

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.

Declaration of interest None. This study was supported by grants MH-65015 and NIMH-8001 from the National Institute of Mental Health.

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

(First received 15 December 2005, final revision 16 January 2007, accepted 1 February 2007)

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.

REFERENCES

- American Psychiatric Association (1994)** *Diagnostic and Statistical Manual of Mental Disorders* (4th edn) (DSM-IV). Washington, DC: APA.
- Brown, G. W. & Harris, T. O. (1978)** *Social Origins of Depression: A Study of Psychiatric Disorder in Women*. Free Press.
- Barron, R. M. & Kenny, D. A. (1986)** The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, **51**, 1173–1182.
- Dyck, D. G., Short, R. & Vitaliano, P. P. (1999)** Predictors of burden and infectious illness in schizophrenia caregivers. *Psychosomatic Medicine*, **61**, 411–419.
- Fadden, G., Bebbington, P. & Kuipers, L. (1987)** The burden of care: the impact of functional psychiatric illness on the patient's family. *British Journal of Psychiatry*, **150**, 285–292.
- First, M. B., Spitzer, R. L., Gibbon, M. B., et al (1996)** *Structured Clinical Interview for Axes I and II DSM-IV Disorders – Patient Edition (SCID-IP)*. Biometrics Research Department, New York State Psychiatric Institute.
- Hollingshead, A. & Redlich, F. C. (1958)** *Social Class and Mental Illness: A Community Study*. Wiley.
- Johnson, K. R. & Roberts, J. E. (1995)** Life events and bipolar disorder: implications from biological theories. *Psychological Bulletin*, **117**, 434–449.
- Koenig, H. G., Westlund, R. E., George, L. K., et al (1993)** Abbreviating the Duke Social Support Index for use in chronically ill elderly individuals. *Psychosomatics*, **34**, 61–69.
- Perlick, D. A., Rosenheck, R. A., Clarkin, J. F., et al (2004)** Impact of family burden and affective response on clinical outcome among patients with bipolar disorder. *Psychiatric Services*, **55**, 1029–1035.
- Phelan, J. C., Bromet, E. J. & Link, B. G. (1998)** Psychiatric illness and family stigma. *Schizophrenia Bulletin*, **24**, 115–126.
- Pollak, C. P. & Perlick, D. (1991)** Sleep problems and institutionalization of the elderly. *Journal of Geriatric Psychiatry and Neurology*, **4**, 204–210.
- Powers, D. V., Gallagher-Thompson, D. & Kraemer, H. C. (2002)** Coping and depression in Alzheimer's caregivers: longitudinal evidence of stability. *Journal of Gerontology Series B: Psychological Science and Social Science*, **57**, 205–211.
- Radloff, L. S. (1977)** The CES-D scale: a self-report depression scale for research in the general population. *Applied Psychological Measure*, **1**, 385–401.
- Russo, J., Vitaliano, P. P., Brewer, D. D., et al (1995)** Psychiatric disorders in spouse caregivers of care recipients with Alzheimer's disease and matched controls: a diathesis-stress model of psychopathology. *Journal of Abnormal Psychology*, **104**, 197–204.
- Sachs, G. S., Thase, M. E., Otto, M. W., et al (2003)** Rationale, design, and methods of the systematic treatment enhancement program for bipolar disorder (STEP-BD). *Biological Psychiatry*, **53**, 1028–1042.
- Scazufca, M. & Kuipers, E. (1999)** Coping strategies in relatives of people with schizophrenia before and after psychiatric admission. *British Journal of Psychiatry*, **174**, 154–158.
- Sheehan, D. V., Lecrubier, Y., Sheehan, K. H., et al (1998)** The Mini-International Neuropsychiatric Interview (M.I.N.I.): the development and validation of a structured diagnostic psychiatric interview for DSM-IV and ICD-10. *Journal of Clinical Psychiatry*, **59** (Suppl. 20), 22–33.
- Struening, E. L., Perlick, D. A., Link, B. G., et al (2001)** The extent to which caregivers believe most people devalue consumers and their families. *Psychiatric Services*, **52**, 1633–1638.

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.

BJP The British Journal of Psychiatry Psych

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

BJP 2007, 190:535-536.

Access the most recent version at DOI: [10.1192/bjp.bp.105.020826](https://doi.org/10.1192/bjp.bp.105.020826)

Supplementary Material

Supplementary material can be found at:
<http://bjp.rcpsych.org/content/suppl/2007/06/01/190.6.535.DC1>

References

This article cites 15 articles, 3 of which you can access for free at:
<http://bjp.rcpsych.org/content/190/6/535#BIBL>

Reprints/permissions

To obtain reprints or permission to reproduce material from this paper, please write to permissions@rcpsych.ac.uk

You can respond to this article at

[/letters/submit/bjprcpsych;190/6/535](http://bjp.rcpsych.org/letters/submit/bjprcpsych;190/6/535)

Downloaded from

<http://bjp.rcpsych.org/> on August 18, 2017
Published by The Royal College of Psychiatrists
