



# Determinants of subjective and objective burden of informal caregiving of patients with psychotic disorders

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## Abstract

**Background:** In a previous study, the objective burden of informal caregiving to patients with psychotic disorders amounted to 22 hours/week, and the subjective burden was huge with predominately anxiety and depression as main symptoms. In this study, determinants of the informal caregiving burden are analyzed to find foci for interventions to ease the size of burden.

**Methods:** Patients with psychotic disorders ( $n = 107$ ) and their informal caregivers ( $n = 118$ ) were included. They were assessed with a comprehensive battery of rating scales including patient and caregiver characteristics as well as the amount and quality of health-care provision.

**Results:** A multiple linear regression analysis showed that the subjective burden was significantly lower when patients had higher levels of functioning and when the health status of the informal caregivers was good. No significant determinants were found for the objective burden, but an association was found between a higher socioeconomic status of the caregivers and the amount of money provided for the patient. An association was also found between a positive perception of caregiving and more hours spent on caregiving.

**Conclusion:** The functioning level of the patients was the main determinant of the subjective burden of informal care. For the objective burden, no main determinant was found.

## Keywords

Informal caregiving, schizophrenia, subjective burden, objective burden, determinants

## Introduction

Schizophrenia ranks among the top 10 causes of disability in developed countries and represents a major public health problem, affecting millions of people and their families worldwide (Lopez & Murray, 1998). The total cost for individuals with schizophrenia spectrum disorders has recently been estimated to be €94 billion per year in Europe alone, including direct costs for health care and indirect cost for production losses (Gustavsson et al., 2011).

Psychotic disorders, especially schizophrenia, are associated with a significant and long-lasting health, social and financial burden, not only for patients but also for close relatives (Knapp, 1997). Constraints on social activities and negative effects on family life together with additional costs through household expenditure and lost earnings make the total costs for schizophrenia significant and also difficult to measure (Awad & Voruganti, 2008). Therefore, research is needed to transform the effects of interventions intended to decrease the subjective and objective burden into health economic units. Health economic evaluation of psychiatric health-care effectiveness by using patients'

improvements in rating scales such as EuroQoL 5 dimensions (EQ-5D) shed light on the societal gains of specific interventions (Rabin & de Charro, 2001).

Informal caregiving is based on a preexisting personal relationship between the caregiver and the patient, and no payment is offered for the time and money spent. Informal caregiving can be split up in two components: the subjective and the objective burden. The objective burden includes the time and finances devoted to care, whereas the subjective burden deals with how the informal caregiver perceives the burden of care. Formal care is the ordinary health care or

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community-based support offered to persons defined as patients or clients. Informal and formal caregivers have been found to be linked together by being each other's substitute. Thus, a 1% decrease in formal care costs for people with schizophrenia is associated with a 4%–6% increase in informal care hours (Clark, Xie, Adachi-Mejia, & Sengupta, 2001). This should be an incitement to include both formal and informal caregiving in health political decisions concerning health care and monetary priorities.

In a previous article, we described the magnitude of subjective and objective care burden for informal caregivers to patients with psychotic disorders (Flyckt, Lothman, Jorgensen, Rylander, & Koernig, 2013). We used a daily diary method to maximize the accuracy of our figures. The main findings were that informal caregivers spent on average half of an ordinary work-week (22.5 hours/week) and about 14% of their gross income on care-related activities. The main subjective perceived burden was anxiety/depression in about half of the caregivers and relational problems especially with the patient. Thus, the informal caregiver burden was considerable and should be taken into account when evaluating the effects of health care provided to patients with psychoses (Flyckt et al., 2013). The public implications of this research have so far been great and led to a decree from the Swedish government directed to the Swedish National Audit Office to inspect the burden of care for the next-of-kin's to patients with chronic diseases with a special emphasis on psychiatric disorders. Therefore, it is important to further explore determinants of the informal care burden to pinpoint actions that may ease it.

In order to ease the caregiver burden, it is of significance to have knowledge of the most important factors driving the size of the burden. Factors that have been shown to increase the subjective caregiver burden are whether the patients have apparent psychotic symptoms or abnormal behavior (Grandon, Jenaro, & Lemos, 2008; Magliano et al., 1998; Parabiaghi et al., 2007). Patients' low levels of global functioning have also been found to predict a high perceived caregiving burden (Kumar, Suresha, Thirthalli, Arunachala, & Gangadhar, 2015; Parabiaghi et al., 2007) as well as patients' poor quality of life, the phase of illness, the caregivers' age and sex and perceived support from formal care providers (Lauber, Eichenberger, Luginbuhl, Keller, & Rossler, 2003; McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Parabiaghi et al., 2007; Winefield & Harvey, 1993). However, caregiving burden may be influenced by cultural aspects and differences in family and societal structures in different countries. This study is the first to examine determinants of care burden in a Swedish cohort. What is more, previous studies of determinants of the objective burden have used recall methods (Grandon et al., 2008). In our previous study of informal caregiving, we showed that a recall method is not valid and a daily diary method should be used (Flyckt et al., 2013). Thus, this is the first study of determinants of the objective burden using a prospective method.

## Objectives

The aim of this study was to identify predictors of the objective and subjective informal caregiver burden among patient, caregiver and health-care-related factors.

## Materials and methods

### Subjects

Patients were recruited within a national multicenter collaboration project between the Stockholm Centre for Psychiatric Research (a joint research organization between Karolinska Institutet and the Stockholm County Council) and AstraZeneca Nordic-Baltic 'The Informal Caregiver Burden Project'. The project has previously been described in an article of the magnitude of the informal burden (Flyckt et al., 2013). After the recruitment of around one-third of the patients, the procedure was changed from consecutive recruitment when patients had an appointment at the respective clinic to a screening method of listed patients in the respective outpatient clinic. This change was motivated by a low recruitment rate and by the aim of including a wider range of patients, both the frequent visitors and those who visited the clinics more seldom. A total of 107 patients (53% female; mean age,  $43 \pm 11$  years) aged  $>18$  years were recruited from nine psychiatric open care centers in Sweden. Patients suffering or having suffered from a psychotic episode and being in need of continuous long-term antipsychotic medication for functional psychoses were considered for the study; another prerequisite was that they should have at least one identifiable informal caregiver, leaving patients without informal caregivers noneligible. One or two of the patients' closest informal caregivers ( $n=118$ ; 67% female;  $58 \pm 15$  years) were recruited during the 2-year recruitment period (2008–2010) (Table 1). The most relevant informal caregiver(s) was chosen based on an appreciation of the amount of caregiving according to the patient and the psychiatric staff. The study was approved by the ethics committee at Karolinska Institutet, Stockholm (Diary number: 2007/1623-31).

The study was designed as a cross-sectional assessment phase (visit 1) followed by a prospective observational follow-up phase of 4 weeks. At visit 1, all assessments of determinants and one of the outcome variables (subjective burden) were made. Factors were assessed that are plausible to constitute determinants of the subjective and objective burden of informal care. Patient-related factors such as symptoms; functioning and quality of life; caregiver-related factors such as sociodemographics, age, gender, salary and position; and health-care-related and support-related factors were collected. Thereafter, in close connection to visit 1, the informal caregivers were given computer (or paper) diaries for the assessments of other outcome variables (the objective burden; time and money spent) during a 4-week follow-up period.

## Potential determinants

**Patient characteristics.** Functional and symptomatic characteristics of the patients were assessed with the eight-item *Positive and Negative Syndrome Scale* (PANSS) remission scale using the Structured Clinical Interview for Symptoms of Remission (SCI-SR) (Andreasen, 2006). The global functioning was assessed by the Global Assessment of Functioning (GAF) scale (Jones, Thornicroft, Coffey, & Dunn, 1995). The suicide ideation was measured using *Scale for Suicidal Ideation* (SSI) (Hoefman, van Exel, Looren de Jong, Redekop, & Brouwer, 2011). The EQ-5D was used to measure health-related quality of life (Rabin & de Charro, 2001). Sociodemographic data on living, occupation and socioeconomic status were collected (Table 1).

**Informal caregiver characteristics.** Data on health status (EQ-5D), global health status (EQ Visual Analogue Scale 1 (VAS 1), health-related quality of life (EQ-5D index) (Burstrom, Johannesson, & Diderichsen, 2001; Rabin & de Charro, 2001) and psychological health or 'utility' (CarerQoL-7D; Hawthorne & Richardson, 2001) were collected at visit 1 (Brouwer, van Exel, van Gorp, & Redekop, 2006). Furthermore, the COPE index was used, a scale that assesses perceived support from others, as well as the Work Productivity and Impairment Questionnaire (WPAI), a scale that assesses the effect on the informal caregivers' work, productivity (Balducci et al., 2008; McKee et al., 2003; Reilly, Bracco, Ricci, Santoro, & Stevens, 2004). Sociodemographic data such as living conditions, income, employment or retirement status, marital status, education, socioeconomic status and factors of importance for the care-situation such as distance to the patient, living together or apart from the patient and having support from others were collected at visit 1.

**Health-care and community support variables.** The frequency and type of contact (doctor, nurse or other) with psychiatry and frequency of contact with community (support in living, other) were assessed at visit 1. Treatments and community-based interventions such as medication, therapy, supported living, supported occupation and such were assessed at visit 1. The treatment given to the patients was unchanged throughout the study.

## Outcome variables

**Subjective burden of informal care.** The subjective burden was measured by the CarerQoL, a new measure designed to measure the overall subjective burden of caregiving (Brouwer et al., 2006). The happiness question is a VAS ranging from 0 to 10 between *completely unhappy* (score 0) and *completely happy* (score 10) (Beck, Morris, & Beck, 1974).

Health status and quality of life were also assessed in the same way as the seven-country European caregiver project EuroFamCare (EFC) (Lamura et al., 2008). A

**Table 1.** Characteristics of informal caregivers and patients.

Variable	Caregivers (n = 118)	Patients (n = 107)
<b>Gender and age</b>		
Women (%)	67	53
Mean age (range), years	58 (17–87)	43 (22–68)
Percent with age of 65 years and above	35	4
<b>Civil status (% in each category)</b>		
Not married and living alone	13.6	64.5
Married or living together with another person	65.3	23.4
Divorced or separated	16.1	12.1
Widow or widower	5.0	0
<b>Living conditions (% in each category)</b>		
Alone	22.0	63.6
With spouse	62.7	21.5
With parents	3.4	5.6
With relatives	5.1	3.8
With children	6.8	1.8
Other	0.0	3.7
<b>Present housing conditions (% in each category)</b>		
Own home	N.A.	86.9
Group living or treatment home	N.A.	10.3
Other	N.A.	2.8
<b>Distance from caregiver to patient (% in each category)</b>		
Living in the same household	N/A	24.6
Within walking distance	N/A	11.9
Within 10 minutes by car or bus or train	N/A	11.9
Within 30 minutes by car or bus or train	N/A	22.0
Within 60 minutes by car or bus or train	N/A	22.0
More than 60 minutes away by car or bus or train	N/A	7.6
<b>Employment status (% in each category)</b>		
Employed or running own enterprise	54	16
Unemployed	0	10
Retired or sick pension	39	51
Sheltered jobs	0	21
Other	7	2
<b>Income per month</b>		
Estimated total income (€) from different sources, mean	2,153	1,205
<b>Main source of income (% in each category)</b>		
Support from public funds	7.6	44.9
Salary	53.4	15.0
Pension (including public retirement funds)	38.1	39.3
COPE negative impact scale <sup>a</sup>	20.0 (2.3)	N/A
COPE positive impact scale <sup>a</sup>	10.7 (1.3)	N/A
Scale for suicide ideation <sup>a</sup>	2.34 (7.09)	
GAF scale <sup>a</sup>	N/A	51.5 (11.2)
Utility <sup>a</sup>	0.765 (0.24)	N/A

N.A.: not assessed; N/A: not applicable; GAF: Global Assessment of Functioning; SD, standard deviation.

The applied exchange rate was €1 = SEK9.75.

COPE: Carers of Older People in Europe; <sup>a</sup>M (SD).

single item assessing the caregiver's health was taken from the Short Form-36 (SF-36; Brazier et al., 1992). It asks the participant to record the general health status on a 5-point scale, anchored by *excellent* (score 1) and *poor* (score 5). From the same instrument, a single item assessed overall quality of life for the preceding 2 weeks, with responses recorded on a 5-point scale anchored by *very good* (score 1) and *very poor* (score 5), here referred to as the SF-36 happiness subscale.

**Objective burden of informal care.** The objective burden in terms of expenses and time spent on informal caregiving was recorded on a daily basis during the first two follow-up weeks, and the expenses were also recorded for another 2 weeks. At the end of the follow-up period, the informal caregivers were asked to recall any major expenses during the preceding 11 months before the study start as a consequence of the mental illness of the care-recipient. In addition, the informal caregivers were instructed to report the 'standby' time, that is, the period of time they had to be available without performing any of their own activities.

### Statistical methods

The variables were summarized using standard descriptive statistics such as means (*M*), medians (*Md*), standard deviations (*SDs*) and frequencies. The subjective and objective burden was analyzed using multiple linear regression with GAF, utility from EQ-5D, gender, age and center as independent variables and burden as the dependent variable as the first analysis. Some of the predictive variables have also been dichotomized to show the direction of the variables, although some information is lost in the process, and the covariate structure is left out (Royston, Altman, & Sauerbrei, 2006).

Since the primary model for objective burden (hour spent and costs) failed, linear regression with forward selection was used including most variables measured in the study, and variables with high explanatory value ( $p < .05$ ) were selected. The variance inflation factor was calculated to delete variables that were showing multicollinearity (correlates with each other) before applying the linear regression model.

SF-36 happiness subscale has a range from 5 (*very poor*) to 1 and has been linear transformed to be similar to the CarerQoL scale which has a range from 0 to 10 (*completely happy*).

## Results

### Clinical and sociodemographic characteristics of patients and caregivers

Most of the patients lived alone (65%) and were not married (65%), while most caregivers (63%) were married. Nearly all had a short distance to travel to the caregiver

(92% less than 1 hour) and 25% lived in the same household. Only 16% of the patients worked, while most caregivers were in employment (54%) or were retired (39%). The caregivers received nearly twice the income of the patients, who relied on the social welfare system or disability pensions as sources of income (84%) (Table 1).

### Determinants of subjective burden

The multiple linear regression analysis showed that the primary model for predicting the subjective burden was good and that the subjective burden was significantly lower when patients had a higher GAF and when the health status of the caregiver was good (measured by utility in EQ-5D of the caregiver; Table 2). The gender and age relationships did not reach statistical significance, although female caregivers had a higher subjective burden, and the subjective burden increased with age for both genders. There was no difference between the different centers.

There was a trend where the informal caregivers' subjective burden improved between GAF values of 30 and 70, reaching a stable level when the GAF value is above 70 (Figure 1).

The subjective burden was measured by two different scales (the CarerQoL VAS and the SF-36 happiness subscale). The two different scales gave identical results (Table 3).

### Determinants of objective burden

The multiple linear regression analysis of the objective burden measured as either number of hours spent caregiving or as economic support, both measured in the daily diary, failed to give results similar to the subjective burden. None of the planned variables (GAF, EQ-5D-VAS, gender, age and center) showed any significant relationship ( $p > .25$  for all) (Table 2).

The forward selection procedure identified that the number of hours spent in support by the caregiver had a correlation with the COPE negative index ( $p < .0001$ ), where the caregiver spent more hours when there was little negative impact of the caregiving (i.e. low COPE negative values; Figure 2).

Predictive factors for economic support were other economic variables and the COPE positive index (Table 4). The economic variable showed that more public support and higher total income of the patient reduced the economic support given by the caregiver. Also, if the caregiver had a higher income, the economic support to the patient was increased. A higher COPE positive index, that is, a higher satisfaction from giving support, created a higher economic support given by the caregiver to the patient.

## Discussion

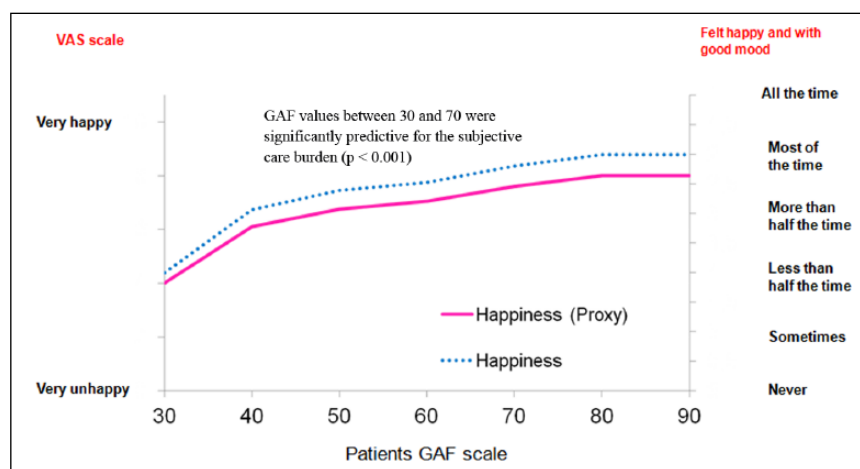
The main result of this study is that the patient's level of functioning measured by GAF and the health state of the

**Table 2.** Determinants of subjective and objective burden of informal caregiving to patients with schizophrenia.

Independent variable	Outcome variable			
	Subjective burden, <i>CarerQoL</i>	Subjective burden, <i>SF-36 happiness subscale</i>	Objective burden, <i>Cost</i>	Objective burden, <i>Hours</i>
GAF	<.001	<.001	.527	.085
Gender	.173	.087	.606	.186
EQ-5D, utility	<.001	<.001	.522	.394
Age	.215	.942	.280	.281
Center	.268	.734	.583	.468

SF-36: Short Form-36; EQ-5D: EuroQoL five dimensions.

The  $p$ -values from a multiple linear regression analysis of outcome variables from independent variables.



**Figure 1.** Subjective burden of caregiver measured by COPE VAS (left vertical axis) or by SF-36 happiness subscale (right vertical axis) versus the GAF score of patients.

informal caregiver measured by the EQ-5D (utility) are the most potent determinants of the subjective burden of the informal caregiver. This is in line with previous findings (Kumar et al., 2015), indicating patient's functioning level to be a determinant of subject burden independent of cultural and societal influence. The importance of the functional outcome has been acknowledged in clinical psychiatric research during the past decade. Antipsychotic medication has been shown to rescue lives both from suicide and mortality due to somatic illnesses, and it leads to positive health economic consequences but, for the majority of patients with schizophrenia, social functioning remains poor (Rabinowitz et al., 2012; Tiihonen et al., 2006). Furthermore, from the time when the remission criteria, defined as the pharmacological response to antipsychotics, are established, it has been found that only about one-third of patients with schizophrenia will reach remission, diminishing the possibility for psychiatry to fully help patients and their next-of-kin (Mosolov, Potapov, & Ushakov, 2012; Ventura et al., 2011).

The second-generation antipsychotics (SGA) have shown favorable effects on symptoms compared to first-generation antipsychotics (FGA), but this has largely been

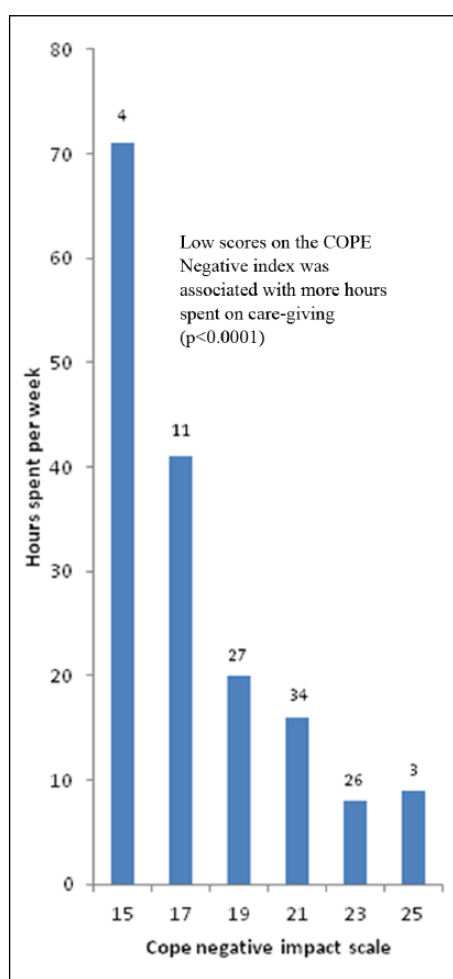
attributable to a better effect on positive symptoms, whereas negative and cognitive symptoms remain largely unaltered, the latter two being to a greater extent responsible for the functional outcome of patients with schizophrenia (Rabinowitz et al., 2012). Thus, future research on psychiatric treatment should focus on functional outcome in the respective fields of pharmacological and psychosocial interventions.

The GAF is an integral part of the standard multi-axial psychiatric diagnostic system (i.e. *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; DSM-IV)) and was used in the study. The GAF is the standard method for representing a clinician's judgment of a patient's overall level of psychosocial functioning. As such, it is probably the most widely and easily used method for assessing impairment among patients with psychiatric disorders. The GAF is also a valuable predictor of outcome. For example, in a study of first-episode psychoses, the GAF at first admission as well as the highest GAF the year prior to the first admission predicted a poor 5-year outcome with a fairly high hit-rate (Flyckt, Mattsson, Edman, Carlsson, & Cullberg, 2006). Good validity, however, requires interrater reliability training and adequate compliance with the

**Table 3.** Subjective burden of informal caregivers to patients with psychotic disorders globally and divided into sub-populations measured by CarerQoL VAS and SF-36 happiness subscales.

Category	Mean happiness from CarerQoL	Mean happiness transformed from SF-36 subscale
Overall	6.75 (1.95)	6.72 (2.8)
Men as caregivers	7.27 (1.9)	7.52 (3.0)
Women as caregivers	6.52 (1.3)	6.30 (2.4)
Caregivers' age below 55 years	7.32 (1.5)	7.02 (2.5)
Caregivers' age above or equal to 55 years	6.40 (2.1)	6.50 (2.6)
Patients' GAF above or equal 70	8.14 (1.1)	8.00 (2.4)
Patients' GAF below 70	6.65 (1.9)	6.60 (2.7)

SF-36: Short Form-36; GAF: Global Assessment of Functioning; VAS: visual analogue scale; SD: standard deviation. Both scales show better happiness with higher values (scales 0–10). Values are mean happiness (SD).



**Figure 2.** Hours spent by caregiver per week versus COPE negative impact scale (higher value shows lower satisfaction to give support). Number above bars is number of patients in each category.

manual (Goldman, Skodol, & Lave, 1992). The results of this study provide support that patients with serious impairments are likely to be burdensome to their relatives, and

**Table 4.** Explanatory variables for the economic burden of informal caregivers to patients with psychotic disorders.

Explanatory variable	SEK per month	
	Coefficient (SEM)	p-value
Public economic support to patient	-851 (267)	.0020
Patients total income	-0.022 (0.008)	.0138
Caregivers' total income	0.011 (0.005)	.0355
COPE positive index	96.1 (43)	.0289

SEM: standard error of the mean. Regression coefficients for predictors of economic burden for selected explanatory variables with significant p-values. €1 = SEK9.75. A negative coefficient shows an inverse relationship.

therefore, GAF, both current and the highest during the previous year, is the most important measure to assess the determinants of the burden of informal caregivers.

No predominant determinants were found for the objective burden. The main result for the monetary burden was that provided the patient's income was low or the caregiver had a good income, more money was given to the care-recipient from the informal caregiver, unless sufficient support was provided by the formal care and support system/general insurance. The interpretation of these findings may be that if patients with monetary needs are provided help from society, the informal caregivers will be relieved to a greater extent from the financial burden vis-à-vis the care-recipient. This interpretation is supported by findings from a study comparing England and Germany that concluded that informal caregivers are less burdened in Germany probably because of a better formal care system relieving the family to a greater extent (Roick et al., 2007).

The time spent on informal care increased if there was a positive perception by the informal caregiver about the caregiving situation and if the alliance between the patient and the formal caregiver was better. Thus, it seemed that patients with an ability to form good-quality relationships are likely to have more support from their family, perhaps

leaving the most severe cases without informal care. This is in line with research showing that adverse behavior increases the psychological burden of informal care, and this may lead to less contact with the care-recipient (Grandon et al., 2008; Lauber et al., 2003; Spruytte, Van Audenhove, Lammertyn, & Storms, 2002). Psychosocial interventions have been shown to decrease relational problems associated with adverse and unpredictable behavior in schizophrenia by tempering the emotional climate in the family which also reduces the relapse rate of the patient (Tarrier et al., 1988; Tattan & Tarrier, 2000).

Female and elderly caregivers experienced a higher degree of subjective burden compared to men and younger caregivers. This is in line with other studies of the subjective burden and should be taken into account in family support and interventions (Awad & Voruganti, 2008).

The present findings suggest that there are different determinants for the subjective and objective burden and that these two types of burdens may represent different dimensions of the caregivers' burden situation. This is supported by findings that the objective burden is lower in schizophrenia than in neurological disorders, while the subjective burden is higher (Flyckt et al., 2013; Lamura et al., 2008). The differences in type of burden are probably attributable to more stigmas, inadequate support and less social acceptance of mental compared to physical or neurological illnesses which in turn distress families of patients with psychoses more than families of patients with neurological illnesses (Awad & Voruganti, 2008).

### Limitations

The direction of determinants on outcome variables should be cautiously interpreted in studies with cross-sectional design; however, the main finding that the level of functioning is a strong contributor to the subjective burden is supported by other studies and is also intuitively assumed (Parabiaghi et al., 2007).

The generalizability of the findings to the wider population of patients with psychoses in open care settings is hard to judge, but the number of patients in remission (35%) as well as their mean GAF score (50) indicates that our patient group appears to be representative (Gaite et al., 2005; Placentino et al., 2009; Van Os et al., 2006). The heterogeneity of the patients in terms of their diagnosis and needs can be looked upon as a limitation, but again, the naturalistic perspective is what we aimed to study, in order to give a picture of the informal caregivers' real-life situation. The wide span of needs also gave more opportunities to study determinants than would have been the case in a more homogeneous sample.

### Conclusion

The main finding was that the subjective burden of informal caregiving to patients with psychotic disorders is

mainly determined by the functional level of patients and the health status, gender and age of the informal caregiver. Thus, lower functional level of the patient, male gender and younger ages of the caregiver predicted a higher subjective caregiver burden. No other determinant contributed significantly to the subjective burden. The objective burden seemed more linked to the socioeconomic situation of the patient and the caregiver as well as the degree of financial support by society. These findings suggest that interventions aiming at relieving the burden should identify the type of predominant burden (i.e. subjective or objective) and then choose the intervention accordingly.

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