

Rewards of Caregiving and Coping Strategies of Caregivers of Patients With Mental Illness

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Objective: The study sought to broaden the focus of research on caregivers' burden by examining caregiving rewards and their relation to coping skills. **Methods:** Data from semistructured interviews with 60 family caregivers of patients with mental illness in Germany were examined by content analysis. Information was gathered with the Freiburg Questionnaire on Coping With Illness. Both t tests and regression analyses were used to analyze data. **Results:** Caregivers made 413 statements about rewards, which were assigned to six categories. "Gratitude and affection from the patient" was the most frequently cited, and "active, problem-oriented coping" was the coping strategy most used. Three variables predicted identification of a greater number of rewards, explaining 39% of variance: "increased religiousness and searching for meaning," "caregiver's younger age," and "more statements about burden." **Conclusions:** To support caregivers, a shift in orientation from focusing on burden to emphasizing resources is necessary. (*Psychiatric Services* 64: 185–188, 2013; doi: 10.1176/appi.ps.001212012)

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In the past three decades, research on caregivers of persons with mental illness has focused primarily on the negative effects of caregiving. In contrast, little attention has been paid to the positive aspects and rewards of caregiving. The first pioneering work on the rewards of caregiving for patients with mental disorders was done by Hinrichsen and colleagues (1), Schwartz and Gidron (2), and Veltman and colleagues (3). A recent PubMed search yielded 946 entries for the keywords "burden", "mental illness," and "caregiver" but only 15 entries for the keywords "reward OR gratification," "mental illness," and "caregiver." The one-sided focus of research on burden does not do justice to the complexity of the numerous changes that result from caring for someone with a mental illness.

Thus this study used a bottom-up approach to qualitatively assess the dimensions of rewards for caregivers of patients with schizophrenia, depression, bipolar disorder, or personality disorder with respect to caregiver burden and coping strategies. Quantitative analyses were also performed, and the impact of sociodemographic and illness-related variables were explored to help inform interventions for caregivers of patients with mental disorders.

Methods

The aim was to interview at least 15 caregivers of patients in each of four diagnostic groups: schizophrenia (ICD-10 code F20), depression (F32–33), bipolar disorder (F31), and personality disorder (F60–F61). A total of 196 psy-

chiatric inpatients at a tertiary referral center in Bavaria, Germany, were recruited consecutively upon admission and asked for their permission to interview the caregiver with whom they had the closest contact. Ninety-seven patients (50%) agreed; ten patients left the hospital before they could be asked for permission, five patients did not have a caregiver, and five patients could not give permission because of their current psychopathology.

We tried to contact the 97 respective caregivers. A total of 28 refused to participate, seven could not be reached either by telephone or letter at the given address, one was severely ill, and a meeting could not be arranged with one caregiver within the study time frame. Therefore, the final sample consisted of 60 patients (42% female and 58% male) and 60 caregivers (65% female and 35% male). The mean \pm SD ages were 37.3 ± 15.4 years for the patients and 48.8 ± 15.0 for the caregivers. [A table summarizing other characteristics of the two groups is available online as a data supplement to this report.] The study protocol was approved by the ethics committee of the Medical Faculty of the University of Regensburg, and all participants gave voluntary, written informed consent to participate.

Following methods described by Wiedemann (4) and Strauss and Corbin (5), we conducted problem-centered, semistructured interviews with caregivers of patients with mental illness to assess their burden and reward from caregiving. To minimize the influence of confounding variables, the interviews were conducted in rooms

separate from the wards and by two researchers who were not involved in the treatment process. The interviews were recorded and transcribed. The introductory question (narrative stimulus) was “Which types of burden/rewards arise/arose for you from your relative’s illness?” Ad hoc questions were asked if deemed necessary for the given topic. In addition, the caregivers’ coping strategies were analyzed with the Freiburg Questionnaire on Coping With Illness (FQCI) (6), which uses a 5-point scale from 1, none at all, to 5, excellent. For further evaluation, the global statements were linked with sociodemographic and illness-related variables of the patients, which were assessed with the German basic psychiatric documentation system DGPPN-BADO (7), and with sociodemographic variables of the caregivers.

The transcripts of the interviews were analyzed with a summarizing qualitative content analysis following procedures described by Mayring (8) and Silverman (9). The technique, which derives from the communication sciences, aims to reduce the material by using five strict steps of transformation. In the end, only the essential global statements carrying content remain (8). Data were analyzed by SPSS Statistics, version 19. With the help of coder training with 12 test interviews, a good interrater reliability ($\kappa=.75$) was obtained between the interviewer and a researcher who was not involved in the interviews. For further evaluation, *t* tests and regression analyses were performed. [Covariates used in these analyses are listed in the online supplement to this report.]

Results

The interviews took from 17 to 85 minutes (mean \pm SD duration, 36.0 ± 12.9 minutes). The burden on caregivers was as multifarious as expected: 787 different statements about burden were made. The burden statements were analyzed, and the results have been reported elsewhere (10).

The caregivers also made numerous statements about rewards: 413 different statements were documented. On average, each caregiver named 13.1 ± 4.9 burdens resulting from the family member’s illness and 6.9 ± 4.0

rewards. No significant differences in the number of caregiver statements about rewards or burdens were noted between the four diagnostic groups. The coping strategies most frequently mentioned by caregivers were “active, problem-oriented coping” (mean FQCI score $3.5 \pm .90$), “distraction and building self-esteem” (2.7 ± 2.8), and “religiousness and searching for meaning” (2.7 ± 3.0). [Tables presenting these findings are included in the online supplement.]

The 413 caregiver statements about rewards were grouped into 23 global statements, which were assigned to six categories (Table 1). The most frequently cited reward was “gratitude and affection from the patient” (57%).

To quantify the influence of single factors, a regression model with “overall reward for the caregivers” as the dependent variable was built by backward elimination and model refinement on the basis of the adjusted R^2 . Three predictor variables explained 39% of the variance in overall reward: “increased religiousness and searching for meaning as a strategy for coping with the illness,” “younger age of the caregiver,” and “more statements about burden.” [A table presenting results of this analysis is included in the online supplement.]

Discussion

This study assessed the rewards of caregiving for caregivers of patients with mental illness with the aim of gaining insight into relevant aspects from the caregivers’ point of view. Correlations with the different types of coping were evaluated as well as the impact of sociodemographic and illness-related variables.

The results are somewhat limited by the relatively large number of patients who refused to allow their closest caregiver to be interviewed ($N=79$; 40%). These patients may have been more severely ill, which would put a particularly large burden on caregivers. The average caregiver burden is therefore likely to be higher than that found in the study. A further limitation is the sex of caregivers: 65% of the caregivers interviewed were women. However, this figure reflects the larger proportion of females in caregiving roles in general. Finally, the

external validity was restricted by the limited sample size inherent in a qualitative study and the setting within the German health care system, which differs in some respects from health care systems in other countries. Despite these limitations, the results provide an initial overview of potential rewards for caregivers of family members with mental illness and their relation to coping strategies and negative aspects of caregiving. The results are based on a qualitative, bottom-up approach and can form the basis and motivation for further (quantitative) research.

The 413 statements about rewards show the relevance and variety of positive aspects of caregiving for caregivers. Intensification of the relationship with the patient or within the family as a result of the illness was documented in previous studies (1,3,11–13) and was also reported by caregivers in this study. In contrast, the statements in two categories—“gains in character and life experience” and “changes of attitudes and opinions”—were not differentiated so clearly in any of the earlier studies. In our study, almost 150 caregiver statements fell into one of these two categories, which can also be described as growth in character and clarification of values.

The regression analysis also found three variables that predicted identification of a greater number of rewards, which have not been documented in any other study: “increased religiousness and searching for meaning as a strategy for coping with the illness,” “younger age of the caregiver,” and “more statements about burden.” One possible explanation of this finding is that younger caregivers may be confronted directly for the first time in their lives with suffering and powerlessness and may thus gain more inner strength and experience more character development than older caregivers, who often have already learned to cope by dealing with personal crises. The association between naming more rewards and naming more burdens may appear surprising at first. Different degrees of reflection or eloquence among the interviewees may explain this relationship.

Previous studies have not linked the coping strategy of “increased religiousness and searching for meaning”

with a caregiver's identification of a greater number of rewards. Various views of religiousness as a coping strategy for caregivers have been presented in the literature (12). However, reviews have found an overall positive effect of religiousness on mental health (13,14). The decisive factor is whether religiousness is defined as a positive, intrinsic, and functional strategy for coping with illness or as a negative, external, dysfunctional strategy. The most frequently demonstrated positive factors include positive self-esteem, hope, joie de vivre, and increased self-respect (14). The caregivers in our study named these as rewarding aspects of caregiving, which may explain our finding of "increased religiousness and searching for meaning" as a predictor.

The caregivers in the sample primarily used active, problem-oriented coping strategies, along with distraction and building self-esteem and religiousness and searching for meaning. In contrast, depressive coping and trivialization and wishful thinking were coping strategies used less often (FQCI scores of 2.4 ± 2.2 and 2.2 ± 1.0 , respectively). If one categorizes the first three coping styles as adaptive and depressive coping and trivialization and wishful thinking as maladaptive, then caregivers mainly used adaptive coping styles. Although patients' coping strategies have been studied relatively often, far too few studies have examined caregivers' coping strategies. The only study to link rewards of caregiving to coping strategies of caregivers of persons with mental illness was conducted by Ramírez García and colleagues (15). This research group found that coping efficacy accounted for significant variance both in caregivers' psychological distress and in their positivity (expressions of praise, approval, or affection toward their ill relatives), beyond that accounted for by the patients' symptoms and caregiver burden.

Furthermore, in our study caregivers of patients in all diagnostic subgroups used religiousness and searching for meaning as a coping strategy surprisingly often. This strategy was the second or third most frequently cited for all diagnostic subgroups and was

Table 1

Six categories of global statements about rewards of caregiving made by 60 caregivers of persons with mental illness^a

Category and global statement	N	%
Appreciation by the patient and others for the caregiving and satisfaction about providing care		
Gratitude and affection from patient	34	57
Recognition and compassion	31	52
Gladness and gratitude about treatment progression and healthy phases	31	52
Satisfaction about being able to help the patient	29	48
Total	125	30
Gains in character and life experience		
Increase in reflection, calmness, and patience	19	32
Increase in maturity and life experience	17	28
Increase in self-confidence and inner strength	15	25
Increase in social competencies	13	22
Gain in technical and practical competencies	13	22
Awareness of the concerns and inner states of others	9	15
Patient's illness as an incentive to solve own problems	8	13
Total	94	23
Gains in successful coping strategies		
More conscious awareness of own needs	25	42
Successful establishment of boundaries with the patient	13	22
Experience-oriented strategies for dealing with the patient	13	22
Consolation and hope through belief and spiritual orientation	5	8
Total	56	14
Increase of cohesion and closer relationships within the family		
Intensification of relationship with patient	31	52
Intensification of relationships and increasing cohesion in the family	23	38
Total	54	13
Changes of attitudes and opinions		
Openness toward people with mental illness	14	23
Appreciation of own health and life situation	14	23
Realignment of priorities and frugality	11	18
Relativization of problems	11	18
Total	50	12
Experience of support by others		
Support from own social environment	23	38
Support from staff in hospital and public institutions	11	18
Total	34	8

^a The 23 global statements were derived from 413 caregiver statements about rewards, and 413 is the denominator for the "Total" rows.

also found in the regression analyses to predict caregivers' identification of more rewards. Unfortunately, the relationship between the positive and negative effects of religious convictions and practices and coping with illness is often not considered in practice. Caregivers' (and patients') dysfunctional religious convictions often remain unaddressed, and the positive factors of religiousness (intrinsicly motivated) and searching

for meaning are rarely promoted, even though they have been shown to have a positive effect on caregivers' subjective burden (13,14). Thus every hospital should offer patients and their caregivers various religious and spiritual supports.

Conclusions

Policy makers and administrators should find ways to develop and promote an awareness of the potential

positive experiences, changes, resiliencies, and coping strategies that can be viewed as rewards by those who provide care to people with mental illness (family members, friends, and professional staff) and by the patients themselves. This can be done without diminishing the multifarious and mostly distressful burdens that result from mental illness. Awareness of the possible rewards of caregiving needs to be promoted in both psychoeducational programs and self-help groups and in the daily interactions between caregivers, patients, and professional helpers. A shift in orientation from focusing on burden to emphasizing resources is necessary in research and practice to do justice to the complex life situations of caregivers of people with mental illness.

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