

# Matching Services to Patients' Beliefs About Depression in Dublin, Ireland

Joanne Cunningham, Ph.D.

Jo Anne Sirey, Ph.D.

Martha L. Bruce, Ph.D., M.P.H.

**Objectives:** This study explored tensions between biomedical and psychosocial illness models and between the public health goal of stigma reduction and patients' perceptions of helplessness. Patients' etiological beliefs and use of language are considered as possible pathways to improved care. **Methods:** Qualitative and quantitative data were obtained from 18 adults attending a mood disorders support group in Dublin, Ireland. **Results:** Respondents reported feelings of helplessness concerning the occurrence of depressive episodes. When describing episodes of wellness and depression, respondents used a "light switch" metaphor to indicate this lack of control. For several respondents, acceptance of biomedical causality was linked to helplessness. In contrast, spiritual beliefs offered hope. **Conclusions:** Alleviating patients' sense of responsibility may reduce their guilt, but patients' perceptions of illness uncontrollability may diminish their sense of agency, reinforce depressive attributional styles, and undermine overall treatment outcomes. Communication and the patients' involvement in decisions are vital to treatment. (*Psychiatric Services* 58:696–699, 2007)

The Decade of the Brain, a 1990s initiative that promoted advances in psychiatric neuroscience, ushered in a new focus on the biological components of thinking and feeling. The greater range and availability of psychiatric medications allowed a shift from personality-level explanations for mental illness to biomedical ones. With this shift came the hope of destigmatization—that people with mental illness would be viewed not as examples of flawed character but simply as persons with unfortunate biological circumstances—as public health messages increasingly emphasized biomedical models of mental illness. Yet it is not clear whether emphasis on the biological basis of illness has decreased stigma.

Understanding patients' beliefs and personal illness models is important given their association with various treatment behaviors and outcomes (1). Some research suggests that promotion of biochemical or genetic causal beliefs for mood disorders can result in fatalism or pessimism (2,3). And, as indicated by Brown and colleagues (1), patients' lower perceptions of controllability of illness may lead to increased use of religious coping and of turning control over to another source.

The aim of this study was to explore the relationship of individuals' language use, etiological beliefs, perception of controllability of depression, and use of religious coping. We used this exploration of language as a window onto the illness experience, with the goal of generating hypotheses to inform the development of interventions to increase the acceptability of mental health treatment and participation in care.

## Methods

The data were collected as part of an institutional review board–approved study exploring the cultural context of patients' experiences and understandings of mental illness. Participant interviews were conducted by the first author with members of a mood disorders support group in Dublin, Ireland, between 1998 and 1999. Participants were self-selected and recruited through a letter distributed to all attendees of Dublin support group chapters during a one-month period. The letter described the study as concerned with individuals' experiences with depression. Of the 22 responses received, three individuals were unavailable at follow-up and one was excluded because of a diagnosis of schizophrenia; 18 interviews resulted. Because the study concerned patients' perceptions of depression, participants with either depression or bipolar disorder were included (2).

Sixteen face-to-face interviews were conducted, taped, and later transcribed verbatim. Two additional interviews (one in person, the other by telephone) were documented by note taking. Informed consent was obtained from all participants. Interview questions were open ended. Respondents were asked about their first experiences with depression and their understanding of what they were experiencing. Specifically, we asked, "Please remember back to when you were first diagnosed with depression. What was your reaction? Before you were diagnosed, did you think something else was wrong? What images or thoughts come to mind when you think about depression?"

*The authors are affiliated with the Institute of Geriatric Psychiatry, Weill Medical College of Cornell University, 21 Bloomingdale Rd., White Plains, NY 10605 (e-mail: joc2038@med.cornell.edu).*

To anchor the qualitative findings psychometrically, 14 respondents completed a questionnaire containing the Center for Epidemiological Studies Depression Scale (CES-D) (4). Scores on the CES-D can range from 0 to 60 points, with scores of 16 or greater indicative of depression. Also included was a measure of coping with low moods that included items on religious coping (Jackson B, Nolen-Hoeksema S, unpublished manuscript, 1998) and demographic questions. Scores on the CES-D can range from 0 to 60 points, with scores of 16 or greater indicative of depression (4). A total of two respondents were unable to complete the assessments because of emotional lability, and two did not return the questionnaire.

Respondents' ages ranged from 23 to 76 (mean±SD=41.3±14.1), and 11 of 18 (61%) were women. All were of Irish ethnicity. Most (14 of 18, or 78%) identified themselves as Roman Catholic, one (6%) as belonging to the Church of Ireland, and three (17%) listed no religious affiliation. Nine were single (50%), eight (44%) were married, and one (6%) was an unmarried clergy member. Education levels ranged from post-primary school to university degrees. Most respondents were employed, with a majority (64%) listing themselves as financially comfortable.

Eight respondents (44%) had depression, and ten (56%) had bipolar disorder. All had been prescribed psychiatric medication for their symptoms, although three (17%) were not taking medication at contact. Using Fisher's exact tests, we found no differences between diagnoses in terms of gender, age, religiosity, or medication adherence.

The verbatim transcripts of the face-to-face interviews were analyzed with the constant comparative method (5). Atlas.ti, version 4.1, qualitative software was used for line-by-line coding. Themes were identified through respondents' metaphor use and patterned repetition of language (6). Coding was conducted by the first author and a research assistant, with disagreements resolved through consensus.

## Results

Analyses of the 16 transcribed interviews identified three dominant narrative themes: etiological beliefs leading to positive and negative consequences, positive and negative outcomes of beliefs about the controllability of depression, and combating helplessness through religious and spiritual beliefs. Although almost all respondents offered a mixture of causal explanations and controllability beliefs, coders were able to identify

■

*With*

*the shift*

*from personality-*

*level explanations*

*for mental illness to*

*biomedical ones came the*

*hope of destigmatization;*

*yet it is not clear whether*

*emphasis on the*

*biological basis*

*of illness has*

*decreased*

*stigma.*

■

fy dominant beliefs for 14 (88%) of the 16 respondents. Fisher's exact tests failed to identify any differences in endorsement of these three themes in terms of participant diagnosis, gender, age, religious beliefs, or socioeconomic status. For respondents with bipolar diagnoses, depression seemed to be the more troubling illness event. As one man said, "[I] couldn't identify highs. I just thought, well, this is normal to me."

Beliefs coded as "biological causality"

included references to biochemical ("chemical") factors, heredity, and genes. The theme of depression as uncontrollable was identified by statements such as "I had no control over the depression" and through use of entrapment or victimization metaphors. Respondents described themselves as "locked," "suspended," "paralyzed," "robbed," "choked," or "held prisoner" by depression. The use of religious coping was directly assessed by the questionnaire.

Etiological beliefs leading to both positive and negative consequences were present in respondents' accounts. Viewing depression as biologically based allowed one man to challenge perceptions of laziness held by those who regarded depression as "just something that people say they have" to stop them from "working or getting on with life." Acceptance of biomedical causality freed a woman with bipolar disorder from "soul searching" for a cause. However, she described herself as hating to have to take medication because it symbolized her "defect": "I blamed God. I'd say, 'What did I do? Like, am I so evil?'" A man with bipolar disorder battled feelings of helplessness caused by medication dependence: "If there is no hope apart from this . . . there is a helplessness in this. And if you feel, well, you are stuck with this, take your medication and there is nothing else you can do, well, I think that is very, very hard to take in. I know they say if you had diabetes, you'd have to take medications. But I think there is something about human beings that wants more than that."

Perceptions of depression as being uncontrollable led to both positive and negative trade-offs. Rather than viewed as an internal event, a depressive episode was experienced by some respondents as an external, overpowering force over which they had no control. A 30-year-old man with depression said, "Because I know when I am down, there is nothing I can do, and it's locked in that sense." A young woman with bipolar disorder said she felt "trapped by this thing," whereas another found the unpredictability of a depressive episode "soul killing."

Emblematic of respondents' per-

ception of depression's uncontrollability was their use of a "light switch" metaphor to describe both being well and being ill. One woman reported that her physician referred to the anhedonic aspect of depression as akin to "your mind is switched off." A woman with bipolar disorder said that her physician described the administration of an antidepressant as similar to a light switch because she "reacted so violently to it." Respondents themselves also used the light switch metaphor to describe being well. A young man said of his depression's remission, "It's like somebody puts on the lights again. Everything is fine and you are full of plans and full of ideas." But it is a switch over which respondents feel they have no control, as indicated by a middle-aged woman with bipolar disorder who said, "I can't take credit for . . . bouncing back, because . . . somebody's just put the lights back on. I didn't do it."

Religious and spiritual beliefs helped respondents combat perceptions of helplessness. For many respondents, religion and prayer—along with support group membership—emerged during the interviews as coping mechanisms linked to solace and hope. The man who felt locked in depression reported praying that "depression stays away." A woman with bipolar disorder said, "It's not so easy to talk to all and sundry about how you are feeling. But sometimes you can pray and God will know how you are feeling and maybe just stand by you a bit, you know." The woman who found depression's uncontrollability "soul killing" reported finding meaning in her illness by conceptualizing it in religious terms as her "cross" to bear.

The religious dimension of coping was further explored by five questionnaire items. Asked whether they considered themselves to be religious or spiritual, 11 of 14 respondents (79%) assented. Of these 11, nine (82%) endorsed the notion that "Spirituality or religion helps you to deal with your problems." In answer to an open-ended question, the youngest respondent said spirituality "gives me a sense of the 'bigger picture' and helps keep things in perspective." The man who felt hopeless about being "stuck with

medication" found empowerment through his religion: "by reminding me that God is not to blame for my problems, that I have the free will to choose good or bad ways of coping with what life and circumstances have brought me." For another woman, religion offered hope.

When asked about specific religious coping strategies, nine of 14 respondents (64%) reported doing one or more of the following when they felt upset: "pray for guidance and/or strength," "seek God's help," or "try to find comfort in my religion" (Jackson B, Nolen-Hoeksema S, unpublished manuscript, 1998). Using Fisher's exact tests, we found that use of religious coping strategies did not vary by gender, age, or diagnosis. Individuals who did not use any religious coping strategies (five of 14, or 36%) showed higher levels of depression severity relative to those who did (CES-D score of  $27.6 \pm SD=23.4$  versus  $16.0 \pm SD=15.6$ ; possible CES-D scores range from 0 to 60, with scores of 16 or greater indicative of clinically significant depressive symptomatology [4]). However, CES-D scores did not differ significantly between the two groups.

## Discussion

A diagnosis of depression or bipolar disorder creates an "interpretive dilemma" for individuals, evoking implicit and explicit assumptions about illness etiology (2). In keeping with other research, our interviews with members of a mood disorders support group in Dublin suggested that acceptance of biological causality can not only relieve guilt but also provoke pessimism (2,3).

In this study patients' beliefs offered positive and negative trade-offs. Belief in biological causality allowed negative dispositional assessments to be disputed and patients' sense of responsibility to be assuaged. However, acceptance of biological causality translated into an external perception of control (that is, depression experienced as an outside force and mood stabilization accomplished through medication). The chronic nature of patients' illnesses was experienced in terms of helplessness and hopelessness. Such perceptions of uncontrol-

lability and unpredictability of illness potentially play upon and compound depressive attributional styles (7). Consideration of patients' perceptions of illness controllability may shed light on the counterintuitive finding that patients with dysthymia or minor depression may be more responsive to antidepressant medication when they see themselves as healthy and their illness as not biological in origin (8).

The limitations of this study include its small sample size and support group context. Sampling from a different setting may generate a sample whose perspectives and language illustrate other metaphors about illness and treatment.

For this group of respondents, religious beliefs acted to buffer feelings of helplessness engendered by perceptions of the uncontrollability of their illnesses. Respondents characterized their beliefs as giving them a sense of hope, purpose, and control, with prayer providing a vehicle for emotional expression. This component of religious activity and belief could be important when working with individuals who, because of cultural prescriptions, generational norms, or personal disposition, are not comfortable with expressing their feelings.

Respondents with bipolar diagnoses tended to focus on depressive episodes and recount seeing their "highs" as "normal." Consistent with other qualitative studies, this study did not indicate differences in perceptions of illness controllability (2,9). This result could be due to depression's being the explicit focus of the study or because depressive episodes are more troublesome and salient for patients (10).

These data are relevant to clinical care; our work and that of others has indicated that reconciliation of patients' personal illness models with recommended treatment contributes to more positive outcomes (1,11,12). Addressing issues of patients' belief in the controllability of their illnesses might improve medication adherence by reducing resistance to antidepressant medication provoked by perceived stigma (13). These findings further support the importance of cli-

nicians' helping patients understand the biomedical underpinnings of their depressive illnesses, while creating the opportunity for them to see themselves as active treatment partners—rather than as passive recipients of “wellness” or “defective” selves controlled by medication (10).

Because of its qualitative nature, the utility of the research centers on its ability to generate hypotheses and potential intervention opportunities. Several empirical questions are raised by this research: What specific strategies could clinicians use to help patients resolve the tension between beliefs in biological causality and positive perceptions of treatment outcome responsibility? How can clinicians tap into patients' illness models to best track changes in their beliefs and treatment adherence? Do patients who engage in positive religious coping behaviors (14) experience less perceived helplessness about their illness than those who do not?

## Conclusions

This research examined patients' underlying beliefs about illness causality and controllability. It highlighted the need for clinicians to attend to the way individuals speak about their illness. Attention to language can dramatize the complex clinical tension created by attempts to alleviate patients' sense of responsibility for having an illness (through emphasis on biomedical illness models), with the attendant risk of increasing patients' perception of illness uncontrollability. Although alleviating patients' sense of

responsibility may reduce their guilt, patients' perceptions of illness uncontrollability may diminish their sense of agency, play into depressive attributional styles, and undermine overall treatment outcomes. We also considered the potential role of patients' spiritual beliefs to empower and to modify extreme understandings of biological causation. The results of this study emphasize the importance of patient-clinician communication and patients' involvement in decision making to achieve optimal treatment matches.

## Acknowledgments and disclosures

This project was supported by predoctoral training grant T32-DA-07267 from the National Institutes of Health and National Institute on Drug Abuse to the University of Michigan, by the University of Michigan Rackham School of Graduate Studies, and by postdoctoral training grant T32-MH-19132 from the National Institutes of Mental Health to the Weill Cornell Institute of Geriatric Psychiatry, Weill Medical College of Cornell University. The authors extend appreciation to the members and executive committee of the support group for their participation in this research.

The authors report no competing interests.

## References

1. Brown C, Dunbar-Jacob J, Palenchar DR, et al: Primary care patients' personal illness models for depression: a preliminary investigation. *Family Practice* 18:314–320, 2001
2. Karp DA: Illness ambiguity and the search for meaning: a case study of a self-help group for affective disorders. *Journal of Contemporary Ethnography* 21:139–170, 1992
3. Phelan JC, Yang LH, Cruz-Rojas R: Effects of attributing serious mental illnesses to genetic causes on orientations to treatment. *Psychiatric Services* 57:382–387, 2006

4. Radloff LS: The CES-D scale: a self-report depression scale for research in the general population. *Applied Psychological Measurement* 1:385–401, 1977
5. Glaser BG, Strauss AL: *Discovery of Grounded Theory: Strategies for Qualitative Research*. New York, Aldine, 1967
6. Ryan GW, Bernard HR: Techniques to identify themes. *Field Methods* 15:85–109, 2003
7. Alloy LB, Lipman AJ, Abramson LY: Attributional style as a vulnerability factor for depression: validation by past history of mood disorders. *Cognitive Therapy and Research* 16:391–407, 1992
8. Sullivan MD, Katon WJ, Russo JE, et al: Patient beliefs predict response to paroxetine among primary care patients with dysthymia and minor depression. *Journal of the American Board of Family Practice* 16:22–31, 2003
9. Foster JLH: Beyond otherness: controllability and location in mental health service clients' representations of mental health problems. *Journal of Health Psychology* 8:632–644, 2003
10. Pope M, Scott J: Do clinicians understand why individuals stop taking lithium? *Journal of Affective Disorders* 74:287–291, 2003
11. Sirey J, Bruce ML, Alexopoulos GS, et al: Stigma as a barrier to recovery: perceived stigma and patient-rated severity of illness as predictors of antidepressant drug adherence. *Psychiatric Services* 52:1615–1620, 2001
12. Scott J, Pope M: Nonadherence with mood stabilizers: prevalence and predictors. *Journal of Clinical Psychiatry* 63:384–390, 2002
13. Sirey J, Bruce ML, Alexopoulos GS, et al: Perceived stigma as a predictor of treatment discontinuation in young and older outpatients with depression. *American Journal of Psychiatry* 158:479–481, 2001
14. Koenig HG, Pargament KI, Nielsen J: Religious coping and health status in medically ill hospitalized older adults. *Journal of Nervous and Mental Disease* 186:513–521, 1998