

Perceived stigma and depression among caregivers of patients with bipolar disorder

DEBORAH A. PERLICK, DAVID J. MIKLOWITZ, BRUCE G. LINK, ELMER STRUENING, RICHARD KACZYNSKI, JODI GONZALEZ, LAUREN N. MANNING, NANCY WOLFF and ROBERT A. ROSENHECK

Summary This study investigates the associations between perceived stigma, depressive symptoms and coping among caregivers of people with bipolar disorder. Caregivers of 500 people with DSM–IV bipolar disorder responded to measures of these constructs at study entry. Patients' clinical and functional status were evaluated within 30 days of the caregiver assessment. Perceived stigma was positively associated with caregiver depressive symptoms, controlling for patient status and socio-demographic factors. Social support and avoidance coping accounted for 63% of the relationship between caregiver stigma and depression. Results suggest that caregivers' perceptions of stigma may negatively affect their mental health by reducing their coping effectiveness.

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Studies have shown that 43% to 92% of caregivers of people with mental illness report feeling stigmatised (e.g. Struening *et al*, 2001) and that perceived stigma is associated with reports of depressive symptoms (e.g. Phelan *et al*, 1998). This study evaluates the roles of caregiver social support and avoidance coping in mediating a hypothesised association between perceived stigma and depressive symptoms among caregivers of patients with bipolar disorder. Because perceived stigma has been associated with withdrawal from supports (e.g. Fadden *et al*, 1987), and social support buffers against recurrence of depression (e.g. Brown & Harris, 1978), we hypothesised that social support might mediate

the association between perceived stigma and depression. Similarly, because avoidance coping has been associated with depression (Powers *et al*, 2002), we hypothesised that it might mediate the association between stigma and depression. We predicted that perceived stigma and avoidance coping would be positively associated – and social support inversely associated – with depressive symptoms after controlling for socio-demographic factors and patient clinical status.

METHOD

Participants were the primary caregivers of 500 patients with bipolar disorder enrolled in the Systematic Treatment Enhancement Program for Bipolar Disorder (Sachs *et al*, 2003). All patients recruited from 1 August 2002 through 31 December 2003 at each of eight sites ($n=778$) were invited to participate; 676 (87%) agreed to do so and identified their primary caregiver using the method established by Pollak & Perlick (1991). Almost three-quarters (74%; $n=500$) of the 676 caregivers invited to participate agreed. Caregivers who participated did not differ statistically from those who declined on age, gender, education, marital status, relationship to the patient and co-residence.

Patient lifetime diagnosis was based on a standardised Affective Disorder Evaluation (Sachs *et al*, 2003), comprising a modified version of the mood and psychosis modules from the Structured Clinical Interview for DSM–IV diagnosis; First *et al*, 1996) and the Mini International Neuropsychiatric Interview (Sheehan *et al*, 1998). The Clinical Monitoring Form, a semi-structured interview, was administered by the treating psychiatrist to evaluate the presence or absence of a DSM–IV episode of affective illness within the past 30 days (Sachs *et al*, 2003). The Global Assessment of Functioning (GAF) score

(American Psychiatric Association, 1994) represented patients' functional status over this time frame. Caregivers were interviewed within 30 days (mean 6 days, $s.d.=25.5$, median 3.0) of a patient assessment by trained research assistants.

Caregiver perceptions of stigma were assessed using the Devaluation of Consumer Families Scale (Struening *et al*, 2001), a seven-item Likert scale (rating of statements such as 'Most people look down on families that have a member who is mentally ill'), summed to yield a total stigma score (Cronbach's $\alpha=0.80$), with higher scores indicating greater stigma. Caregiver depressive symptoms were assessed using the Center for Epidemiological Studies – Depression scale (CES–D; Radloff, 1977) (Cronbach's $\alpha=0.90$). Avoidance coping was assessed using the sub-scale from Scazufca & Kuipers's (1999) measure. Items describe a cognitive or behavioural strategy for coping with a stressful event, e.g. 'Avoided other people'. Caregivers rated how often they used each strategy to handle the most stressful situation with their relative in the past month on five-point Likert scales, with higher scores indicating higher avoidance. The 11-item Abbreviated Duke Social Support Index (ADSSI; Koenig *et al*, 1993) was used to measure subjective support and social interaction; higher numbers represented higher levels of support.

RESULTS

Using a hierarchical regression model, the CES–D was regressed on socio-demographic variables (step 1), caregiver stigma (step 2), patient clinical status (step 3) and hypothetical mediating variables (steps 4, 5) (see data supplement to online version of this paper). Caregiver stigma was significantly and positively associated with CES–D score and contributed an additional 4% variance after controlling for socio-demographic factors (F change_{1,337}=14.09, $P<0.001$). Patient status was not significantly associated with CES–D score. The unique contribution of stigma was reduced by over 50% with the entry of social support measures (step 4), indicating these explained about half of the contribution of stigma to CES–D score. The addition of social support and avoidance coping measures (step 5) increased the variance explained by 18% and 6% respectively. The combined effect of

social support and avoidance coping explained nearly two-thirds (63%) of the contribution of stigma to CES-D score. The significant associations of the social support measures and avoidance coping with CES-D score and resulting decrease in the associations between stigma and CES-D, coupled with significant associations between stigma and social support (subjective support, Pearson $r = -0.24$; instrumental support, Pearson $r = -0.19$) and between stigma and avoidance coping (Pearson $r = -0.18$; all P values < 0.001) support the hypothesised mediating effects of social support and avoidance coping in the relationship between perceived stigma and depressive symptoms (Barron & Kenney, 1986). Exploratory analyses found that the overall pattern of associations between caregiver stigma, support and coping, and CES-D scores did not differ for caregivers in different age groups, of different gender and with different relationships to the patient.

DISCUSSION

Our finding that greater perceptions of stigma towards caregivers were associated with significantly higher levels of depressive symptoms suggests that in addition to posing a barrier to the recovery of people with mental illness, stigma erodes the morale of the family members who help care for them. The finding that social support and avoidance coping together largely explained the association between stigma and depression offers a plausible explanation for the depressive symptoms commonly reported by up to 40% of caregivers of people with mental illness (Dyck *et al*, 1999): caregivers may retreat from social support and adopt avoidance coping in order to fend off anticipated rejection and/or embarrassment. Because social support is a well-established buffer against recurrence of depression, withdrawal from potential supporters as an adaptation to stigmatisation illustrates the double jeopardy confronting caregivers of patients with mental illness.

Because this study uses cross-sectional data we cannot make causal inferences. Although it is possible that stigmatisation might engender feelings of hopelessness, it is also possible that caregiver depression in bipolar disorder is at least in part due to genetic transmission of this illness. However, recurrence of depression has been linked to psychosocial stressors such as

DEBORAH A. PERLICK, PhD, Department of Psychiatry, Yale University School of Medicine, New Haven, Connecticut; DAVID J. MIKLOWITZ, PhD, Department of Psychology, University of Colorado at Boulder, Colorado; BRUCE G. LINK, PhD, ELMER STRUENING, PhD, Mailman School of Public Health of Columbia University, New York; RICHARD KACZYNSKI, PhD, Department of Psychiatry, Yale University School of Medicine, New Haven, Connecticut; JODI GONZALEZ, PhD, Department of Psychiatry, University of Texas, San Antonio, Texas; LAUREN N. MANNING, BA, Brigham & Women's Hospital, Harvard Medical School, Boston, Massachusetts; NANCY WOLFF, PhD, School of Planning and Public Policy, Rutgers University, New Brunswick, New Jersey; ROBERT A. ROSENHECK, MD, Department of Psychiatry, Yale University School of Medicine, New Haven, Connecticut, USA

Correspondence: Dr D. A. Perlick, Mount Sinai School of Medicine, One Gustave L. Levy Place, New York, NY 10029, USA. Tel: +1 718 584 9000, ext. 5231; fax: +1 718 364 3576; email: deborah.perlick@mssm.edu

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negative life events (Johnson & Roberts, 1995) and caregiving strain (Russo *et al*, 1995), and contending with social rejection and attendant feelings of shame and embarrassment constitutes a major caregiving strain (Perlick *et al*, 2004). Longitudinal studies including caregivers with and without a history of affective disorder, and using clinically validated measures of depression, are needed to disentangle the relative contributions of pre-existing affective illness and societally based discrimination to caregiver depression. The potential for recurrence of depressive symptoms among the family members of patients with bipolar disorder in relation to the stresses of mental illness stigma underscores the seriousness of this social problem and the need for investigations of effective interventions to enhance caregiver coping.

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DATA SUPPLEMENT

Table DSI Effects of caregiver-focused stigma, social support and avoidance coping on caregiver depressive symptoms, controlling for patient clinical status and demographic characteristics

| Independent variables | Step 1 | Step 2 | Step 3 | Step 4 | Step 5 |
|--|---------|---------|---------|----------|----------|
| Step 1: Demographic factors | | | | | |
| Patients | | | | | |
| Gender ¹ | -0.10 | -0.11* | -0.12* | -0.12* | -0.11 |
| Age | 0.00 | 0.02 | 0.01 | -0.05 | -0.09 |
| Caregivers | | | | | |
| Gender ¹ | 0.03 | 0.02 | 0.03 | 0.03 | 0.01 |
| Age | -0.21** | -0.20** | -0.21** | -0.14* | -0.07 |
| Relationship: spouse ² | 0.10 | 0.12 | 0.12 | 0.05 | 0.00 |
| Relationship: parent ³ | 0.12 | 0.12 | 0.12 | 0.08 | 0.06 |
| Socio-economic status ⁴ | 0.17** | 0.15** | 0.14** | 0.11* | 0.08 |
| Step 2: Stigma | | | | | |
| Caregiver focused | | 0.20*** | 0.19*** | 0.09 | 0.07 |
| Step 3: Patient's clinical status | | | | | |
| GAF ⁵ | | | -0.10 | -0.08 | -0.08 |
| Clinical status ⁶ | | | 0.07 | 0.06 | 0.04 |
| Length of illness, years | | | 0.06 | 0.06 | 0.06 |
| Step 4: Support | | | | | |
| Subjective support | | | | -0.38*** | -0.33*** |
| Social interactions | | | | -0.14** | -0.11* |
| Step 5: Coping | | | | | |
| Avoidance coping | | | | | 0.26*** |
| <i>R</i> ² | 0.08*** | 0.12*** | 0.14*** | 0.32*** | 0.38*** |
| Adjusted <i>R</i> ² | 0.06 | 0.10 | 0.11 | 0.29 | 0.35 |
| ΔR^2 | 0.08*** | 0.04*** | 0.02* | 0.18*** | 0.06*** |

1. Male, 1; female, 2.

2. Spouse, 1; other, 0.

3. Parent, 1; other, 0.

4. Evaluated by the Hollingshead–Redlich two-point scale (Hollingshead & Redlich, 1958). Higher numbers represent lower socio-economic status.

5. Global Assessment of Functioning score based on past 30 days; higher numbers reflect better functioning.

6. Negative, 0; positive, 1; on DSM–IV criteria for current affective episode.

P* < 0.05, *P* < 0.01, ****P* < 0.001.

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