

Family Caregiving in Schizophrenia: Domains and Distress

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Abstract

This article focuses on (1) the dimensionality of the caregiving concept; (2) the relation between the identified caregiving dimensions and characteristics of the patient, the caregiver, and their relationship; and (3) the relation between caregiving dimensions and caregiver distress. Findings are based on data from 480 members of the Dutch family organization for patients with schizophrenia/chronic psychosis who completed (1) the Involvement Evaluation Questionnaire (IEQ), which assesses general information (e.g., household characteristics), caregiving, help seeking, coping and distress, and (2) a questionnaire comprising questions on onset and course of the patient's disorder and symptoms characteristic of schizophrenic disorders. Four caregiving domains were found: tension, supervision, worrying, and urging. These domains were strongly related to the patient's symptomatology, contact between the relative and the patient's mental health professional, and the number of hours of mutual contact between the patient and the relative. The connection between patient, caregiver, and relationship variables and the caregivers' distress could be explained substantially by the overall caregiving score. Our findings suggest that caregiving tasks and problems may be diminished and related distress lowered by reducing the patient's symptomatology, increasing relatives' coping capacities, and decreasing the number of contact hours. If distress is reduced, relatives may use less psychotropic medication and may visit their general practitioner less often.

Key words: Caregiving, distress in relatives, Involvement Evaluation Questionnaire.

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Severe mental illness, like schizophrenia, has far-reaching consequences for both patients and their relatives (Hatfield and Lefley 1987; Tessler et al. 1987). For patients themselves, self-care may be impeded, the capacity for social relationships diminished, and employment opportunities reduced. Mental illness creates obstacles to independent living and may diminish life satisfaction (Schene 1990).

Patients' relatives experience feelings of loss and grief (Miller et al. 1990). They are confronted with uncertainty and emotions of shame, guilt, and anger. Like the patient, they feel stigmatized and socially isolated (Wahl and Harman 1989). Their lives may be disrupted by providing more care than would normally be appropriate for someone of the patient's age. In those cases where reciprocity between family members is out of balance, normal care changes into caregiving. Addition of the caregiving role to already existing family roles may become stressful, both psychologically and economically (Clark 1994; Schene et al. 1996).

Consequences for patients' relatives—formerly referred to as family or caregiving burden—have been studied for almost four decades (Platt 1985; Schene et al. 1994). Initially, studies were purely descriptive. In the early 1970s, research instruments were developed (Spitzer et al. 1971) and subsequently used in epidemiological studies and randomized clinical trials (Washburn et al. 1976; Herz et al. 1977; Fenton et al. 1979; Test and Stein 1980).

Developers of those instruments more or less agree about the different aspects of caregiving, although their

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accents and their operationalizations differ widely. Most of them make some distinction in objective and subjective consequences. Objective consequences are related to patients' behavior and constituted by the new and enduring caregiving tasks and the intra- and extrafamilial problems associated with taking care of the patient. Subjective consequences arise from the fact that relatives have to cope with these caregiving tasks and problems. If the relatives are not successful, they experience psychological distress or minor psychiatric disorders.

In recent years, the experiences of caregivers for patients with chronic diseases have been described in theoretical models (Maurin and Barmann Boyd 1990; Schene 1990; Gallop et al. 1991). For the most part, these models combine system and stress-appraisal-coping theories (Elliot and Eisdorfer 1982; Schene 1990; Biegel et al. 1991; Szmuckler et al. 1996). The chronic illness of a family member is considered as an objective stressor that because of the caregiving tasks results in role strain for the caregiver or the relative. To what extent caregiving will have an impact on the caregivers' mental and physical health depends on characteristics of the patient, the relative, their relationship, and their environment.

In psychiatry, little empirical research is available about what exactly constitutes different domains of caregiving and how these are related to the caregiver's distress. A review of the 21 available instruments for measuring caregiving in psychiatry made clear that only 5 developers had carried out any conceptual research like factor analysis (Schene et al. 1994).

The aims of this article are to describe (1) the dimensionality of the caregiving concept; (2) the connection between the identified caregiving dimensions and characteristics of the patient, the caregiver, and their relationship; and (3) the connection between caregiving dimensions and caregiver distress. We use data from 480 relatives of chronic psychiatric patients who mainly have schizophrenia.

Methods

Instrumentation. To assess caregiving and distress we used the Involvement Evaluation Questionnaire (IEQ; Schene and van Wijngaarden 1992; Schene et al. 1996), which has been developed over the past 10 years and is based on an extensive review of the literature between 1940 and 1992 (Schene 1986; Schene et al. 1994). The IEQ contains three sections: (1) general information: patient, caregiver and household characteristics, relationship between patient and caregiver, degree of mutual contact, help seeking and coping (32 items); (2) caregiving consequences (36 items); and (3) a distress scale (8 items);

this distress scale comprises 8 psychosomatic symptoms that, according to the literature (Schene 1986, 1990), frequently occur among family members of psychiatric patients.¹

Since the principal aim in developing the IEQ was to achieve a reliable change-sensitive measure, we dropped from earlier versions items relating to stigma, guilt, social network loss, patient suicide attempts, and other aspects that either happen rarely or are insensitive to change. For the same reason, a timeframe of the foregoing 4 weeks was chosen. Most items are scored on 3- or 5-point Likert scales.

For the present study, a 25-item questionnaire comprising questions on the onset and course of the patient's disorder (6 items) and symptoms characteristic of schizophrenic disorders (19 items) was added. Symptom severity during the previous 4 weeks was scored on a 3-point scale (1 = never, 2 = sometimes, 3 = often). The 19 symptom items in this additional questionnaire originated from the Positive and Negative Syndrome Scale (Kay et al. 1987) and were adapted for use in a questionnaire for relatives of patients with schizophrenia.² The formulations were judged by four psychiatrists on clarity, feasibility, and appropriateness. Factor analysis of the 19 symptom items revealed 4 underlying factors: *psychosis* (3 items; $\alpha = 0.79$), *agitation* (4 items; $\alpha = 0.71$), *apathy* (3 items; $\alpha = 0.66$), and *affect* (depression and anxiety; 3 items; $\alpha = 0.57$). Both the IEQ and the additional questionnaire can be obtained from the primary author.

Procedure. This study was carried out among members of Ypsilon, the Dutch family organization for patients with schizophrenia and/or chronic psychosis. This organization has 2,700 members; 2,000 main members (relatives representing a household), 500 supporting members (relatives living in the same household as a main member but having joined Ypsilon themselves), and 200 professional members (e.g., psychiatrists, psychologists, etc.). The IEQ was mailed to a random sample of 1,000 of the (2,000) main members. After one reminder, 700 IEQs

¹Items of the distress scale are headache, muscle pain, lack of appetite, sleeplessness, nervous tension, depression, quick temper, and extreme tiredness. The scalability of the eight distress items has been tested with nonparametric latent trait analysis (Mokken scaling; Mokken 1971). The items form a cumulative scale (Loevinger's coefficient $H = 0.45$) with good reliability ($\rho = 0.81$). The total distress-scale score ranges from 8 to 24, with a mean of 13.6 (SD = 4.0).

²Relatives were asked whether the patient talks much, doesn't talk or talks just a little, is restless, hardly does a thing, does the same thing over and over again, is aggressive, is withdrawn, has a bad level of self-care, hears sounds that do not exist, has delusional thoughts, sees things that are not there, is frightened or anxious, is somber or depressed, bothers other people, is quickly irritated, is forgetful, behaves strangely, sleeps badly, or is confused.

(response rate: 70%) were received. Because of missing data, 680 were suitable for analysis.

Sample. The sample has been described in detail elsewhere (Schene and van Wijngaarden 1993, 1995). We found quite substantial differences among our sample of main members in the degree of direct contact with the patient (including telephone calls); per week 29.4 percent had contact lasting less than 1 hour, 20.9 percent had 1 to 4 hours, 21.8 percent had 5 to 16 hours, 6.8 percent had 17 to 32 hours, and 21.2 percent had more than 32 hours. Because respondents whose contact with the patient lasted less than an hour would not be able to answer most of the questions, the analyses pertain to the 480 relatives who had at least 1 hour per week personal contact with the patient.

Most of the 480 respondents were female (71.3%); their mean age was 55.9 (standard deviation [SD] = 11.8) years; 81.0 percent were parents of the patient, 7.3 percent were siblings, 9.2 percent were partners, 0.8 percent were ex-partners, 1.3 percent were children, and 0.4 percent had another relationship with the patient; 77.9 percent were living with their partner and/or children, 17.9 percent lived alone, 3.1 percent lived with other family members, and 1.1 percent were living in other circumstances.

Most patients were male (72.9%) with a mean age of 32.6 (SD = 9.8) years. Female patients were, on average, 2 years older than their male counterparts (34.1 vs. 32.0 years). Their psychiatric diagnoses (made by mental health professionals and reported by the respondents) included schizophrenia (86.0%), chronic psychosis (5.4%), manic-depressive disorder (5.2%), borderline personality disorder (2.0%), or others (1.4%). The duration of the disorder (years since onset) was more than 10 years (48.9%), 4 to 10 years (40.4%), 1 to 3 years (9.7%), and less than 1 year (1.0%). The mean age of onset was 22.0 years for men and 22.8 years for women. A minority of the patients (12.3%) had children.

Approximately one-third of the 480 relatives were living with the patient in the same household; these included parents (72%) and partners (18%). Those not living with the patient were mainly parents (85%) and siblings (10%). Of all parents, 25.7 percent lived with the patient; 79 percent of partners did so.

Results

Caregiving Domains. A principal component analysis on the 36 caregiving items (section 2) of the IEQ revealed 4 distinct caregiving domains (see table 1):

- *tension* ($\alpha = 0.85$): This domain refers to the strained interpersonal atmosphere between patient and relatives.

- *supervision* ($\alpha = 0.77$): This domain refers to the caregiver's tasks of ensuring and guarding with regard to patient's intake of medicine, sleep, and dangerous behavior.

- *worrying* ($\alpha = 0.80$): This domain covers painful interpersonal cognitions, such as concern about the patient's safety, general health, and the kind of care he or she is receiving.

- *urging* ($\alpha = 0.71$): This domain refers to activation and motivation, that is, stimulating patients to take care of themselves, to eat enough, and to undertake activity.

The two interpersonal domains, *tension* and *worrying*, have a substantial correlation (0.50). This was also true of the two other domains, *supervision* and *urging* (0.48). All other correlations between domains were 0.35 or lower.

Caregiving Overall Score. To assess overall caregiving, a scale was constructed using the SPSS (Norusis 1988) program Reliability. This scale comprised 29 of the 36 caregiving items and has a broad coverage of the caregiving concept (see table 1). In addition to the 20 items of the 4 caregiving factors (tension, supervision, worrying, and urging), it comprises 9 additional items (e.g., extra costs, alcohol intake, direct help to the patient). The internal consistency (α) of the overall caregiving scale was 0.90, the range 29 to 145 and its mean score 55.5 (SD = 15.3).

Relation Between Caregiving and Patient, Caregiver, and Relationship Characteristics. The second aim was to study the influence of characteristics of the patient (set A), the caregiver (set B), and their relationship on the four caregiving domains and the overall caregiving score (set C). This was done by multiple regression analyses (see table 2). The patient characteristics (set A, table 3) consisted of seven items from section 1 of the IEQ and the four symptom scores derived from the additional questionnaire. The caregiver characteristics (set B, table 3) consisted of five and the set relationship characteristics (set C, table 3) consisted of four items from section 1 of the IEQ. In these regression analyses all items per set were entered simultaneously.

Both at the dimensional and overall caregiving level, patient characteristics show the strongest relation with caregiving tasks and problems. They account for 28 percent of the variance in the overall caregiving score. At the dimensional level, patient characteristics are mainly related to *tension* and *worrying*. Characteristics of the caregiver and the relationship are less strongly related to caregiving. That is, 12 percent of the variance of the overall caregiving score can be accounted for by caregiver

Table 1. Factor structure¹ and loadings of the Involvement Evaluation Questionnaire (IEQ)

	Tension	Supervision	Worrying	Urging
Factor items²				
Strained atmosphere	0.75			
Quarrels caused by the patient	0.75			
Respondent annoyed by the patient's behavior	0.72			
Others annoyed by the patient's behavior	0.63			
Felt threatened by the patient	0.64			
Considered moving out	0.65			
Global burden	0.55			
Ensuring intake of required medicine		0.60		
Guarding from committing dangerous acts		0.67		
Guarding from self-inflicted injury		0.57		
Guarding from taking illegal drugs		0.55		
Ensuring that the patient got enough sleep		0.74		
Sleep disturbed by the patient		0.61		
Worrying about the patient's safety			0.72	
Worrying about the kind of help			0.75	
Worrying about the patient's general health			0.69	
Urging the patient to take proper care of himself/herself				0.76
Helping the patient to take proper care of himself/herself				0.63
Urging the patient to eat enough				0.61
Urging the patient to undertake activity				0.71
Additional items³				
Accompanying the patient on outside activities		0.42		
Guarding the patient from drinking too much alcohol				0.49
Carry out tasks normally done by the patient		0.46		
Urging the patient to get up in the morning		0.44		
Ability to pursue own activities and interests				0.41
Total costs during the previous 4 weeks				0.46
Worrying about how the patient would manage financially if no longer helped by relative			0.50	0.56
Worrying about the patient's future			0.45	
Worrying about one's own future	0.44			

¹Principal component factor analysis conducted on 36 caregiving items using the following criteria: (1) variables should load ≥ 0.50 on a factor and ≤ 0.40 on all others, (2) a factor should contain at least 3 variables. The 4 factors explain 45 percent of the total variance (36 variables) and 60 percent of the variance of the 20 items fulfilling the factor analysis criteria.

²Items fulfilling the factor criteria: ≥ 0.50 on a factor, ≤ 0.40 on all other factors.

³Items not fulfilling the factor criteria but with item-total correlation ≥ 0.30 ; only factor loadings ≥ 0.40 are displayed.

characteristics and 6 percent by relationship characteristics. At the dimensional level, caregiver characteristics are mainly related to tension and relationship characteristics to supervision. Characteristics of the patient, the caregiver, and their relationship each account for relatively unique parts of the explained variance of the caregiving domains and the overall score. (See table 2: The sum of the explained variance [$R^2_{\sum A,B,C}$] using either of the three sets of variables does not substantially exceed the R^2_{A+B+C} found by regression analysis entering all characteristics of the three sets together.)

Stepwise regression analysis was used to single out which patient, caregiver, and relationship characteristics are the most predictive in relation to the caregiving domains and the overall caregiving score (see table 3).

With regard to patient characteristics, symptomatology during the previous 4 weeks was consistently related to caregiving tasks and problems. Although there are some differences between the four caregiving domains, the overall caregiving score is related to all four separate symptom groups.

In the case of caregiver characteristics, the ability to cope with the patient's mental health problems and being in contact with the patient's mental health professional are significantly related to most caregiving domains as well as to the overall caregiving score. Surprisingly, more contact with the patient's mental health professional implies more tension, supervision, and urging, and an increased overall caregiving score. Apart from the number of personal contact hours, the relationship characteristics

Table 2. Proportion explained variance of caregiving domains (R^2) by characteristics of patient, caregiver, and their relationship

	Tension	Supervision	Worrying	Urging	Overall score
A. Patient characteristics	0.38	0.15	0.23	0.13	0.28
B. Caregiver characteristics	0.17	0.05	0.11	0.04	0.12
C. Relationship characteristics	0.02	0.11	0.01	0.03	0.06
$R^2_{\Sigma A,B,C}$	0.57	0.31	0.35	0.20	0.46
R^2_{A+B+C}	0.44	0.31	0.28	0.20	0.42

Note.— $R^2_{\Sigma A,B,C}$ = summation of the explained variance of each separate set of predictors; R^2_{A+B+C} = explained variance, entering all characteristics at once.

Table 3. Connection between caregiving dimensions/overall score and characteristics of patient, caregiver, and their relationship

	Tension	Supervision	Worrying	Urging	Overall score
A. Patient characteristics					
Female					
Age					—
Duration of disorder					
Course with psychotic episodes					
Clinical status improves over time					
Clinical status unchanged over time					
Patient receives mental health care					
Psychosis (scale score)		+		+	+
Agitation (scale score)	+	+	+		+
Apathy (scale score)				+	+
Affect (scale score)		+	+		+
B. Caregiver characteristics					
Female					
Age	—				
In contact with the patient's mental health professional	+	+		+	+
Used to patient's mental health problems		—	—		—
Able to cope with patient's mental health problems	—		—	—	—
C. Relationship characteristics					
Number of personal contact hours	+	+		+	+
Caregiver living alone					
Caregiver living alone with the patient					
Caregiver living with others but without the patient					

Note.—Only β 's significant at the 0.05 level are included; + = positive relation; — = negative relation.

between patient and caregiver have no impact ($R^2 = 0.06$).

Caregiving and Distress. The final aim of our study was to describe the relation between caregiving dimensions and caregiver distress. This relation was analyzed using multiple regression analysis. Patient, caregiver, and relationship characteristics entered in separate analyses explained respectively 13 percent (0.36^2), 11 percent (0.33^2), and 3 percent (0.16^2) of the distress score variance. Entered together, these characteristics accounted for 24 percent (0.49^2) of the distress score variance.

Characteristics of the patient, the caregiver, and their relationship each account for relatively unique parts of caregiver's distress score.

Next, the relationship between caregiving and distress was analyzed. The correlation between the IEQ overall score and the distress score was 0.50. In particular, the tension and worrying subscales were substantially related to the caregiver's distress. Correlations were respectively 0.45 and 0.43. Correlations between the supervision and urging subscales and the distress score were lower: 0.28 and 0.29, respectively.

The 200 relatives who had less than 1 hour per week contact with the patient showed more worrying (mean score 8.1 vs. 7.5; $t = 1.98$, degrees of freedom [df] = 678, $p < 0.05$) but less distress (mean score 12.4 vs. 13.6, $t = 3.36$, $df = 678$, $p < 0.001$), compared with relatives with more than 1 hour per week contact.

Explanatory Power of Caregiving. To assess the role of the caregiving concept in the connection between caregivers' distress and patient, caregiver, and relationship characteristics, we used a scheme (figure 1) that is a translation of the caregiving models described in the introduction.

In this scheme, we separate the relationship between each of the three sets of independent variables (patient, caregiver, and relationship characteristics) and the distress score into two paths, which were further analyzed by path-analysis (Wright 1985): a *direct* path (the direct effect of a set of independent variables on the distress score) and an *indirect* path (the effect mediated by caregiving; the caregiving overall score). Of course, the total effect of a set of independent variables is the sum of the direct and the indirect path. This means that we will find an indirect path of zero if the IEQ overall score does not explain anything about the connection between a set of independent variables and distress. In this case, the ratio

indirect/total will be zero. If, however, the IEQ overall score totally explains that relationship, we ought to find a direct path of zero and a ratio indirect/total of 1.

Table 4 shows that caregiving explained a substantial part of the relation between caregivers' distress and patient, caregiver, or relationship characteristics. The caregiving concept appears to be most important in the connection between distress and relationship characteristics, and least important in the connection between distress and caregiver characteristics.

Discussion

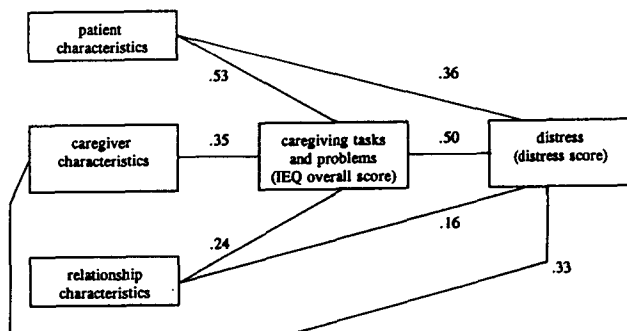
For professionals working with families of patients with schizophrenia, it is important to know more about the different aspects of caregiving and possible causes of distress in relatives. This study focused on these issues, especially the connection between caregiving, distress, and the characteristics of the patient, the caregiver, and their relationship.

Drawing on the experience of 480 family members of patients suffering from long-term psychotic disorders, we found four distinct caregiving domains. Tension points to the strained interpersonal atmosphere between the patient and the relatives: the quarrels, annoyances, and occasional threats. Worrying covers painful interpersonal cognitions, such as concern about the patient's safety, general health, and the kind of help he or she is receiving. Supervision has to do with the caregiver's tasks of ensuring and guarding, for instance, the patient's intake of medicine, sleep, and dangerous behavior. And urging relates to activation and motivation of the patient to take care of himself or herself, to eat enough, and to undertake activity.

Of the four domains, the two interpersonal domains, tension and worrying, are substantially correlated. The same holds for the two behavior-related domains, supervision and urging. These last two domains resemble Gubman's "don't's and do's" (Gubman and Tessler 1987), respectively preventing dangerous behavior and initiating and motivating healthy behavior.

It is interesting that the single IEQ item focusing on "global burden of caregiving," was related to the tension factor. This may indicate that the integrated evaluation of

Figure 1. Patient, caregiver, and relationship characteristics, caregiving and distress: Multiple regression coefficients



IEQ = Involvement Evaluation Questionnaire (Schene and van Wijngaarden 1992).

Table 4. Predicting the distress score by the characteristics of the patient, the caregiver, and their relationship: Multiple correlation coefficients

	Total effect	Indirect effect	Direct effect	Ratio indirect/total
A. Patient characteristics	0.36	0.23	0.13	0.64
B. Caregiver characteristics	0.33	0.15	0.18	0.45
C. Relationship characteristics	0.16	0.12	0.04	0.75

the caregiving tasks and problems related to psychiatric disorders is best represented by this factor.

Although caregiving is considered to be a multi-dimensional concept, we were able to compose an overall caregiving score with a broad coverage of the caregiving concept (Platt 1985; Wasow 1994). In addition to the four dimensions mentioned, this overall caregiving score also includes information about economic consequences, worries about the future, and care issues like urging patients to get up in the morning, accompanying them on outside activities, and preventing them from drinking too much alcohol. When the coverage of the IEQ was compared with results obtained from factor analysis by other researchers (Schene et al. 1994),³ the IEQ shows, in our opinion, good content validity.

For almost all caregiving aspects, contact between patient and relative is obligatory. This does not hold for worrying. On the contrary, worrying is a consequence that we found to be more intense in the 200 families having little or no direct contact with the patient and therefore being uninformed about his or her condition or whereabouts (see also Wasow 1994).

The second aim of this study was to describe the relationship between characteristics of the patient, the caregiver, and their relationship on the one hand, and caregiving and distress on the other. Using these characteristics, we were able to explain 42 percent of the variance in the overall caregiving score and 24 percent of the variance in distress score. Patient characteristics, in particular current symptomatology, showed the strongest relationship with caregiving and caregivers' distress.

Is there any differential relation between symptomatology and caregiving (Gubman and Tessler 1987)? It seems so. Psychotic symptoms, for instance, are strongly related to increased supervision and urging but were not related to tension and worrying. Apathy, on the other hand, has a substantial relationship with urging, but is not related to tension, supervision, and worrying. Our data do not support other researchers' findings that positive (Wing et al. 1959; Grad and Sainsbury 1963; Ral et al. 1991) or negative symptoms (Creer and Wing 1974; Fadden et al. 1987) specifically cause greater caregiver burden.

³Results from factor analysis of 21 psychiatric caregiving instruments, names of factors as mentioned by original authors (Schene et al. 1994): feelings of connection, emotional involvement, positive/negative feelings about involvement, preoccupation, ongoing responsibility, behavioral problems, familial discord, worries, objective and subjective burden, critical attitudes, economic hardship, care, control, overall burden, family disruption, client dependency, stigma, strain, subjective burden, patient's harming self, patient's harming others, disrupted activities, personal distress, time perspective, guilt, basic social functioning, and behavioral problems.

With the exception of age—older patients needed more caregiving—patient characteristics like gender and disorder characteristics, such as onset type (acute vs. slow), duration, presence or absence of psychotic episodes, and overall development of the clinical status over time, were not related to the caregiving tasks and problems. These results correspond with studies on somatic chronic illnesses, which have shown that the current severity of the illness has the greatest impact on caregiving (Biegel et al. 1991).

In contrast to other studies on somatic (Biegel et al. 1991) and chronic psychiatric disorders (Mandelbrote and Folkard 1961), in which spouses and men reported a higher degree of caregiving than parents and women (Fadden 1984), our study suggests that neither type of family member (parent, child, spouse, etc.) nor their age and gender are significantly related to the degree of caregiving for a psychiatric patient.

An important finding of our study is that relatives in regular contact with the patient's mental health professional reported more caregiving strains than those not in contact, a finding also reported by Winefield and Harvey (1993). There are three possible explanations for this: First, these relatives belong to a subgroup that experiences caregiving as more burdensome than other relatives. As a consequence, they themselves tend to seek or maintain contact with the patient's mental health professional or this professional maintains contact with them. Second, contact with mental health professionals may influence the way relatives interact with the patients themselves. They may, more than relatives *not* in contact, see themselves as cotherapists, perhaps even encouraged by clinicians to take that particular role, but nevertheless more often burdened with the task of supervising and urging the patient. Third, as mentioned by Winefield and Harvey (1993), the fact of seeing a doctor may itself imply a crisis in the patient's health, a deterioration of symptomatology, that increases caregiver distress.

A specific caregiver characteristic related to tension, worrying, and urging, as well as to the overall caregiving score, is the conception of being able to cope with the patient's illness. A sense of mastery (Hansen and Hill 1964) decreased the scores on three domains (tension, urging, and worrying) and on the total caregiving and distress scores.

Of the relationship characteristics, the total number of hours of personal contact was the only predictor of caregiving severity. Our study does not support Biegel and colleagues' (1991, p. 206) finding that caregivers of the mentally ill living in smaller households feel more burdened than those in larger households.

Our final aim was to study the connection between caregiving and caregiver distress. Caregiving seems to be

one of the mediating variables in the causal pathway between patient, caregiver, and patient/caregiver relationship characteristics and caregiver distress. This mediating role appears to be most important in the connection between distress and relationship characteristics and least important in the connection between distress and caregiver characteristics. The distress scale score correlated only moderately with the caregiving scores, particularly with tension and worrying.

This study has several methodological limitations. First, the 4-week timeframe of the questionnaires, the reason for which was described in the Methods section, excludes long-term caregiving aspects, like the loss of social contacts or stigma. Second, the sample—a family organization—mostly mothers of chronically ill sons, raises questions about the generalizability of our results to all caregivers. Third, all information, including information about symptom severity, was obtained from relatives, which makes it difficult to exclude appraisal as an underlying phenomenon explaining the different connections. Finally, path analysis, an inherently longitudinal method, was used to describe the connection between caregiving and distress, while strictly speaking, our data are cross-sectional.

Caregiving is an important public health issue. Despite all limitations, we believe our findings corroborate the importance of caregiving for the general well-being of family members. Additional analysis showed that relatives mentioning more distress also used significantly more psychotropic medication and consulted their general practitioners more frequently.

Our findings tentatively suggest that caregiving and distress can be lowered by reducing the patient's symptomatology, by increasing the coping capacity of relatives (Hatfield 1981; Hatfield and Lefley 1987), and by decreasing the number of personal patient/relative contact hours. These are relevant interventions, especially in relation to three caregiving end points, substantiated in the literature and already commented on by Biegel et al. (1991): the decision to institutionalize the patient, changes in the caregiver role, and the psychiatric and physical morbidity of the caregiver. Colerick and George (1986) in their study, for instance, showed that the use of psychotropic drugs by caregivers doubled the chances of patient institutionalization.

As yet, empirical data about causal pathways are still missing. The relationship between components of the family climate such as expressed emotion (Kavanagh 1992), affective style and communication deviance (Miklowitz 1994), and the course of schizophrenia has been studied repeatedly (Kavanagh 1992). Recently Scazufca and Kuipers (1996) showed in a cross-sectional study that expressed emotion and caregiver burden are

related. This connection may be explained by the finding of Barrowclough et al. (1996) that caregivers' cognitive appraisal processes of the illness experience (attributions) are related to both expressed emotions and caregivers' distress. An intriguing question that still remains unanswered concerns the causal pathway between the patient's symptomatology/functioning, caregiving, family-member distress, and the further interaction with concepts like expressed emotion. Our study shows that future studies will need to examine the reciprocity between these different concepts.

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