

# Caregiver burden in chronic mental illness: the role of patient and caregiver characteristics

Anne Maria Möller-Leimkühler · Andreas Wiesheu

Received: 9 February 2011 / Accepted: 13 April 2011 / Published online: 3 May 2011  
© Springer-Verlag 2011

**Abstract** The aim of the present study is to identify the relative contribution of patient and caregiver characteristics in a sample of primary carers of patients with chronic mental disorders living in the community. As carers were recruited from caregiver organizations, mainly mothers of an adult child suffering from schizophrenia participated in the study ( $n = 102$ ). Within a comprehensive transactional stress model, burden was assessed with respect to objective and subjective burden, cognitive-emotional well-being, psychological distress and subjective quality of life. Primary stressors include illness-related characteristics of the patient, and a number of personal dispositions and resources of the caregivers were included as potential moderating variables. Multiple regression analyses were separately calculated for each dimension of burden. Interaction of carers' expressed emotion and external locus of control with the patient's problem with family communication as well as perceived social support was most predictive for objective and subjective burden, whereas carers' neuroticism appeared as the most relevant predictor of their well-being, psychological distress and subjective quality of life. Among the patients' variables, regular employment contributed significantly to reduce carers' distress and enhance their well-being. As the sample was recruited from caregiver organizations, a selection bias has to be taken into account. To reduce caregiver burden, especially mothers' burden, the patients' occupational abilities should be strongly enhanced at an early stage. Family interventions should improve dysfunctional interactions, enhance

the carers' social activities and focus more intensely on the carers' own dispositions.

**Keywords** Caregiver burden · Expressed emotion · Neuroticism · Perceived social support · Patients' employment

## Introduction

Caregiver studies have documented numerous adverse effects of caregiving for a mentally ill family member on the carers' quality of life, such as time lost from work, financial loss, limited time for leisure and socializing, as well as adverse health effects such as elevated symptoms of distress, feelings of stigmatization, poorer self-rated health, chronic medical conditions, greater use of tranquilizers and antidepressants and increased risk of medical hospitalization [14, 38, 39, 48]. Despite these numerous and severe impairments, less is known about the relative impact of contributing factors to caregiver burden.

Traditionally, studies on caregiver burden have mostly focused on the impact of patients' symptomatology and social functioning with inconclusive results. While some studies document a weak association between clinical ratings of the patients' functional status and caregiver burden [46], others found more stronger relationships [13, 23], and still others found no effect of patients' symptomatology [16, 30]. Male gender and younger age of the patient were shown to be related to increased caregiver burden [28, 38]. More consistently, caregiver sociodemographic characteristics could be identified as predictors of burden: being female, especially mother, low socioeconomic status and living with the patient are linked with higher levels of burden [1, 36]. Concerning

A. M. Möller-Leimkühler (✉) · A. Wiesheu  
Department of Psychiatry, Ludwig-Maximilian-University  
of Munich, Nußbaumstr. 7, 80336 Munich, Germany  
e-mail: anne-maria.moeller-leimkuehler@med.uni-muenchen.de

caregivers' psychosocial characteristics, which either may have main or moderating effects on their stress experience, relative consistent evidence points to the role of expressed emotion, coping strategies and perceived social support [2, 25, 29, 47].

There are no consistent findings concerning the question, which predictors are most important for caregiver burden, and which predictors interact with patients' illness characteristics. There is generally evidence for self-efficacy, neuroticism, assertiveness or perceived social support having direct as well as indirect effects on stress outcome, but there are also findings showing neither main nor moderator effects of relatives' resources on their stress experience [41, 43]. Thus, it is of considerable interest to further analyse this question.

The aim of the present study is to identify the relative contribution of patient and caregiver characteristics in a sample of primary carers of patients with chronic mental disorders. The study was performed in the theoretical context of the Munich 5-year follow-up study on caregivers of first-hospitalized schizophrenic and depressed patients, of which results have been published previously [30–34]. This study was based on a comprehensive stress model. While it has focused on the development of caregiver burden since the first admission of schizophrenic and depressed patients during a 5-year follow-up period, the present study aims at analysing the same stress model cross-sectionally under the conditions of chronic disease. The theoretical background of the study refers to the transactional stress model of Lazarus and Folkman [26] and their assumption that stress results from an interaction between situational demands and individual coping capacity. This means that the impact of objective stressors on experiencing stress is moderated by individual appraisal and individual resources. Thus, in this study, burden is defined as stress outcome being potentially modified by specific illness-related coping strategies of the caregivers, general coping strategies, expressed emotion, personality factors, beliefs of control, perceived social support and personal maturation. Burden is operationalized by an objective and subjective assessment, cognitive-emotional well-being, psychological distress and global satisfaction with life.

## Subjects and methods

### Subjects

The participants of the present study were key relatives who were recruited from two German caregiver organizations, one of Brandenburg (LApK) and one of Munich (ApK).

The chairperson of the caregiver organization of Brandenburg was asked to forward 110 questionnaire packages to the members together with a cover letter of the chairperson and the first author pointing to the relevance and anonymity of the survey as well as offering the possibility to talk to the first author, if they would have any questions. After 3 weeks, only 21 completed questionnaires were sent back.

The recruitment procedure was different in the Munich caregiver organization due to the concerns of the chairperson that the survey would be an unreasonable demand for the members (high number of questionnaires). All 365 members were informed about the study and told to contact the first author if they wanted to participate in the study. One hundred and two members contacted the author, and they were sent the questionnaires. Eighty-one completed questionnaires were sent back. Taken together, the sample includes 102 participants.

### Methods

#### *Patients' variables as assessed by their key relative*

Patients' variables were assessed by their key relative, including data on their diagnosis, duration of illness, number of hospitalizations and severity of symptoms during the past 3 months. Patients' difficulties in leisure time, everyday duties, communication and family life were rated by the key relative on a 6-point scale (0 = no difficulties, 5 = very large difficulties). Additional questions refer to regular employment and frequency of contact.

#### *Carers' expressed emotion*

The German *Family Questionnaire* [53] was used to assess the key relatives' expressed emotion. Twenty items concerning typical reactions towards the patient (criticism and emotional overinvolvement) were evaluated by the relative on a 4-point scale, ranging from 'never' to 'very often'. Relatives were rated as high EE, if their sum score on the scale 'criticism' and/or their sum score on the scale 'emotional overinvolvement' exceed the cut-off points.

#### *Carers' expressed emotion as perceived by the patients*

This is the only questionnaire the patients were asked to complete. Patients' perceived emotion was measured by the German Fragebogen zur Erfassung der Familienatmosphäre (FEF, a questionnaire assessing family atmosphere) [10]. This scale consists of 27 items referring to the dimensions criticism (e.g. 'He/she rebukes me a lot'), overprotection (e.g. 'he/she takes over important

decisions for me') and resignation (e.g. 'He/she is not interested in how I am doing') and are rated dichotomously ('true'/'not true'). According to Feldmann et al., reliability and validity of the FEF are satisfying.

### *Objective and subjective burden*

Burden was measured with the *Family Burden Questionnaire* (FBQ), which was adapted by the author from the semi-structural interview of Pai and Kapur [37]. With regard to several life domains (daily living, family atmosphere, leisure, financial aspects and well-being), objective and subjective aspects of burden are assessed with 29 items for the last 3 months. Objective burden is defined as observable changes in routine arrangements and is bipolarly assessed by the relative (e.g. 'Does his/her behaviour disturb daily routine?') The answer is yes or no). Subjective burden refers to each item of objective burden with the question how burdensome this is for the relative. The answer consists of a three-point scale: not at all/moderate/very burdensome. While Pai and Kapur offer only one global score of subjective burden, the first author has constructed several scores for objective and subjective burden, once with regard to each life domain and once with regard to a global measure of the objective and subjective dimension of burden. To make the scores more perceptual, the quotients (sums of item values are divided through number of items) are transferred to percentage by multiplication with 100. Reliability test ( $n = 83$ ) for the global percentage of objective burden resulted in  $\alpha = .83$ , for the global percentage of subjective burden in  $\alpha = .88$  and for the entire scale  $\alpha$  was .92.

### *Coping*

The German questionnaire '*Stressverarbeitungsbogen*' (SVF) [22] was chosen to measure general coping strategies of the caregivers. Strategies aimed to cope with typical symptoms/events of the illness were assessed with the German version '*Skala zur Erfassung des Bewältigungsverhaltens*' (SEBV) [11] of the 'Ways of Coping Checklist' [12], which differentiates two scales: problem-focused and emotion-focused coping.

### *Subjective beliefs of competence and control*

General beliefs about one's competence to solve problems and one's control over the environment represent an important coping resource and were measured with the '*Fragebogen zu Kompetenz- und Kontrollüberzeugungen*' (FKK) [24]. The questionnaire consists of four scales, two of them related to internality and two of them related to externality. These four scales are summed up into two

secondary scales 'general self-efficacy' and 'general externality of control beliefs'.

### *Personality*

In order to assess the influence of further personality dimensions on the caregivers' burden, the German Version of the '*NEO Five-Factor Inventory*' (NEO-FFI) [3] was used. The five personality descriptors are neuroticism, extraversion, openness to experience, sociability and conscientiousness. They are self-rated on a five-point scale.

### *Perceived social support*

Perceived social support represents an important dimension of social resources, being measured with the short form of the German '*Fragebogen zur Sozialen Unterstützung*' (SOZU) [49] including 22 items and a five-point rating scale.

### *Subjective well-being*

In order to assess the current subjective well-being of the caregivers, the German '*Befindlichkeitsskala*' (Bf-S) [55] was used, which includes a broad scope of bipolar structured cognitive-emotional states.

### *Psychological distress*

Occurrence and degree of current psychiatric symptoms were self-rated by the caregivers by using the '*Symptom-Checklist-90-R*' (SCL-90) [8]. It evaluates a broad range of psychological problems and symptoms of psychopathology consisting of 90 items and yielding nine scales along primary symptom dimensions (e.g. somatization, obsessive-compulsiveness, interpersonal sensitivity, depression, anxiety and hostility) and three scores among global distress indices. In the present study, only the GSI, the global severity index which refers to all 90 items, is used.

### *Subjective quality of life*

Subjective quality of life was assessed with a German adaptation of the '*Lancashire Quality of Life Profile*' (LQLP) by Priebe et al. [42]. Questions ask for objective conditions in different life domains, for subjective satisfaction with these domains and for global satisfaction with life, which is rated on a 7-point scale (1 = totally dissatisfied to 7 = totally satisfied).

### *Potential personal maturation*

Potential personal maturation was measured by the German version of the '*Posttraumatic Growth Inventory*' [27]

according to [50]. It consists of 21 Items being attributed to the following subscales: new possibilities, relationship to others, personal strength, appreciation of life and religious changes.

### Changes in life

Caregivers were asked which life domains have changed due to the mental illness of their family member. These changes were assessed by 11 different categories, including number of friends, sexual satisfaction, financial situation, leisure activities or assertiveness, being rated on a 5-point scale ranging from 'strongly improved' to 'strongly worsened'.

### Statistical analyses

Descriptive statistics were used to describe the sample characteristics and the results from each scale. Differences between groups were identified with Student's *t*-test or  $\chi^2$  test. Correlation and partial correlation analyses were performed using either Pearson's correlation coefficient or Spearman's Rho depending on the distribution of the variables. Multiple linear regression analyses were separately calculated for each stress indicator. Analyses were performed with SPSS 12.0.0 for Windows.

## Results

The sample consists predominantly of mothers (71.1%) of an adult child suffering from schizophrenia (67.7%). Notable is a relative high average age of 65.17 (SD 8.71) and a high educational level (42% had finished university). Due to the high average age, half of the caregivers are retired (54.9%), 29.4% are homemakers, and only 10.8% report a fulltime employment. Most relatives are living apart from the patients (68%), and in most cases, the contact is less than 15 h per week. About half of the caregivers (57.4%) attend a self-help group. Most patients have been suffering from schizophrenia with an average duration of 17.82 years (SD 11.61; min: 1 year, max: 62 years) and 6 hospital admissions (SD: 5.88; min: 0, max: 30). As rated by the relatives, most of the patients (60%) are still suffering from moderate to severe symptoms (3–5). Their difficulties in different life domains are perceived as moderate (appr. 2.72 SD 1.50 on a scale from 0 to 5). Nevertheless, more than half of the patients are reported to have a regular employment (58%). At the time of assessment, only a few patients had been actually in hospital.

Caregivers' stress outcome, EE status and other characteristics

As is shown in Table 1, stress indicators, namely subjective well-being, psychological distress and global quality of life differ significantly from the respective norm values, indicating a considerably higher psychological impairment of the carers.

With respect to psychological distress, highest scores are reported for depressiveness, compulsivity and somatization (Table 2).

With regard to illness-related changes in life, 8 of 11 life domains are reported not to have changed whereas negative changes were reported for the financial situation (64.4%), family life (50.5%), sexuality (49.0%) and global quality of

**Table 1** Caregivers' stress outcome: illness-related burden, well-being, psychological distress and global subjective quality of life

Stress indicator	Mean	SD	Norm value
Objective burden (FBA) (0–100)	41	20	–
Subjective burden (FBA) (0–100)	30	19	–
Well-being (Bf-S) ( <i>t</i> values)	<b>55.93***</b>		50 ± 10
Psychological distress (SCL-90R, GSI (0–1))	<b>0.60***</b>		0.41 ± 0.36
Global quality of life (0–7)	<b>4.72***</b>		5.30 ± 0.73

\*\*\*  $P < 0.0001$ , with respect to norm values

**Table 2** Age-adjusted (>60 years) scores of the SCL-90-R scales

Scale	Caregivers	Norm value	<i>P</i>
Somatization	Mean 0.72	0.63	<0.0001
	SD 0.62	0.52	
Obsessive–compulsive	Mean 0.79	0.50	<0.0001
	SD 0.60	0.45	
Interpersonal sensitivity	Mean 0.54	0.34	<0.0001
	SD 0.48	0.43	
Depression	Mean 0.82	0.47	<0.0001
	SD 0.60	0.48	
Anxiety	Mean 0.51	0.38	0.0117
	SD 0.49	0.42	
Hostility	Mean 0.46	0.24	<0.0001
	SD 0.55	0.30	
Phobic anxiety	Mean 0.20	0.27	n.s.
	SD 0.33	0.39	
Paranoid ideation	Mean 0.55	0.36	<0.0001
	SD 0.56	0.47	
Psychoticism	Mean 0.28	0.19	0.0018
	SD 0.31	0.28	

Comparison between the caregiver sample ( $n = 100$ ) and norm values of the German population ( $n = 2,179$ ) (Hesse et al. 2001)

life (67.7%). Interestingly, there is one domain that has been improved in 43% of the caregivers: assertiveness.

Concerning caregivers' assessed resources and dispositions, the scores of general stress response, personality factors, as well as subjective beliefs of control and competence are within the respective norm values.

Carers' index of expressed emotion is high for 76%, including a combination of criticism and emotional overinvolvement for most of the part (45%). There is a good concordance between carers' expressed emotion and the patients' view, if carers are low EE (24% expressed and 21.1% perceived low EE) or high EE with mixed criticism and emotional overinvolvement (45% expressed and 42.1% perceived high EE). With respect to overinvolvement alone, there is an overestimation by 16.3% of the patients, while, in contrast, carers' criticism is underestimated by 10.5% of the patients.

As has been expected, high EE is significantly associated with higher scores of negative strategies within general stress response, illness-related emotional coping strategies, neuroticism and external locus of control as well as lower scores of perceived social support and extraversion. High EE carers report significantly higher levels of patients' symptoms and difficulties in everyday life ( $P < 0.05$  and less). Additionally, significant differences can also be observed with respect to reported changes in life domains dependent on the EE status: Consistently, high EE relatives perceive more negative changes in their life.

#### Correlates and predictors of caregivers' stress outcome

A number of patients' illness variables and caregivers' characteristics are significantly linked to caregivers' stress outcome as is shown in Table 3.

As carers' EE status significantly influences carers' perception of the patients' symptoms and problem behaviour as well as intercorrelates with a number of the carers' own personal dispositions, it is important in bivariate correlation analyses to take into account the possible confounding effects of the carers' EE status. As to evaluate these effects, non EE controlled values are also shown in Table 3 (in brackets).

Living together with the patient (not shown in the tab.), duration of illness and severity of symptoms do not significantly contribute to the level of caregivers' stress. However, moderate but significant correlations can be observed for the patients' problems with family life and regular employment of the patient with objective and subjective burden, and the patients' problems with communication with respect only to subjective burden. The confounding effect of EE on the perception of the patients' problem is especially visible in the primary stress indicators (objective and subjective burden).

With regard to caregivers' characteristics, neuroticism and emotion-focused coping loose significance in influencing carers' perception of burden, when EE is controlled for. As can be seen in Table 3, controlling for EE status makes some important differences, but nevertheless, significant links remain particularly for social support, neuroticism, negative stress response and beliefs of control. Beside EE, which particularly moderates the relationships between perceived patients' characteristics and caregivers' objective and subjective burden, social support and neuroticism are the most relevant correlates of all stress indicators.

With respect to multivariate linear regression, multicollinearity and the bivariate effects of interactions between caregiver and patient characteristics were tested. Although the moderator variables were intercorrelated, they comply with the requirements of multiple linear regression analysis, as intercorrelations were under the critical limit of .60. Interactions between patients' severity of symptoms and problems with different domains of life and caregivers' EE, neuroticism, negative stress response, emotion-focused coping, internal and external locus of control and personal maturation were significantly associated with caregivers' stress outcome, so that they were entered as additional potential predictors into the multiple regression analyses. Regression analyses were separately calculated for each stress indicator and result in differential combinations of predictors for each stress dimension (Table 4).

Interaction effects between caregivers' EE resp. external locus of control and perceived patients' problems with family life contributed in predicting caregivers' objective and subjective burden, but main effects appear more predictive. In particular, social support is predictive for illness-related burden, and neuroticism is the most relevant predictor for carers' well-being, their psychological distress and their quality of life. Among the patients' variables, patients' regular employment appears most important in reducing caregivers' psychological distress and enhancing their well-being.

#### Discussion

The present study aimed at identifying caregivers' burden and predictors of burden in chronic mental illness on the basis of a comprehensive stress model according to Lazarus and Folkman [26]. This multidimensional model has been applied previously in first-admission patients in the context of the Munich 5-year follow-up study [30–34]. Although the different samples cannot be compared, a shared result of these studies is to document the high relevance of caregiver characteristics as contributing factors

**Table 3** Partial correlations of patient and caregiver characteristics and caregiver stress outcome by controlling for caregiver EE status

	Objective burden	Subjective burden	Well-being	Psychological distress	Quality of life
<b>Patients</b>					
Duration of illness	−0.11; n.s. (−0.07; n.s.)	−0.14; n.s. (−0.10; n.s.)	−0.03; n.s. (0.06; n.s.)	−0.05; n.s. (−0.03; n.s.)	0.11; n.s. (0.12; n.s.)
Severity of symptoms	0.21; n.s. <b>(0.29; <i>P</i> = 0.005)</b>	0.12; n.s. <b>(0.29; <i>P</i> = 0.005)</b>	0.11; n.s. <b>(0.23; <i>P</i> = 0.023)</b>	0.13; n.s. <b>(0.23; <i>P</i> = 0.027)</b>	−0.07; n.s. (−0.13; n.s.)
Problems with leisure	0.12; n.s. <b>(0.25; <i>P</i> = 0.014)</b>	0.09; n.s. <b>(0.23; <i>P</i> = 0.024)</b>	−0.01; n.s. (0.11; n.s.)	−0.04; n.s. (0.12; n.s.)	−0.10; n.s. (−0.14; n.s.)
Problems with everyday duties	0.11; n.s. <b>(0.25; <i>P</i> = 0.015)</b>	0.08; n.s. <b>(0.23; <i>P</i> = 0.022)</b>	−0.05; n.s. (0.10; n.s.)	−0.02; n.s. (0.12; n.s.)	0.16; n.s. (−0.05; n.s.)
Problems with communication	0.17; n.s. <b>(0.26; <i>P</i> = 0.010)</b>	<b>0.22; <i>P</i> = 0.032</b> <b>(0.32; <i>P</i> = 0.001)</b>	0.11; n.s. (0.16; n.s.)	0.07; n.s. (0.16; n.s.)	−0.01; n.s. (−0.10; n.s.)
Problems with family life	<b>0.21; <i>P</i> = 0.049</b> <b>(0.33; <i>P</i> = 0.001)</b>	<b>0.23; <i>P</i> = 0.027</b> <b>(0.36; <i>P</i> = 0.000)</b>	0.11; n.s. <b>(0.21; <i>P</i> = 0.037)</b>	0.16; n.s. <b>(0.26; <i>P</i> = 0.011)</b>	−0.07; n.s. (−0.19; n.s.)
Regular employment	<b>−0.28; <i>P</i> = 0.007</b> <b>(−0.34; <i>P</i> = 0.001)</b>	<b>−0.26; <i>P</i> = 0.011</b> <b>(−0.30; <i>P</i> = 0.002)</b>	−0.12; n.s. <b>(−0.28; <i>P</i> = 0.005)</b>	−0.13; n.s. <b>(−0.21; <i>P</i> = 0.040)</b>	0.05; n.s. (−0.15; n.s.)
<b>Caregivers</b>					
EE status	<b>0.37; <i>P</i> = 0.000</b>	<b>0.36; <i>P</i> = 0.000</b>	<b>0.43; <i>P</i> = 0.000</b>	<b>0.42; <i>P</i> = 0.000</b>	<b>−0.36; <i>P</i> = 0.000</b>
Social support	<b>−0.21; <i>P</i> = 0.045</b> <b>(−0.33; <i>P</i> = 0.001)</b>	<b>−0.20; <i>P</i> = 0.051</b> <b>(−0.31; <i>P</i> = 0.002)</b>	<b>−0.23; <i>P</i> = 0.028</b> <b>(−0.45; <i>P</i> = 0.000)</b>	<b>−0.23; <i>P</i> = 0.027</b> <b>(−0.52; <i>P</i> = 0.000)</b>	0.20; n.s. <b>(−0.40; <i>P</i> = 0.000)</b>
NEO-FFI neuroticism	0.14; n.s. <b>(0.21; <i>P</i> = 0.039)</b>	0.19; n.s. <b>(0.25; <i>P</i> = 0.013)</b>	<b>0.60; <i>P</i> = 0.000</b> <b>(0.66; <i>P</i> = 0.000)</b>	<b>0.63; <i>P</i> = 0.000</b> <b>(0.68; <i>P</i> = 0.000)</b>	<b>−0.47; <i>P</i> = 0.000</b> <b>(−0.54; <i>P</i> = 0.000)</b>
NEO-FFI extraversion	−0.01; n.s. (−0.06; n.s.)	−0.01; n.s. (−0.04; n.s.)	<b>−0.33; <i>P</i> = 0.001</b> <b>(−0.42; <i>P</i> = 0.001)</b>	−0.17; n.s. <b>(−0.24; <i>P</i> = 0.018)</b>	<b>0.22; <i>P</i> = 0.030</b> <b>(0.30; <i>P</i> = 0.003)</b>
NEO-FFI openness	−0.04; n.s. (−0.04; n.s.)	−0.04; n.s. (−0.03; n.s.)	0.02; n.s. (0.03; n.s.)	−0.08; n.s. (−0.06; n.s.)	0.09; n.s. (0.01; n.s.)
NEO-FFI agreeableness	−0.18; n.s. (−0.12; n.s.)	−0.10; n.s. (−0.11; n.s.)	−0.20; n.s. <b>(−0.22; <i>P</i> = 0.029)</b>	<b>−0.41; <i>P</i> = 0.000</b> <b>(−0.40; <i>P</i> = 0.000)</b>	0.10; n.s. (0.12; n.s.)
NEO-FFI conscientiousness	−0.03; n.s. (−0.02; n.s.)	−0.05; n.s. (−0.00; n.s.)	−0.15; n.s. (−0.15; n.s.)	−0.16; n.s. (−0.19; n.s.)	0.16; n.s. (0.16; n.s.)
SVF positive strategies	0.12; n.s. (0.10; n.s.)	0.10; n.s. (0.07; n.s.)	−0.12; n.s. (−0.14; n.s.)	0.07; n.s. (0.05; n.s.)	−0.03; n.s. (0.05; n.s.)
SVF negative strategies	0.08; n.s. (0.18; n.s.)	0.00; n.s. (0.16; n.s.)	<b>0.40; <i>P</i> = 0.000</b> <b>(0.44; <i>P</i> = 0.000)</b>	<b>0.49; <i>P</i> = 0.000</b> <b>(0.55; <i>P</i> = 0.000)</b>	−0.19; n.s. <b>(−0.27; <i>P</i> = 0.006)</b>
Emotion-focused coping	0.18; n.s. <b>(0.21; <i>P</i> = 0.048)</b>	0.12; n.s. (0.16; n.s.)	0.21; n.s. <b>(0.32; <i>P</i> = 0.003)</b>	<b>0.26; <i>P</i> = 0.016</b> <b>(0.33; <i>P</i> = 0.002)</b>	−0.13; n.s. (−0.17; n.s.)
Problem-focused coping	0.01; n.s. (0.09; n.s.)	0.06; n.s. (0.03; n.s.)	−0.13; n.s. (−0.06; n.s.)	0.10; n.s. (0.16; n.s.)	0.09; n.s. (0.02; n.s.)
Internal locus of control	−0.10; n.s. (−0.13; n.s.)	−0.11; n.s. (−0.15; n.s.)	<b>−0.40; <i>P</i> = 0.000</b> <b>(−0.42; <i>P</i> = 0.000)</b>	<b>−0.38; <i>P</i> = 0.000</b> <b>(−0.40; <i>P</i> = 0.000)</b>	<b>0.29; <i>P</i> = 0.005</b> <b>(0.29; <i>P</i> = 0.004)</b>
External locus of control	0.15; n.s. (0.16; n.s.)	0.12; n.s. (0.13; n.s.)	<b>0.27; <i>P</i> = 0.010</b> <b>(0.25; <i>P</i> = 0.012)</b>	<b>0.34; <i>P</i> = 0.001</b> <b>(0.33; <i>P</i> = 0.001)</b>	<b>−0.32; <i>P</i> = 0.002</b> <b>(−0.29; <i>P</i> = 0.003)</b>
Personal maturation	0.09; n.s. (0.12; n.s.)	0.09; n.s. (0.12; n.s.)	<b>−0.27; <i>P</i> = 0.010</b> <b>(−0.20; <i>P</i> = 0.008)</b>	0.06; n.s. (0.07; n.s.)	0.07; n.s. (0.03; n.s.)

Non-controlled data are shown in brackets; significant correlations are printed in bold

to different aspects of caregiver stress and their moderating effect on the links between patients' characteristics and caregivers' stress outcome. The selection of different,

although interrelated stress indicators has proven to be important, due to the fact that differential combinations of predictors appeared and that the impact of the patients'



**Table 4** Patient and caregiver predictors of different indicators of caregiver burden

Predictors	Stress indicators	Beta	F	P	Explained variance $R^2$ (%)
Interaction of external locus of control and patient's problems with family	Objective burden (FBQ-OB)	.278	9.68	.008	27.9
EE status		.250		.028	
Social support		-.225		.039	
Interaction of EE and patient's problems with family	Subjective burden (FBQ-SB)	.415	15.14	.000	28.2
Social support		-.293		.003	
Neuroticism	Well-being (Bf-S)	.604	46.03	.000	54.8
Patients' employment		-.348		.000	
Neuroticism	Psychological distress (SCL-90-R, GSI)	.570	26.92	.000	52.5
Patients' employment		-.265		.002	
Agreeableness		-.195		.022	
Neuroticism	Global quality of life (LQ)	-.450	18.98	.000	29.0
EE status		.188		.044	

Results of multivariate linear regression analyses (stepwise method)

employment went beyond the carers' illness-related perception of burden, significantly affecting also their cognitive-emotional well-being as well as their level of psychological distress. How carers perceive their objective and subjective burden is mainly predicted by the joint effects of their belief of control, EE status and the patients' problems with family life as well as the carers' perceived social support. The perception of burden appears to be mainly the result of complex social interactions within the closer family and the social network of the caregiver rather than being determined by illness-related characteristics of the patient. When comparing contributing factors to burden, which resulted from the longitudinal study with those resulting from the present study, it is interesting that social support was not predictive for caregivers' stress outcome in the baseline and follow-up studies of the Munich 5-year follow-up study. Probably, social support becomes more influential in the longer course of the illness as a protective factor for the caregivers. The role of social support in reducing caregiver burden has been widely acknowledged [9, 40], but further research is needed concerning the protective impact of perceived social support on caregivers' health.

The personality factor neuroticism acts as a powerful predictor of caregivers' well-being, psychological distress and global quality of life. This result is in line with the general mental health literature documenting the impact of personality factors, especially neuroticism, in shaping subjective assessment and coping strategies [35, 51], as well as with studies on caregiver burden related to different diagnosis [5, 7, 18, 19]. High levels of neuroticism are also strongly associated with high EE [32, 33]. In addition,

carers' psychological distress is also predicted by agreeableness, although to a lesser extent. As an antagonist of neuroticism agreeableness may act as a protective factor in the stress process by limiting psychological distress probably through more listening and responding to the patient as well as more tolerant and respectful interactions and less negative reactions. Concerning EE, findings of this study support EE as an established and relevant predictor, but in the multivariate context of caregiver burden, EE is only one among other predictors.

The present study has a number of limitations, which clearly limit the conclusions that can be drawn. First of all, there is a sample bias due to the recruitment of the participants from caregiver organizations. It is well known that these organizations predominantly include mothers of adult children suffering from chronic schizophrenia, what is reflected in the present study. Therefore, the findings cannot be generalized to other relatives and younger age groups. Nevertheless, it has to be considered that in most studies investigating family carers of patients suffering from schizophrenia, about 70% of the carers are mothers [52]. Additionally, evidence points to gender differences in caregiving and indicates that females more commonly care for individuals with chronic illness, report higher levels of burden and have a higher risk for psychiatric morbidity [54]. Although most of this research is related to caregivers of patients with neurodegenerative disorders, a similar pattern has been also found for caregivers of schizophrenic patients [45] with mothers reporting more problems and needs for intervention than fathers [52]. The reasons for this include gender role expectations for caregiving, higher scores of neuroticism and emotion-focused coping

strategies in women, which result in greater caregiving involvement of female compared to male caregivers. However, it can be assumed that prior research may have underestimated the effects of caregiving on fathers [15]. Within this context, the findings of our study support the specific burden and needs of mothers caring for an adult child with schizophrenia.

Beside the sample bias, an additional methodological problem of the present study may derive from the recruitment procedure and the low response rates of 20 and 28%. As part of the participants (ApK Munich) had to actively contact the first author, a selection bias could have occurred. With respect to response rates, the highest possible rates are usually desirable. However, high response rates are not automatically indicative for better data, and it has even been shown that a low response rate to a survey may be not a fault but a necessary precondition for meaningful research [44]. Furthermore, a severe response bias in the present study is not very probable, because the survey was not based on random sampling.

A further limitation is the fact that all data are based on self-report measures what might have result in biased ratings, particularly concerning the patients' variables which were assessed as reported by the caregivers and the caregivers' self-rated psychological distress.

With respect to patients' psychopathology, it was not possible to get clinical expert ratings. However, some arguments support the usefulness of caregiver ratings. It has been shown that patients' and caregivers' reports of the patients' actual symptomatology are often concordant and correspond with the expert rating [4]. There is also evidence that caregivers' information may be more valid than the patients' own ratings [17]. Last but not least, feelings of burden may be rather affected by caregivers' subjective perception of the patients' condition than by objective expert ratings. This assumption is also supported by the baseline results of the Munich 5-year follow-up study [30]: Clinical expert ratings of the patients' psychopathology at first admission and discharge as well as expert ratings of the patients' pre-morbid psychosocial adaptation did not correlate with caregivers' burden.

With respect to caregivers' self-rated psychological distress, one can argue that subjective measures of health are essential in predicting morbidity and mortality, even if they are assessed as one global item [20, 21]. Interestingly, concerning social support, perceived and objectively received support do not have the same effects. Many studies have demonstrated that perceived social support can better predict health outcomes and distress than received social support among caregivers [6].

Despite the above-mentioned limitations, the strength of the present study is the comprehensive multifactorial

design of caregiver burden and predictors contributing to a better understanding of the stress process.

## Conclusion

The present study provides support for carers' EE, neuroticism, perceived social support and patients' regular employment being significant predictors of different dimensions of caregivers' stress outcome in chronic mental illness. Although the sample is highly selective and consists predominantly of mothers of adult children with schizophrenia, the results have important clinical implications for psychosocial therapy and family interventions. With respect to psychosocial therapy, the patients' occupational abilities should be strongly enhanced at an early stage, because patients' regular employment seems to be a major protective factor in caregiver burden. Concurrently, family interventions should be offered early on to reduce burden and specifically mothers' risk for psychiatric morbidity. Efforts should aim to improve dysfunctional interactions between patients and caregivers, to enhance the caregivers' social activities and to focus more intensely on the caregivers' own dispositions.

Since the effects of caregiving on fathers may be underestimated in caregiver studies, further research should focus more intensely on the experiences of fathers in order to adapt interventions more appropriately to the needs of mothers and fathers.

**Conflict of interest** None.

## References

1. Baronet AM (1999) Factors associated with caregiver burden in mental illness: a critical review of the research literature. *Clin Psychol Rev* 19:819–841
2. Barrowclough C, Parle M (1997) Appraisal, psychological adjustment and expressed emotion in relatives of patients suffering from schizophrenia. *Br J Psychiatry* 171:26–30
3. Borkenau P, Ostendorf F (1993) NEO-Fünf-Faktoren Inventar (NEO-FFI) nach Costa und McCrae. Hogrefe, Göttingen-Bern-Toronto-Seattle
4. Bottlender R, Jäger M, Kunze I, Groll C, Borski I, Möller H-J (2003) Negative Symptome schizophrener Patienten aus der Perspektive der Psychiater, der Patienten selbst und deren Angehörigen. *Nervenarzt* 74:762–766
5. Carter PA, Acton GJ (2006) Personality and coping: predictors of depression and sleep problems among caregivers of individuals who have cancer. *J Gerontol Nurs* 32:5
6. Chiou CJ, Chang H-Y, Chen IP, Wang HH (2009) Social support and caregiving circumstances as predictors of caregiver burden in Taiwan. *Arch Gerontol Geriatr* 48:419–424
7. De Jong GM, van Sonderen D, Emmelkamp PM (1999) A comprehensive model of stress: the roles of experienced stress and neuroticism in explaining the stress-distress relationship. *Psychother Psychosom* 68:290–298



8. Derogatis LR (1977) SCL-90-R, administration, scoring and procedures. Manual for the R(evised) Version. John Hopkins University School of Medicine, Baltimore
9. Edwards NE, Scheetz PS (2002) Predictors of burden for caregivers of patients with Parkinson's Disease. *J Neurosci Nurs* 34:184–190
10. Feldmann R, Buchkremer G, Minneker-Hügel E, Hornung P (1995) Fragebogen zur Erfassung der Familienatmosphäre (FEF): Einschätzung des emotionalen Angehörigenverhaltens aus der Sicht schizophrener Patienten. *Diagnostica* 41:334–348
11. Ferring D, Filipp S-H (1989) Bewältigung kritischer Lebensereignisse: Erste Erfahrungen mit einer deutschsprachigen Version der "Ways of Coping Checklist". *Zeitschrift für Differentielle und Diagnostische Psychologie* 10:189–199
12. Folkman S, Lazarus RS (1989) An analysis of coping in a middle-aged community sample. *J Health Soc Behav* 21:219–239
13. Gallant MP, Connel CM (1997) Predictors of decreased self-care among spouse caregivers of older adults with dementing illnesses. *J Aging Health* 9:373–395
14. Garretero S, Garcés J, Ródenas F, Sanjosé V (2009) The informal caregiver's burden of dependent people: theory and empirical review. *Arch Gerontol Geriatr* 49:74–79
15. Gosh S, Greenberg J (2009) Aging fathers of adult children with schizophrenia: the toll of caregiving on their mental and physical health. *Psychiatr Serv* 60:982–984
16. Harvey K, Burns T, Fahy T, Manley C, Tattan T (2001) Relatives of patients with severe psychotic illness: factors that influence appraisal of caregiving and psychological distress. *Soc Psychiatry Psychiatr Epidemiol* 36:456–461
17. Ho BC, Flaum M, Hubbard W, Arndt S, Andreasen NC (2004) Validity of symptom assessment in psychotic disorders: information variance across different sources of history. *Schizophr Res* 68:299–307
18. Hooker K, Frazier LD, Monahan DJ (1994) Personality and coping among caregivers of spouses with dementia. *Gerontologist* 34:386–392
19. Hooker K, Monahan DJ, Bowman SR, Frazier LD, Shifren K (1998) Personality counts for a lot: predictors of mental and physical health of spouse caregivers in two disease groups. *J Gerontol B Psychol Sci Soc Sci* 53:73–85
20. Idler EI, Benyamini J (1997) Self-rated health and mortality: a review of twenty-seven community studies. *J Health Soc Behav* 38:21–37
21. Idler EL, Kasl S (1991) Health perceptions and survival: do global evaluations of health status really predict mortality? *J Gerontol* 46:55–65
22. Janke W, Erdmann G (1997) Streßverarbeitungsfragebogen. Hogrefe, Göttingen-Bern-Toronto-Seattle
23. Koukia E, Madianos MG (2005) Is psychosocial rehabilitation of schizophrenic patients preventin family burden? A comparative study. *J Psychiatr Ment Health Nurs* 12:415–422
24. Krampen G (1991) Fragebogen zu Kompetenz- und Kontrollüberzeugungen (FKK). Hogrefe, Göttingen-Toronto-Zürich
25. Kuipers E, Bebbington P, Dunn G, Fowler D, Freeman D, Watson P, Hardy A, Garety P (2006) Influence of carer expressed emotion and affect on relapse in non-affective psychosis. *Br J Psychiatry* 188:173–179
26. Lazarus RS, Folkman S (1984) Stress, appraisal, coping. Stringer, New York
27. Maercker A, Langner R (2001) Persönliches Wachstum (Personal Growth) durch Belastungen und Traumata: Validierung zweier deutschsprachiger Fragebogenversionen. *Diagnostica* 47:153–162
28. Magana SM, Ramirez Garcia JI, Hernandez MG, Cortez R (2007) Psychological distress among Latino family caregivers of adults with schizophrenia: the roles of burden and stigma. *Psychiatr Serv* 58:378–384
29. Magliano L, Fadden G, Economou M, Held T, Xavier M, Guarneri M, Malangone C, Marasco C, Maj M (2000) Family burden and coping strategies in schizophrenia: 1-year follow-up data from the BIOMED I study. *Soc Psychiatry Psychiatr Epidemiol* 35:109–115
30. Möller-Leimkühler AM (2005) Burden of relatives and predictors of burden. Baseline results from the Munich 5-year-follow up study on relatives of first hospitalized patients with schizophrenia or depression. *Eur Arch Psychiatry Clin Neurosci* 255:223–231
31. Möller-Leimkühler AM (2006) Multivariate prediction of relatives' stress outcome one year after first hospitalization of schizophrenic and depressed patients. *Eur Arch Psychiatry Clin Neurosci* 256:122–130
32. Möller-Leimkühler AM, Mädger F (2010) Personality factors and mental health outcome of caregivers of first hospitalized schizophrenic and depressed patients. *Eur Arch Psychiatry Clin Neurosci* 261:165–172
33. Möller-Leimkühler AM, Obermeier M (2008) Predicting caregiver burden in first admission psychiatric patients. *Eur Arch Psychiatry Clin Neurosci* 258:406–413
34. Möller-Leimkühler AM, Jandl M (2010) Expressed and perceived emotion over time: does the patients' view matter for caregivers' burden? *Eur Arch Psychiatry Clin Neurosci* Dec 21 [Epub ahead of print]
35. Moor C, Zimprich D, Schmitt M, Kliegel M (2006) Personality, aging self-perceptions, and subjective health: a mediation model. *Int J Aging Hum Dev* 63:241–257
36. Navaie-Waliser M, Spriggs A, Feldman PH (2002) Informal caregiving: differential experiences by gender. *Med Care* 40:1249–1259
37. Pai S, Kapur RL (1981) The burden on the family of a psychiatric patient: development of an interview schedule. *Br J Psychiatry* 138:332–335
38. Papastavrou W, Charalambous A, Tsangari H, Karayiannis G (2010) The cost of caring: the relative with schizophrenia. *Scand J Caring Sci* 24:817–823
39. Perlick DA, Rosenheck RA, Miklowitz DJ, Chessik C, Wolff N, Kaczynski R, Ostacher M, Patel J, Desai R, the STEP-BR (2007) Prevalence and correlates of burden among caregivers of patients with bipolar disorder enrolled in the systematic treatment enhancement program for bipolar disorder. *Bipolar Disord* 9:262–273
40. Pohl JM, Given CW, Collins CE, Given BA (1994) Social vulnerability and reactions to caregiving in daughters and daughters-in-law caring for disabled aging parents. *Health Care Women Int* 15:385–395
41. Pot AM, Deeg DJH, van Dyck R (2000) Psychological distress of caregivers: moderator effects of caregiver resources? *Patient Educ Cons* 41:235–240
42. Priebe S, Gruyters T, Heinze M, Hoffmann C, Jäkel A (1995) Subjektive Evaluationskriterien in der psychiatrischen Versorgung–Erhebungsmethoden für Forschung und Praxis. *Psychiatr Prax* 22:140–144
43. Pruchno RA, Resch NL (1989) Mental health of caregiving spouses: coping as mediator, moderator, or main effect? *Psychol Aging* 4:454–463
44. Ray JJ, Still LV (1987) Maximizing the response-rate in surveys may be a mistake. *Pers Individ Dif* 8:573–574
45. Reichhart T, Pischel-Walz G, Kissling W, Bäuml J, Schuster T, Rummel-Kluge C (2010) Gender differences in patient and caregiver psychoeducation for schizophrenia. *Eur Psychiatry* 25:39–46
46. Russo J, Vitaliano PP, Brewer DD, Katon W, Becker J (1995) Psychiatric disorders in spouse caregivers of care recipients of Alzheimer's disease and matched controls: a diathesis-stress model of psychopathology. *J Abnorm Psychol* 104:197–204

47. Scazufca M, Kuipers E (1996) Links between expressed emotion and burden of care in relatives of patients with schizophrenia. *Br J Psychiatry* 168:580–587
48. Sha AJ, Wadoo O, Latoo J (2010) Psychological distress in carers of people with mental disorders. *BJMP* 3:a327
49. Sommer G, Frydrich T (1989) Soziale Unterstützung: diagnostik, Konzepte, F-SOZU. Dt. Ges. für Verhaltenstherapie, Tübingen
50. Tedeschi RG, Calhoun LG (1996) The Posttraumatic Growth Inventory: measuring the positive legacy of trauma. *J Trauma Stress* 9:455–471
51. Van Os J, Park SB, Jones PB (2001) Neuroticism, life events and mental health: evidence for person-environment correlation. *Br J Psychiatry Suppl* 40:72–77
52. Wancata J, Freidl M, Krautgartner M, Friedrich F, Matschnig T, Unger A, Gössler R, Frühwald S (2008) Gender aspects of parents' needs of schizophrenia patients. *Soc Psychiatry Psychiatr Epidemiol* 43:968–974
53. Wiedemann G, Rayki O, Feinstein E, Hahlweg K (2002) The family questionnaire: development and validation of a new self-report scale for assessing expressed emotion. *Psychiatr Res* 109:265–279
54. Yee JL, Schulz R (2000) Gender differences in psychiatric morbidity among family caregivers: a review and analysis. *Gerontologist* 40:147–164
55. von Zerssen D (1976) Die Befindlichkeitsskala: parallelförmige Bf-S und Bf-S'. Beltz-Test, Göttingen