy of deinstitutionalising psychiatric patients has highlighted the role of the family as main providers of care. Two family factors that have been examined in detail since the early stages of community oriented care are the quality of the social interaction between carer and patient, as measured by the level of expressed emotion (EE), and the burden imposed by the caring role. EE has been seen as exerting a significant influence on the course of schizophrenia (Brown *et al*, 1972; Bebbington & Kuipers, 1994), whereas the impact on family members caring for a patient with schizophrenia seems to affect the family in several aspects of their lives (Gibbons *et al*, 1984; Fadden *et al*, 1987). Although the predictive validity of EE has been well established, the conceptual origins of EE are not. Findings that the EE status of a relative may change over time (Hogarty *et al*, 1986; Tarrier *et al*, 1988) support the idea that EE may represent complex interactions between patient and caregiver, or the circumstances of the relationship (Kuipers & Bebbington, 1988).

Despite similarities in topic, remarkably few studies have systematically investigated the relationship between EE and burden of care in families of patients with schizophrenia. Jackson *et al* (1990) found that high criticism in relatives was associated with higher levels of burden. Smith *et al* (1993) showed that high-EE relatives reported higher levels of disturbed behaviour in patients, more subjective burden, and perceived themselves as coping less effectively than low-EE relatives. High-EE relatives also report that patients function less well than low-EE relatives (Barrowclough & Tarrier, 1990; Otsuka *et al*, 1994). The present study was designed to examine to what extent EE levels in relatives were related to aspects of the circumstances of the relationship, measured by relatives' burden of care and relatives' perceptions of patients' social role performance (SRP). Socio-demographic characteristics of patients and relatives, and patients' illness-related variables were also examined in relation to EE level, burden, and perceived patients' SRP. This study is part of an

ongoing longitudinal investigation of the relationship between EE and burden of care.

Hypotheses tested were (i) high-EE relatives will be rated as having significantly higher levels of burden of care than low-EE relatives and (ii) high-EE relatives will perceive the patients' social role performance as significantly poorer than low-EE relatives.

Method

Sample

Patients had to satisfy the following criteria: (i) aged 17 to 65 years old, (ii) admitted to psychiatric hospital in an acute crisis within the last month, (iii) living or in close contact (at least once per week) with a relative for up to 3 months before admission to hospital, (iv) a diagnosis of schizophrenia or schizophreniform disorder according to DSM-III-R (American Psychiatric Association, 1987), (v) living within the area of Greater London, (vi) reasonable English speaker, (vii) informed consent to be interviewed and to have relative(s) interviewed. Exclusion criteria included evidence of an organic brain syndrome, or if there were a primary problem of drug or alcohol abuse.

Relatives had to satisfy these criteria: (i) living within the area of Greater London, (ii) reasonable English speaker, and (iii) informed consent to be interviewed.

Assessments

The study had a cross-sectional design. A standard form was used to collect information on socio-demographic characteristics of patients and relatives.

Instruments used with patients were the 9th version of the Present State Examination (PSE; Wing *et al.*, 1974), used to assess the presence of psychiatric symptoms during the month prior to the interview; and the negative scale of the Positive and Negative Syndrome Scale (PANSS; Kay *et al.*, 1989), used to evaluate the negative dimensions of the schizophrenic disorder.

Instruments used with relatives were (i) Camberwell Family Interview (CFI) (shortened; Vaughn & Leff, 1976), used to assess EE. All interviews were tape recorded. A relative was considered high EE when he/she made six or more critical comments, or revealed any degree of hostility, or was rated equal or greater than 3 on emotional overinvolvement. In these interviews some questions regarding burden, social role performance and social and behaviour problems were included in the CFI to avoid

repetition. It was possible to derive three summary scores from the objective information usually gathered from the CFI, such as impact on aspects of family life as 'relationship and household affairs', relatives' perception of patients' social and behaviour problems, and role functioning. A similar version was used by MacCarthy *et al.* (1989). The main investigator (MS) was trained by the second author (EK) to do reliable ratings on EE.

(ii) Burden of care was assessed using the 'Social and Behaviour Assessment Schedule' (SBAS; Platt *et al.*, 1980), and items from the CFI concerning the informants' relationship with the patient. It is possible to use the SBAS partially without losing its psychometric properties (Platt *et al.*, 1980). The section of the SBAS used was 'adverse effect on others'. The schedule used in the present study had 19 items covering the following areas: patient and informant relationship, effect on household affairs, effect on informant's social life, effect on informant's employment, and effect on household and informant's finance. Each of the five areas covered had items on 'objective' and 'subjective' burden. Items were scored when they were applicable, otherwise they were rated as a missing value. The period covered was the month before the patient's admission to hospital. Ratings ranged from 0 (absence of the problem) to 2 (severe presence of the problem). An overall score of all items, subscores for all 5 areas investigated, and subscores for 'objective' and 'subjective' burden were derived.

(iii) Patients' social functioning was assessed with the Social Role Performance (SRP) schedule developed as part of the MRC Needs for Care Assessment (Brewin *et al.*, 1987). The ratings depend on the relatives' perception of patients' ability to perform tasks, such as cooking, shopping, tidying up, etc., and the amount of support they require to achieve a minimal level of functioning. The schedule has 14 items, scored on a three-point scale, from 0 (patient performs adequately without any support) to 2 (patient rarely performs the task adequately, even with much supervision). When the relative did not expect the patient to perform a task, the item was not scored. The reliability and validity of the original schedule was assessed with good results (Brewin *et al.*, 1987). The period covered was the month prior to the patient's admission to hospital.

(iv) A short version of the MRC Social Behaviour Schedule (SBS; Wykes & Sturt, 1986; Brewin *et al.*, 1990) was used. This version of the SBS has 18 items, rated on a 3-point scale (from 0 – absence of the problem, to 2 – presence of the problem with some intensity for more than half of

the time), on the basis of the informant's report of frequency and severity of the target behaviour. When the informant was not able to give the information about the target behaviour, the item was not scored. The SBS scores were added to provide an overall indication of behavioural disturbance. The validity and reliability figures of the SBS were published by Wykes & Sturt (1986). The period investigated was the month before the patient's admission to hospital.

Procedures

Case notes of patients recently admitted to wards at Bethlem Royal Hospital and Maudsley Hospital, in south London, were screened to identify subjects for the study. Patients who were willing to participate in the study were interviewed in the ward, as soon as possible after admission.

Key relatives interviewed were those who lived with the patient, and when the patient did not live with relatives, the key relative was the one who had most contact with the patient. When more than one key relative was interviewed, the primary carer was considered to be the relative who spent more time with the patient, and was more involved with the patient's care. Relatives were interviewed soon after patients, preferably in their homes. All patients and relatives were interviewed by the main investigator (MS).

Analysis

Analysis was carried out using the SPSS for Windows, version 6.0. Only the assessments with primary carers were used in the analysis, to avoid pseudoreplication (Dunn, 1994). Weighted overall mean scores for burden, SRP and SBS were used in order to avoid bias against relatives who scored on more items (or areas investigated). Descriptive analysis was followed by univariate analysis for comparison between groups (high/low EE). T-tests were used for comparing means between 2 groups (the *t*-test for unequal variances was used when the variances of the 2 groups examined were not homogeneous; *P*-value for the test of homogeneity of variances <0.1). ANOVA was used for comparison of means between several groups; χ^2 tests were used for comparing proportions between categorical variables. Product-moment correlation was used to examine the association between continuous variables. Logistic regression was performed to construct a statistical model that could best predict EE level, and to control for potential confounders on the association found in the univariate analysis. A stepwise procedure was used

with a forward selection, with a test for backward elimination (Hosmer & Lemeshow, 1989).

Results

Characteristics of the sample

Sixty-three patients fulfilled the inclusion criteria. Four refused to participate in the study, and nine were excluded because their relatives refused to participate in the study. Fifty patients took part in the study, and 67 relatives were interviewed. Of these, 50 relatives were considered primary care givers, and their assessments were used in the analysis.

Patients who participated in the study were on average younger than those who did not participate ($n=13$) (26.5 years *v.* 33.5 years, respectively; $P=0.049$), had on average fewer admissions to hospital (2.6 *v.* 4.2, $P=0.10$), and had on average shorter duration of illness (5.0 years *v.* 11.9 years, $P=0.041$). Patients who took part in the study did not differ from those patients who did not participate on ethnicity and on whether they were living or not with a primary caregiver.

Inter-rater reliability

Inter-rater reliability was carried out with 12 randomly selected interviews of primary carers. EK acted as a reliability rater who was blind to patients' symptoms and had not interviewed relatives. The Kappa value for agreement on EE categories was 0.80 (95% CI: 0.43 to 1.0), with 91.7% of agreement between the two raters (only in one interview was there disagreement). The intra-class correlation coefficients (ICC) for agreement on the EE components critical comments (CC), hostility (H), and emotional overinvolvement (EOI) were $r_i=0.72$ (95% CI: 0.26 to 0.92), $r_i=0.66$ (95% CI: 0.14 to 0.90), and $r_i=0.97$ (95% CI: 0.90 to 1.0), respectively. The ICC for agreement on scores of burden of care, SRP, SBS, and for number of hours/week in contact between patients and relatives were $r_i=0.72$ (95% CI: 0.25 to 0.92), $r_i=0.99$ (95% CI: 0.96 to 1.0), $r_i=0.98$ (95% CI: 0.93 to 1.0), and $r_i=0.93$ (95% CI: 0.65 to 0.99), respectively.

Characteristics of patients and relatives

Thirty-seven patients (74%) were men. Patients of both sexes had on average the same age (mean women = 26.08, s.d. = 5.3; mean age men = 26.68, s.d. = 6.3). Only one patient was living with a partner, and three patients were working regularly

before admission to hospital. By contrast, 38 (76%) out of the 50 relatives included in the study were women. Forty relatives (80%) were parents, of whom 33 were mothers; nine (18%) were siblings (five sisters), and one was a partner. Twenty-six relatives (52%) were in employment, being a similar proportion for female and male relatives (55.3% v. 41.7%, respectively). Female relatives were on average slightly older than male relatives (mean age female = 51.95, s.d. = 11.5; mean age male = 45.41, s.d. = 16.3). Thirty-two relatives (64%) were not living with a partner, of whom 27 (54%) were women. Thirty-four relatives (68%) were living with the patient. Twenty-seven relatives (54%) had more than 35 hours/week face-to-face contact with patients, 11 (22%) had up to 19 hours, and 12 (24%) had between 20 and 35 hours of contact with the patients. Twenty relatives (40%) were European-white, 25 (50%) were black Afro-Caribbean or African, and 5 (10%) had other ethnic origins.

Thirty relatives (60%) were rated high EE (23 women and 7 men), with a predominance of critical and/or hostile relatives (56.7%), followed by EOI (26.7%), and a mixed type (16.6%). Frequency of high-EE types was similar for relatives of both sexes.

Thirteen patients (26%) had not been admitted to a psychiatric hospital before, 22 (44%) had one to three admissions, and 15 (30%) had more than three admissions. Men had on average twice as many admissions to hospital as women (3.0 v. 1.4, respectively), and had been on average ill for a slightly longer period (5.2 years v. 4.4 years, respectively), but became ill at similar age (21.4 years old v. 21.7 years old, respectively). Men had a slightly higher mean score on the PSE (23.05 v.

19.07, respectively). According to the CATEGO system, 36 patients (72.0%) were classified as class 'S+' (schizophrenic psychosis), two were assigned to class P+ (paranoid psychosis), 2 to class O+ (other psychoses), and 10 to uncertain psychoses classes (P?, M?, O?). Patients of both sexes had similar mean scores on negative symptoms (women = 24.23, s.d. = 8.0; men = 25.08, s.d. = 9.0).

Relationships of EE levels with burden of care, perceived patients' SRP and SBP

The total mean score for burden of care for high-EE relatives was almost twice as high as the total mean score for low-EE relatives (Table 1). High-EE relatives had significantly higher scores on objective and subjective burden, and in four of the five areas of burden examined. Critical and/or hostile, EOI and mixed type of high-EE relatives had higher mean scores for burden of care (12.19, 11.04, and 15.63, respectively) than low-EE relatives. The total mean score for perceived patients' SRP was significantly higher for high-EE relatives compared to the score for low-EE relatives. The total mean score for the SBS was higher for high-EE relatives compared with low-EE relatives, but the difference was not statistically significant.

Relationship between EE levels and characteristics of relatives and patients

None of the socio-demographic characteristics of patients and relatives, except employment status of the relative, was statistically associated with EE level. Low-EE relatives were twice as likely to be in employment as high-EE relatives (75% low

Table 1
Relationship between expressed emotion (EE) levels with burden of care, perceived patients' social role performance (SRP) and social and behaviour problems (SBP)

	Low EE (n=20)		High EE (n=30)		Diff. (95% CI) ¹	P
	mean	s.d.	mean	s.d.		
Total burden score	6.78	5.05	12.46	7.53	5.68(2.10, 9.25)	0.002
Objective burden	4.68	3.61	8.54	5.78	3.86(1.18, 6.53)	0.006
Subjective burden	2.19	2.12	4.04	2.32	1.85 (0.55, 3.13)	0.006
Effect on relationship	2.23	1.54	3.59	2.46	1.36 (0.22, 2.49)	0.021
Effect on household affairs	0.87	1.36	2.28	2.10	1.41 (0.42, 2.39)	0.006
Effect on social life	1.55	1.61	2.81	2.57	1.26(0.75, 2.45)	0.038
Effect on finances	0.95	1.58	1.58	1.81	0.63(-0.36, 1.63)	0.208
Effect on employment	0.83 ²	1.22	2.64 ²	1.86	1.81 (0.44, 3.16)	0.013
SRP score	10.34	6.59	16.22	6.89	5.88(1.94, 9.81)	0.004
SBP score	13.12	6.43	16.09	5.75	2.97(-0.53, 6.47)	0.095

1. 95% Confidence interval for the difference between means of high- and low-EE relatives.

2. Low EE (n=15), high EE (n=11).

Table 2
Relationship between EE levels and patients' psychopathology

	Low EE (n=20)		High EE (n=30)		Diff. (95% CI) ¹	P
	mean	s.d.	mean	s.d.		
PSE score	23.75	14.46	20.87	11.41	-2.88 (-10.26, 4.49)	0.44
Negative symptoms	24.15	9.05	25.33	8.62	1.18 (-3.92, 6.29)	0.64

1. 95% Confidence interval for the difference between means of high- and low-EE relatives.

EE v. 36.7% high EE). Table 2 shows that patients in contact with high- and low-EE relatives presented similar levels of psychopathology, as measured by the PSE, and the negative schedule of the PANSS.

Relationship of patients' and relatives' characteristics with total scores of burden of care and perceived patients' SRP

Relatives living with patients had significantly higher scores of burden of care (mean=11.78, s.d.=6.82) than relatives not living with patients (mean=6.79, s.d.=3.88) ($t=3.01$, d.f.=47.78, $P=0.004$). A linear comparison between the three groups of number of hours in contact between relatives and patients showed that scores of burden of care increased as relatives spent more hours in contact with patients ($F=9.19$, d.f.=49, $P=0.004$). Relatives in employment had similar scores of burden of care (mean=9.78, s.d.=8.27) than relatives not in employment (means=10.63, s.d.=5.87). Burden of care was not associated with the sex of the relatives (means: women=10.26, s.d.=7.28; men=9.94, s.d. 7.06), and was not correlated with age of relative ($r=-0.18$, $P=0.21$).

Mean scores of SRP were similar for those patients living (mean=14.34, s.d.=7.39) or not living (mean=12.86, s.d.=7.28) with relatives. On average, relatives not in employment perceived significantly more deficits in patients' functioning (mean=16.55, s.d.=7.01) than relatives in employment (mean=11.39, s.d.=6.79) ($t=-2.64$, d.f.=48, $P=0.011$). Age of relatives was not correlated with the total score on SRP ($r=-0.12$, $P=0.41$). Relatives reported on average more deficits in patients' functioning for male patients (mean=14.9, s.d.=6.8) than for female patients (mean=11.0, s.d.=8.32).

Scores on burden were not correlated with PSE total scores at a statistically significant level ($r=-0.25$, $P=0.08$), or with scores on negative symptoms ($r=0.20$, $P=0.17$). Scores on SRP were not correlated with PSE total scores ($r=-0.12$,

$P=0.42$), but were positively correlated with scores on negative symptoms ($r=0.36$, $P=0.01$).

There was a strong positive correlation between total score of burden of care and total score of SRP ($r=0.61$, $P<0.001$).

Multivariate analysis for the relationship between EE and explanatory variables

Explanatory variables were chosen based on their statistical association with EE level, burden of care and SRP scores. The criterion for entry was a P value of <0.10 . The variables chosen for the analysis were total score on burden of care, SRP, SBP, negative symptoms, whether the relative was living with the patient, employment status of relatives, and number of hours per week in contact with the patient.

When perceived patients' SRP was added to the model containing burden of care, both its association and the association of burden with EE levels were weakened and not statistically significant, the reason being that SRP and burden of care were highly correlated. It was then decided to construct the model using burden of care.

Table 3 shows the models that best fitted the data. The first model included burden of care and employment status. Burden scores were positively associated with high EE. Relatives who worked had a lower probability of being high EE. None of the other variables improved the model or changed the associations between the above variables and EE levels. Burden of care was then divided into quartiles to examine whether the assumption of a linear relationship between burden scores with EE levels was true. When employment status was added, the ORs for the second and third quartiles of burden were close to one, and the OR for the fourth quartile was higher, 26.06, suggesting that the association between burden of care and EE levels was not linear. A new model was then constructed with employment status and the burden variable recoded into two groups. The first three quartiles were grouped as low burden, as opposed to the last quartile, which was recoded as high

burden. The results were similar to the previous model.

Discussion

The main findings of the present study were that high-EE relatives reported more burden of care in all areas examined, perceived more deficits in patients' SRP, and were less likely to be working than low-EE relatives. No other characteristics of patients and relatives were associated with EE levels. The results confirmed our hypotheses and showed in a reasonably large sample that EE, burden of care and perceived patients' SRP are related. Our results are in agreement with two other studies that examined the relationship between EE level and burden of care (Jackson *et al*, 1990; Smith *et al*, 1993).

Methodological limitations of the study

Patients who took part in the study were younger and had been ill for a shorter period than those who did not take part, indicating that the study sample was composed of a slightly less chronic sample of patients with schizophrenia than those who met our criteria. Nevertheless, none of these factors were associated with EE levels, suggesting that no bias was introduced by non-participation.

The fact that patients were interviewed prior to relatives by the same interviewer could have had the effect of biasing the ratings of the interviews with relatives. This is unlikely to have happened, however, as there were no associations between patients' assessments (PSE scores and negative symptoms scores), EE and burden scores. Another problem that might have arisen from the use of a slightly modified version of the CFI (which combined assessments of EE, burden, SRP, and SBS) would be that the assessments of burden, SRP, and SBP would interfere with the ratings of EE that were carried out after the interviews. However, the results of inter-rater reliability were satisfactory, both raters having a good agreement concerning EE status, scores of burden, SRP, and SBS, suggesting that the findings of the present study were not just an artefact imposed by methodology.

EE levels, burden of care and perceived patients' social role performance

It is interesting to note that the only demographic characteristics of relatives and patients that were associated with burden of care and SRP scores, and with EE levels were those that were related to

Table 3
Logistic regression models for Expressed Emotion (EE) as the dependent variable

Terms in the model	OR ¹	95% CI	LRS ²	P
Model I				
burden of care ³	1.15	1.03–1.29	15.615	<0.001
employment status (yes)	0.18	0.05–0.70		
Model II				
burden of care (quartiles)				
2nd	1.07	0.16–7.17	20.247	<0.001
3rd	0.82	0.11–5.97		
4th	26.06	2.22–319.40		
employment status (yes)	0.09	0.02–0.47		
Model III				
burden of care (high)	26.98	2.65–274.50	20.166	<0.001
employment status (yes)	0.10	0.02–0.44		

1. Odds ratio.

2. Likelihood Ratio Statistics.

3. Continuous variable.

contact between patients and relatives. This is in line with a review study carried out by Bebbington & Kuipers (1994) which reconfirmed that high contact with a high-EE relative increases the risk of relapse for a patient.

The employment status of the relative was the only demographic characteristic of patients and relatives which was statistically associated with, and found to be an independent predictor of, EE level. Brown (1959) reported that employment status of relatives was associated with patients' relapse, in that patients with relatives who were at work were less likely to relapse. This led to the assumption that relapse could be prevented by reducing the amount of face-to-face contact between patient and relative (Leff & Vaughn, 1985). The association we found complements Brown's earlier findings, although the present study did not investigate relapse rates. We can suppose that relatives who are employed have certain features, perhaps a larger social network, and less time to be involved with the routine of the patient, which might either predispose or contribute to them being less critical of, or overinvolved with the patient. Relatives who were in employment also perceived fewer deficits in patients' functioning than those who were not working, suggesting that having an outside job could also contribute to a more realistic expectation of the patient as a person more able to deal with everyday demands. An alternative explanation for the relationship between low EE and having a job might be that relatives who are not overinvolved are more able to leave the patient and take on a job, while overinvolved relatives would

not consider having a job or would leave their job and stay at home to look after the patient.

As in Glynn *et al* (1990), the present study did not find any difference in level of negative symptoms between patients in contact with high- and low-EE relatives. Our results also showed that relatives' assessment of patients' SRP were in the same direction of the objective assessment of negative symptoms, but the association we found was only partial. This finding supports the idea of Glynn *et al* (1990), that at least some negative symptoms, as measured in the clinical practice, have relatively little correspondence with behaviour in a non-clinical setting.

The association we found between high-EE level of relatives and significantly worse perceived patients' SRP, rather than between independent clinical measures is consistent with findings from previous studies (Brown *et al*, 1972; Tarrier *et al*, 1988). Brown *et al* (1972) suggested that patients' functioning, rather than clinical characteristics, were possible determinants of EE. Both studies found that an improvement in patients' functioning over time was accompanied by a decrease in EE level.

Implications for EE research

We found that measures of burden of care and EE are more dependent on relatives' appraisal of the patient condition than on their actual deficits. This is in line with the approach proposed by Lawton *et al* (1989), who understand a caregiving burden as an example of an external demand or potential threat that has been appraised as a stressor. They suggested that the caregivers' assessment of the personal qualities of the patient and the quality of the relationship between caregiver and the patient (that are the main characteristics of the EE measure) might be considered another facet of caregiving appraisal, and therefore may be a reflection of caregiver's perception of threat. The results we have presented may be similarly interpreted. The EE measure may then be conceptualised as a measure of the quality of the relationship between patients and relatives viewed through relatives' appraisal of the circumstances.

The fact that high-EE relatives reported higher levels of burden than low-EE relatives does not of course mean that low-EE relatives are not also affected by the impact of care. Our results show that both groups cope with high levels of demand and often have to help with a range of basic tasks that would not normally be expected when living with another adult (Kuipers, 1993).

Clinical implications

- The majority of the carers in our sample and in other studies are women, and special attention should be paid to their needs in order to help alleviate the role that such carers have taken on.
- The fact that EE and burden are linked might make it easier to identify which families might benefit most from intervention.
- Intervention programs focusing on impaired patients' functioning, and on the family ability to negotiate about these aspects, might be particularly valuable in improving carers' burden of care.

Limitations of the study

- This study did not investigate whether the informant's burden of care and perceived patients' social functioning are also predictors of relapse.
- The study sample did not allow us to examine the relationship between burden of care and specific types of high EE.
- The sample of the study represents an inner city population, and findings may not be generalised to a more rural setting.

Acknowledgements

The authors would like to thank Dr Graham Dunn for his statistical advice, and Dr T. Rushe, Dr P. R. Menezes, and Dr P. Bebbington, for their helpful comments on earlier drafts of this paper. Marcia Scazufca was funded by the CNPq-Brasilia, Brazil.

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Marcia Scazufca, MPhil, **Elizabeth Kuipers**, PhD, Department of Psychology, Institute of Psychiatry

Correspondence: Marcia Scazufca, Department of Psychology, Institute of Psychiatry, De Crespigny Park, London SE5 8AF

(First received 2 August 1995, final revision 24 October 1995, accepted 17 November 1995)