The Association between Expressed Emotion, Illness Severity and Subjective Burden of Care in Relatives of Patients with Schizophrenia. 
*Findings from a Southern European population*

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Abstract

**Background:** An appropriate understanding of the association between high-Expressed Emotion (EE) in family members of people with schizophrenia and patient’s and relative’s correlates is needed to improve adaptation of psychoeducational interventions in diverse cultures. The objective of the current study was to test the hypothesis that relatives’ high EE would be associated with patients’ illness severity and with relatives’ subjective burden of care.

**Method:** We performed secondary analyses of baseline data from a randomized controlled trial conducted in Italy.

**Results:** High-EE relatives reported more subjective burden of care in disturbed behaviours and adverse effects areas, but did not perceive more deficits in social role performances. As regards illness severity characteristics, neither the number of previous hospital admissions nor the duration of illness was associated with high-EE. However, patients’ previous psychosocial functioning, as measured by educational attainments, seems to protect the relative from high-EE status.

**Conclusion:** There is a need for cross-cultural comparisons of the subjective experience of distress and burden among high EE carers as a target for intervention, reducing family stress as much as improving patient outcomes.

**Keywords:** Schizophrenia; Family; Expressed Emotion; Burden of Illness
Background

The predictive ability of the family Expressed Emotion (EE) construct has been demonstrated in a variety of international community settings [1-3]. Research on EE in relatives of people with schizophrenia has indicated that such an index, as rated by the Camberwell Family Interview (CFI) [4], is predictive of relapse after hospital discharge [5]. Further evidence has shown that relatives’ perceptions of burden in caring for family members with schizophrenia are correlated with their high-EE attitudes [6-8]. It may well be plausible that some of the illness characteristics of relapse-prone patients might prompt high levels of EE in family members, causing vulnerable patients to relapse [9]. However, the available evidence highlights also the role of culture in the expression of critical or emotionally overinvolved attitudes [10]. These may be more culturally accepted in some ethnic groups [11], and has suggested the need for different cutting scores to define high or low EE in cross-cultural studies [12]. Similarly, the ways in which relatives cope with patients and the burden imposed by the caring role might be influenced by cultural factors which affect relatives' appraisal of the patients' situation [13-16]. However, little is known about the relationship between high-EE, illness characteristics and burden in non Anglo-Saxon countries.

The present study was undertaken with a view to remedying these limitations and was designed to examine to what extent EE levels in relatives were related to their subjective burden of care imposed by the caring role, in a representative Southern European sample. The aim of this study was to test the hypothesis that relatives’ high EE would be associated with their subjective burden of care, and also with objective variables that indicate illness severity i.e. number of previous hospitalizations and duration of illness.

We performed secondary analyses of baseline data from a prospective, randomized trial which assessed the medium and long term outcomes of two programmes of family intervention for the care of schizophrenia, compared to the standard community mental health care, in Italy [15].
Methods

Setting
The study was carried out in a non-profit, family advocacy and support agency, the Association for Research on Schizophrenia (ARS), which is supported by a charity (Cazzullo-Legrenzi Foundation) in Milan, Italy. The Lombardy Health System encourages non statutory charities, funded by the National Health Service (NHS), to complement existing teams by providing treatments that are not otherwise available. ARS provides programs just for relatives of people with schizophrenia due to organizational and cultural barriers to patient’s participation. NHS community mental health centres in the metropolitan catchment area refer the relatives.

Participants
A more detailed description of the different therapeutic options provided as well as details about sampling and randomization procedures are fully described elsewhere [15]. In brief, from those who had been referred to ARS consecutively from 1995 to 2000 (n=320), relatives were selected with the following inclusion criteria (n=205):

- they were living with someone suffering from schizophrenia and had not attended family groups or other support services before the study intervention;
- the patient was clinically stable (having had no psychiatric hospitalization or any relapse for six months prior to study entry) and was not receiving any psychosocial or rehabilitative treatment other than standard care;
- the patient did not have a primary diagnosis of alcohol or drug dependence or organic disease.

Relatives were randomly selected, using a random numbers table, to enter the study. In total, 101 out of 112 relatives agreed to participate, and gave informed consent. The family programs which were offered involved only one relative from each patient’s family, and all patients received
standard care, which entailed key worker’s management and consistent pharmacological interventions monitored by consultant psychiatrists in community mental health centres of the Milan metropolitan area.

**Measures and procedures**

Research assistants were not involved in the treatment and carried out the interviews at the office. Patient’s and caregiver’s data for this study were obtained at study entry. Community-based service managers were contacted to check the following criteria: a) patients’ DSM-IV diagnoses of schizophrenia [17]; b) current satisfactory functioning, as measured by a Global Assessment Scale-GAS score of 30 or more [18]; and c) consistency of prescribed pharmacological treatment, with all but 3 patients receiving standard doses (300-1000 mg chlorpromazine equivalents). In addition, at induction each relative was given a standardized questionnaire on clinical and social characteristics of the patient and family. Clinicians from the community settings supplied missing information on treatment variables.

The relatives’ EE was evaluated by the Camberwell Family Interview-CFI [4]. Every interview was tape recorded. The two evaluators had been formally trained by Dr Christine Vaughn. Relatives were defined as high EE if they made six or more critical comments (CC), expressed hostility, or were rated as four or more on the Emotional Overinvolvement (EOI) scale in the course of the interview. The latter is in accordance with the Italian field study on predictive value [19] and not with the classical (>3) scoring criteria [20]. Positive remarks (a frequency count) and warmth (a 6-point scale: 0–5) were rated as well.

Subjective burden of illness over the previous 6 months was measured with the Social Behaviour Assessment Schedule (SBAS) [21]. The questionnaire was translated into Italian, and back translated into English. Adjustments were made to increase the clarity and precision of the Italian version of the questionnaire. SBAS is a validated, semistructured interview used to
investigate the perceptions of caregivers regarding patient’s disorders and the caregivers’ subjective and objective burden. In terms of reliability, SBAS has shown intraclass correlation coefficients ranging from 0.92 to 0.99 [21] and weighted \( \kappa \) between 0.83 and 0.98 [22] for the six subscales. In this study, only three of the six sections of the instrument were retained. The use of these sub-scales of the SBAS can be done without losing its psychometric properties [21]. The three sections and related dimensions dealt with: (a) disturbed behaviours; (b) change in social role performance; and (c) adverse effects of the illness on the household and the caregiver’s work and leisure time. For each item, SBAS distinguishes between the objective change related to the occurrence of a problem, from the perceived distress - scored separately - and subjective burden caused. The level of distress reported by the relative, and created by each problem presented by the patient or existing within the household, ranges on a scale 0=no distress, 1=moderate distress, 2=severe distress. Research assistants were trained in the use of the interview and coding, which were discussed in the group. Inter-observer reliability was evaluated using Cohen's kappa, with kappa values ranging from 0.82 for patient’s disturbed behaviours and 0.91 for change in social role performance. Different researchers conducted EE and SBAS interviews. The SBAS has 35 items from the 3 sections mentioned above, relevant to all informants, with 22 items on disturbed behaviours of patients, 5 items on social role performance and 8 items on adverse effects. We followed similar methodologies used in previous studies [23, 24]. For each dimension, the mean distress score was computed as the sum of scores divided by the number of applicable items. The total score for subjective burden in each dimension ranged from 0.0 to 2.0.

**Ethics**

The study was approved by the regional ethical review board in Milan, Italy and conducted according to the 1964 Declaration of Helsinki. All the participants signed an informed consent form.
Statistical Analysis

Analyses were carried out using STATA version 10 for Windows [25]. All statistical tests used the 5% level of significance, and all p-values were two-tailed. Descriptive analysis was followed by assessment of bivariate relationships between groups (low/high EE). T-tests were used for continuous variables. However the t-test for unequal variances was used -as the variances of the two subgroups examined were often not homogeneous when checked with one-way ANOVA- and the Welch’s approximation of the degrees of freedom was produced. Chi-square and Fisher’s exact tests were used for nominal variables. Secondly binary logistic regression with a stepwise procedure was used to analyze the association between the dichotomized outcome (low/high EE) and all the variables that were significantly related to caregiver’s high EE (p<.05) at the univariate analysis, together with hypothesized patient and family correlates as explanatory variables. The outcome variable was analyzed yielding odds ratios (ORs) with 95% confidence intervals (CIs), and p values. The goodness of fit for models was evaluated via Hosmer-Lemeshow test.

Results

Characteristics of patients and relatives

The overall mean age of patients was less than 30 years, and 28% were women. Furthermore, medium levels of education did not support consistent regular employment status (24/101) and only a few (11%) had stable intimate relationships, with most patients still living with their family of origin. The clinical profile corresponded to that usually reflected in studies of this type in terms of onset age, duration of illness, and number of previous hospitalizations. Most of the key-relatives were parents (79%), typically middle-aged, Italian mothers (71% overall), with a corresponding mean age, and rate (77%) of high contact dichotomized as more or less than 35 hours per week. Thirty-nine relatives (39%) were rated high EE (24 women and 15 men). Within the high EE subgroup, critical relatives were mainly represented (81%), followed by hostile (68%) and EOI
ones. Comparison of study participants and non-participants on all measures used in the study showed no significant differences.

**Relationship between EE levels and characteristics of relatives and patients**

As regards the relationship between EE levels and characteristics of relatives and patients, there were few significant differences on all measures used in the study (Table 1). None of the socio-demographic characteristics of patients and relatives, except educational status of the patient, was statistically associated with EE level. Low-EE patients had spent significantly more years in formal educational programmes. The total mean score for high EE-relatives on distress as measured by SBAS was more than twice on disturbed behaviours section, but almost three times as high as the total mean score for low-EE relatives on social role performance and adverse effects dimensions ($P < 0.0001$ for all).

**Table 1 about here**

**Multivariate analysis for the relationship between EE and explanatory variables**

All significant correlates of high EE were entered into a stepwise multiple logistic regression model. Patient age and education were also investigated as possible confounders of caregiver burden. The first was included – given the high proportion of relatives among carers - because of its close association with the duration of relationship between carer and patient; the latter as a proxy measure of psychosocial functioning in terms of educational attainment in people with schizophrenia. Finally, as regards variables that indicate illness severity, patient’s number of previous hospitalizations and duration of illness were included.

Table 2 shows the model that best fitted the data, as the Hosmer-Lemeshow goodness-of-fit-test statistic was 7.3 ($p > 0.50$). Burden scores were positively associated with high EE on disturbed behaviours and adverse effects dimensions, though on social role performance section scores did
not reach the significance level. None of the clinical and socio-demographic variables of patients changed the associations between the above variables and high EE, apart from educational attainment - appearing to have some protective effect - with an odds ratio per year increase in formal education significantly lower than 1.0. Models using as outcome variables the most relevant EE components - EOI and CC dichotomized into high/low categories - did not fit the data better than the overall EE measure.

Table 2 about here

Discussion

Main findings

The main findings of the present study are that high-EE relatives reported more subjective burden of care in disturbed behaviours and adverse effects areas, but did not perceive more deficits in social role performances. As regards illness severity characteristics, neither the number of previous hospital admissions nor the duration of illness remained associated with high EE in the regression analysis. However, patient’s previous psychosocial functioning, as measured by years successfully spent in formal education, seems protecting the relative from high-EE status. No other characteristics of relatives were associated with EE levels.

Relationship between EE levels and clinical and socio demographic characteristics of patients

Our results are in agreement with other studies that examined the relationship between EE levels in relatives of people with schizophrenia and their characteristics at a single point in time. Several reports did not actually find any association between EE levels and demographic [6, 26-28] or clinical [7, 29-32] characteristics of patients. In our study, the educational status of the patient was the only demographic characteristic of patients and relatives which was statistically associated with, and found to be an independent predictor of, high EE. Although we found no univariate association between relative’s hours per week spent in contact with the patient, and EE status, we
can presume that patients with higher educational attainments have had a larger social network, and less time to be actively engaged in the routine of the relatives. This in turn might either predispose or contribute to them being less critical of, or overinvolved with the patient. As a whole, once more, patients' functioning, rather than clinical characteristics, is possible determinant of EE [33, 34].

**EE levels and subjective burden of care**

The study demonstrated in a realistically large sample that relatives’ high EE and subjective burden of care are associated. This is consistent with most of [6], though not all [35], studies which used the SBAS, and different burden measures [28, 36]. The two dimensions seem actually related and dependent on relatives’ appraisal of the patient condition rather than on his/her illness severity [6]. However, as measured by SBAS, only sections on disturbed behaviours and adverse effects of the illness on the caregiver’s work and leisure time remained statistically associated independent predictors of EE level, which was not the case for the social role performance area. The present results seemed to reflect this distinction in that there appeared to be a tolerance or resignation by relatives about social performance deficits, whereas patients’ (disturbed) behaviours and direct effects on relatives induced critical responses to a significant degree. In the context of our study, high EE in relatives of people with chronic illness seems more related to personal reactions to the direct and indirect tasks of care than to actual caregiving, which is the case for first episode psychoses [37]. If long-term carers believe that they are not in control of patient’s illness, they feel more stress and depression, have more negative views of the impact of care [38], and the lack of proactive strategies based on avoidant coping, may increase their levels of burden [39].

Although there appears to be broad agreement about the evidence that the EE-relapse association replicates, but is moderated, within different cultural contexts, there remains an increasing need to assess EE correlates and their significance internationally [9]. The prevalence of high-EE attitudes
varies, with relatives of Indian and Latino patients being frequently classified as low rather than high [40, 41] and levels of criticism significantly different across cultures [42]. Furthermore, ethnicity seems to influence the extent to which high criticism or EOI are culturally tolerable [11]. In particular EOI cannot be considered inevitably unfavourable as regards patients’ relapse risks, medicalizing what may be a cultural norm, though there is the need to balance the opposite risk it being ignored [43].

As much as the components of EE differ in relation to their predictive validity [9] and cultural significance [11], also the association between EE and burden may vary across different cultures. This study sought to examine such association in a non Anglo-Saxon cultural context. It seems important to understand cultural factors when planning and delivering interventions with the families of patients from distinct cultures [44]. EE should be regarded in an integrative model, in which the quality of the dyadic relationship, as assessed by EE, is the product of complex interactions between patient’s and relatives’ issues [7]. In our study the most burdensome issues seem related to the patient's disturbed behaviour and the adverse effects on the household, thus relevant family interventions need to focus on patients’ current - not past - characteristics. A problem-solving approach may show that the user with psychosis is still capable of functioning as an adult. On the other hand, the more hostile and critical carers may positively react to information and advice, possibly on an ongoing basis within a group [45], by suggesting to them that patients’ thoughts and behaviours are not entirely under their control, being affected by symptoms of psychosis [46]. No improvement in relatives' burden may be realistically expected without specifically focusing on their appraisal of the patients’ condition as regards specific areas. Our study shows that there is a need for interventions aimed at improving the impact of the caring role in areas of caregivers’ lives such as work and leisure time, as well as of behaviours which they perceive to be disturbing.

**Limitations and strengths of the study**
The cross-sectional design of the study means that it is impossible to determine whether there is a causal relationship between EE and burden. Furthermore putting our results into the context of published research will be hindered by the variety of measures used about EE and family burden. However, we have used internationally validated instruments which would allow further sound replications [47].

The study was carried out at a non-profit agency in inner-city Milan, which is not part of statutory mental health services providing patient care, and this may limit its generalisability to other populations. Access was based on referral by community staff and such recruitment could have affected the generalisability of the findings. The relative’s motivation to accept family intervention not otherwise available could be similar to that in early family programs [48] and could have biased the results. Moreover subgroup analyses based on small numbers must be treated as preliminary. However, a relatively limited number of correlations were explored, so that the probability of chance findings was low, and more importantly the role of possible confounders has been addressed at the stage both of design (random sampling) and of analysis (use of multivariate statistical techniques and of goodness-of-fit test to assess the models’ performance). Observer bias was unlikely, since different - mutually blind - research assistants conducted EE and SBAS interviews.

**Conclusions**

Despite general agreement about the effectiveness of family psychosocial interventions for the care of people with schizophrenia [49], there is the need to overcome organizational barriers - though retaining basic components of successful family treatments for schizophrenia. Consistently, further research should investigate the subjective experience of distress and burden among high EE carers as a target for intervention, reducing family stress as much as improving patient outcomes. Customs and traditions may define not only the sort of behaviours that warrant criticism [42], but also the burden linked to the relationship between patients and relatives as appraised by the latter, and every attempt should be made to pick up culturally sensible issues of maladjusted interactions between
patients and carers. Future cross-cultural comparisons might shed light on crucial adaptations in family psychosocial interventions.
Competing interests
The authors declare that they have no competing interests.

Author’s contributions
GC planned the study, developed the measures, performed the data analysis and drafted the first version of the manuscript. CLC made substantial contributions to conception, acquisition of data, and commented on an earlier draft of the manuscript. MC made substantial contributions to conception, acquisition of data, and reviewed and revised the manuscript.

Acknowledgements
† Carlo Lorenzo Cazzullo was the Father of Italian Psychiatry and the first Professor of Psychiatry in Italy as well as the founder of the Association for Research on Schizophrenia (ARS). Carlo Lorenzo Cazzullo died on May 4, 2010. He was a splendid scientist and a great source of inspiration to us. He will be greatly missed. We thank Fiona Nolan (University College London) for comments on an earlier version of the article.
References


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Table 1 Patients’ and relatives’ characteristics by level of Expressed Emotion

<table>
<thead>
<tr>
<th></th>
<th>Low EE n=62</th>
<th>High EE n=39</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PATIENTS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age: Mean (SD), yrs.</td>
<td>30.4 (8.7)</td>
<td>28.8 (8.5)</td>
<td>0.359&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Gender: No. (%)</td>
<td></td>
<td></td>
<td>0.587</td>
</tr>
<tr>
<td>Male</td>
<td>46 (74)</td>
<td>27 (69)</td>
<td></td>
</tr>
<tr>
<td>Education: Mean (SD), yrs.</td>
<td>12.4 (3.4)</td>
<td>11.1 (2.7)</td>
<td>0.041&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Ordinary employed, No. (%)</td>
<td>17 (27)</td>
<td>7 (18)</td>
<td>0.276</td>
</tr>
<tr>
<td>Married/cohabiting: No. (%)</td>
<td>7 (11)</td>
<td>4 (10)</td>
<td>0.871&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>Living conditions: No. (%)</td>
<td></td>
<td></td>
<td>0.345&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
<tr>
<td>In parental home</td>
<td>51 (82)</td>
<td>29 (74)</td>
<td></td>
</tr>
<tr>
<td>In conjugal home</td>
<td>6 (10)</td>
<td>3 (8)</td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>5 (8)</td>
<td>7 (18)</td>
<td></td>
</tr>
<tr>
<td>Onset age: Mean (SD), yrs.</td>
<td>20.1 (6.3)</td>
<td>20.3 (7.3)</td>
<td>0.881&lt;sup&gt;d&lt;/sup&gt;</td>
</tr>
<tr>
<td>Duration of illness: Mean (SD), yrs.</td>
<td>11.2 (8.6)</td>
<td>8.5 (7.2)</td>
<td>0.088&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>Previous hospitalizations: Mean (SD), No.</td>
<td>3.2 (4.8)</td>
<td>3.4 (5.5)</td>
<td>0.857&lt;sup&gt;g&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>RELATIVES</strong></td>
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<td></td>
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<tr>
<td>Relationship to Patient</td>
<td></td>
<td></td>
<td>0.309&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Parent</td>
<td>46 (74)</td>
<td>34 (87)</td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>11 (18)</td>
<td>3 (8)</td>
<td></td>
</tr>
<tr>
<td>Spouse/Partner</td>
<td>5 (8)</td>
<td>2 (5)</td>
<td></td>
</tr>
<tr>
<td>Gender: No. (%)</td>
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<td>0.524</td>
</tr>
<tr>
<td>Male</td>
<td>20 (32)</td>
<td>15 (38)</td>
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<tr>
<td>Age: Mean (SD), yrs.</td>
<td>54.4 (11.7)</td>
<td>55.1 (8.4)</td>
<td>0.737&lt;sup&gt;h&lt;/sup&gt;</td>
</tr>
<tr>
<td>Education: Mean (SD), yrs.</td>
<td>9.87 (4.1)</td>
<td>9.84 (3.5)</td>
<td>0.974&lt;sup&gt;i&lt;/sup&gt;</td>
</tr>
<tr>
<td>Relative’s hours per week spent in contact with the patient&gt;35: No. (%)</td>
<td>46 (74)</td>
<td>32 (82)</td>
<td>0.359</td>
</tr>
<tr>
<td><strong>SBAS distress scores: Mean (SD)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disturbed behaviour</td>
<td>0.66 (0.62)</td>
<td>1.30 (0.56)</td>
<td>&lt;0.0001&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>Social role performance</td>
<td>0.37 (0.52)</td>
<td>0.94 (0.56)</td>
<td>&lt;0.0001&lt;sup&gt;m&lt;/sup&gt;</td>
</tr>
<tr>
<td>Adverse effects</td>
<td>0.59 (0.55)</td>
<td>1.30 (0.52)</td>
<td>&lt;0.0001&lt;sup&gt;n&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

EE: Expressed Emotion; SBAS: Social Behaviour Assessment Schedule.

<sup>a</sup>t test with unequal variances, (Welch's degrees of freedom): \( t=0.9207, (83.9717) \); \( t=2.0679, (95.2897) \); \( t=-0.1495, (73.787) \); \( t=1.7224, (93.2407) \); \( t=-0.1798, (74.1124) \); \( t=-0.3357, (99.5407) \);

<sup>b</sup>t=0.0319; \( t=-5.3459, (88.6777) \); \( t=5.1921, (78.1816) \); \( t=-6.5012, (86.9995) \);

<sup>c</sup>Fisher’s exact test
Table 2 Variables associated with High EE in logistic regression

<table>
<thead>
<tr>
<th>Number of subjects included in the analysis</th>
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</tr>
</thead>
<tbody>
<tr>
<td>LR(^1)</td>
<td>51.63</td>
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<tr>
<td>P</td>
<td>&lt;0.0001</td>
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<tr>
<td>Odds ratio (95% CIs)</td>
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<tr>
<td>PATIENTS</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.98 (0.90 to 1.07)</td>
</tr>
<tr>
<td>Education</td>
<td>0.80 (0.66 to 0.99)</td>
</tr>
<tr>
<td>Duration of illness</td>
<td>0.93 (0.84 to 1.02)</td>
</tr>
<tr>
<td>Previous hospitalizations</td>
<td>1.01 (0.90 to 1.14)</td>
</tr>
<tr>
<td>RELATIVES</td>
<td></td>
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<tr>
<td>SBAS distress scores</td>
<td></td>
</tr>
<tr>
<td>Disturbed behaviour</td>
<td>3.17 (1.11 to 9.07)</td>
</tr>
<tr>
<td>Social role performance</td>
<td>2.40 (0.77 to 7.42)</td>
</tr>
<tr>
<td>Adverse effects</td>
<td>4.79 (1.09 to 20.9)</td>
</tr>
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</table>

\(^1\)Likelihood Ratio