Family Burden and Family Stigma in Major Mental Illness

Harriet P. Lefley

University of Miami School of Medicine

Mental illnesses are unique in their etiological attributions. They are categories of disorder treated by medical means but viewed as induced by the behavior of others. Despite increasing evidence of diathesis, on the one hand, and on the other, a wide range of nonfamilial environmental stressors that may trigger decompensation (Day et al., 1987), families continue to be viewed as primary toxic agents, particularly in schizophrenia. The hard data emerging from the replications of the expressed emotion (EE) research (Vaughn, Snyder, Jones, Freeman, & Falloon, 1984) and the documented success of correlative psychoeducational interventions (Hogarty et al., 1986) have shifted the emphasis from etiology to potential precipitants of relapse. The EE investigators have cautioned that their research neither implies causality nor explains the decompensation of patients who have little or no contact with families, so that extramural environmental events must be explored (Vaughn et al., 1984). Indeed, many families are perturbed by the implication that, as primary targets of EE research and behavioral training, they may be viewed as the major caregivers of deinstitutionalized patients (Hatfield, 1987). This is an undesired social role with the potential for creating an at-risk population among aging parents, young children, and other relatives whose mental health may be affected by living with the stresses and sorrows occasioned by the psychotic disorder of a family member (Lefley, 1987b).

The question of predictive deviance in families of persons with schizophrenia continues to be an issue (Goldstein, 1985) although the research data invariably demonstrate that investigator-defined patterns of deviance are in no way modal or normative in this population. In the EE research, moreover, the calm, benign affects of low EE rather than the critical overinvolvement of high EE are the prevailing worldwide norms among families of schizophrenic individuals (Jenkins, Karno, de la Selva, & Santana, 1986; Leff & Vaughn, 1985), a finding that tends to contradict stereotypes of schizophrenogenesis. Over the years, numerous authors have cautioned that deviance in families, when observed, might be reactive to the experience of living with an individual who has a psychotic disorder. The reactive viewpoint, however, has focused largely on sympathetic or isomorphic responses to the cognitive deficits and aberrant communicative styles of the schizophrenic family member, rather than on the catastrophic impact of mental illness on the family system. Although there are claims of "epistemological confusion" among those who infer directionality from systems-oriented approaches (Dell, 1980), the organizational/systems model, when contrasted with the biologically based stress/vulnerability paradigm (Rohrbaugh, 1983), nevertheless assigns a functional value to the patient's symptoms and views them as precipitated and maintained for familial homeostasis. In contrast, a conceptualization of families of the mentally ill in terms of a model of stress, coping, and adaptation (Hatfield & Lefley, 1987) views familial behaviors as coping strategies. These represent modes of adjustment, both positive and negative, to the chronic strain of long-term psychosis and its attendant patterns of crises and remissions.

Life Stress and Family Burden

The literature on stressful life events devotes far less attention to continuous or chronic stressors than to discrete events (Kessler, Price, & Wortman, 1985). Yet, in surveying the most widely used scales, Angermeyer (1985) pointed out, "You will find every major event conceivable in an individual's life but you will miss the fact that a close relative has become mentally ill . . . one of the most devastating and catastrophic events that they can experience" (p. 473). Research on the strains of living with psychiatrically impaired persons is relatively sparse despite its pronounced social importance in an age of deinstitutionalization (Noh & Turner, 1987). Over the years, a small literature has developed on family burden, typically encompassing two descriptive categories. "Objective burden" deals with the actual, objective problems, and "subjective burden" with the psychological distress engendered by the illness. There is some evidence of commonalities of objective burden in families in which a member has a chronic developmental, mental, or physical disability. Frequently, families experience financial hardships due to medical bills and the patients' economic dependency, disruptions of household functioning, curtailment of social activities, and altered relationships with friends and relatives because of the excessive demands of caregiving. Typical also is an attentional focus on the patient together with time commitments that often lead to neglect of others in the family (Black, Cohn, Smull, & Crites, 1985; Leffley, 1987a; McCubbin et al., 1982). In many cases, the illness necessitates role and occupational changes for the major caregiver. Thurer (1983) has defined deinstitutionalization as a feminist issue because care of the chronically disabled has historically been assigned to women. In today's world, this may mean a woman's career options will be limited with no commensurate rewards.
for playing a self-sacrificing role that no longer brings approbation from society.

There are, however, components of objective and subjective burden that are specific to mental illness. Regardless of diagnostic category, there are cycles of exacerbation and remission of symptoms with concomitant patterns of hope and disappointment in family members. Objectively, this means failure of the patient to carry out age-appropriate role functions on any consistent basis. Families invest time and energy in help seeking and negotiating the intricacies of the mental health system, and their interactions with service providers are often frustrating, confusing, and humiliating (Hatfield, 1982; Holden & Lewine, 1982; Unger & Anthony, 1984). Families experience stressors in the form of periodic crises involving interactions with emergency services or the police, involuntary commitment procedures that pit families in an adversarial posture against their loved ones, and difficulties in finding appropriate alternatives to hospitalization, especially for persons with bizarre or abusive behavior. The negative impact of the patient's behavior on other family members, particularly children and adolescents, is an ongoing concern and may result in a need for ancillary interventions and a new generation of psychotherapists' bills.

Behavior management issues are ongoing tensions between patients and families. Relatives frequently must contend with the patient's abusive or assaultive behaviors, mood swings and unpredictability, socially offensive incidents in public places, conflicts with neighbors, patterns of losing or squandering money, poor personal hygiene, property damage and fire hazards, sleep reversal patterns that keep the household awake, and rejection of medications despite known patterns of relapse. The patient's positive symptoms of paranoid ideation and unprovoked aggression may alternate with negative symptoms of amotivation or anhedonia, attentional deficits, and prolonged silences. In either case, family members are deprived of the rewards and reciprocities of human interaction that most people expect from those they love.

Surveys of family experiences show the effects of stress on the psychological and sometimes the physical health of caregivers, inability of caregivers to make or fulfill personal plans, and their worries about what will happen to the patient "when I am gone," particularly among elderly parents of chronic patients (Lefley, 1987a). Relatives also report the agony of decisions about involuntary commitment of persons whose behavior or self-neglect may be life-threatening and guilt about leaving a loved one in hospitals or community placements of inferior quality—unhappy choices that the patient may resent and hold against them.

Perhaps the most devastating stressor for families, however, is learning how to cope with the patient's own anguish over an impoverished life. Even regressed patients are often aware of their impaired functioning and poor future prospects in relation to others in their age group. Families often mourn the loss of the premorbid personality, perhaps once bright with promise, but patients' own grieving for lost developmental stages of learning, failed aspirations, and restricted lives can be uniquely stressful for those who love them and can feel their pain.

**Stigmatization of Families**

Although there has been much discussion of stigmatization of the mentally ill, stigma also generalizes to their families. Social barriers are frequently erected against the relatives and households of negatively valued persons. The behaviors of persons with psychotic disorders may further isolate the family, diminish its reputation, and jeopardize relationships with friends and neighbors.

In the case of mental illness, moreover, there is also an iatrogenic component that may reinforce the self-stigmatization of families. Both the professional community and the society that reflects its values have given them a message of their own culpability in generating or precipitating the devastating illness of a loved one. Although many parents have overcome the Kafkaesque nightmare of trying to determine how, when, why, and under what conditions their behaviors could have led to such horrendous consequences and have decided they did not necessarily cause their offspring's illness (Hatfield, 1981), there is residual and often unjustified guilt. Family members frequently berate themselves for angry responses to provocation, demands that may have been too stressful, expectations that may have been too high, and failure to distinguish between volitional and avolitional behavior in someone retrospectively perceived as ill (Lefley, 1987b).

**Stress From Mental Health Professionals**

Parents of deinstitutionalized mentally ill adults, many of whom have been ill for 20 or more years, have endured the life strains of their adult children's illness during an epoch of theories of family pathogenesis and correlative treatment models. They have been informed by the media that there are "crazymaking families" and have been given messages by mental health practitioners that, in Goldstein's (1981) words, informed them that "the patient's illness was their fault and they should go away, shrouded in guilt, and leave the professional to undo the damage" (p. 2). Embedded in the emerging self-reports of families' experiences (Deahr, Labenski, Mott, & Pellegrini, 1986; Group for the Advancement of Psychiatry, 1986; Walsh, 1985; Wechsler, 1983) and inferrable from some of the critiques of family research (Hirsch & Leff, 1975; Howells & Guirguis, 1985) are four possible sources of iatrogenic damage. These include the psychologically disturbing impact of avoidant or recriminative responses to familial overtures for information and support, particularly when the family is in a condition of great distress; double-binding messages; modes of intervention whose sequels may alienate the patient's support system; and a self-fulfilling prophecy that may stimulate particular types of behavior in family-provider interactions.
Surveys of families indicate general dissatisfaction with the service delivery system in the treatment of persons with major mental illnesses (Hatfield, 1982; Holden & Lewine, 1982; Unger & Anthony, 1984). There is a pronounced failure of the system to provide substantive help or information to persons with a major role in caregiving or continuity of support. Families report frustrations in attempting to elicit answers to legitimate questions and in dealing with reluctant, ambiguous, and sometimes hostile communications from mental health professionals. In contrast to the earlier exclusion of family members, the contemporary practice is to catapult them into family therapy, often without clear information and explicit informed consent (McElroy, 1987). Many families perceive systems-oriented (as opposed to supportive and psycho-educational) family therapies as a superimposed and often irrelevant treatment model that ignores their expressed needs for developing appropriate expectations and managing difficult behaviors.

The iatrogenic double bind refers to the cognitive dissonance evoked by contradictory messages from mental health professionals. There is a confusion of options in dealing with multiple therapists of differing persuasions and treatment approaches (see Wechsler, Schwartztol, & Wechsler, 1988), and there are conflicting directives on the appropriate behavior of family caregivers. Thurer (1983) described the mental health risks of the overburdened caregiver, typically the mother of a deinstitutionalized adult patient. She is suffering from the pain of her child’s illness, the stigmatization of having “caused” it, and the burden of overseeing a treatment plan that may be unrealistic in terms of time, energy, money, and demands from the rest of the family. At the same time, she is trying to balance conflicting advice from professionals.

When things do not go smoothly, she is blamed. Should she discourage her child from unnecessary risks, she may be deemed overprotective. Should she encourage independence and seek residential placement, she may be deemed neglectful or rejecting. Should she demur from following any professional advice, she may be called a “saboteur.” (Thurer, 1983, p. 1163)

McFarlane and Beels (1983) have suggested that dual messages are often conveyed to families by basically disapproving clinicians.

If one accepts that double-bind interactions can create distorted, even irrational, communication, then many ‘therapeutic’ situations can be seen as pathogenic: For instance, covert blame of the family by professionals is often combined with overt attempts to help them, while the contradiction is denied. (p. 316)

When the clinician also conveys the message to a fragile patient that his or her symptoms are useful to others and fulfill some function in the family system and a long-suffering family member is confronted with hostility rather than gratitude for forbearance, this may pave the way for premature separation and loss of the patient’s support system (Lefley, 1987b).

One also wonders whether the perceived negative attributions of clinicians evoke defensive strategies in family members that reinforce the clinicians’ preconceptions of devianc. Does the family member’s history of experiences with providers, which may span many years, generate expectancies of evasiveness, dissembling, deflection of questions, or attitudinal rejection? Do these expectancies in turn produce anticipatory aggressive or demanding behavior in order to receive answers or services? Or, alternatively, does the expected rejection reinforce a tendency to (a) become overly submissive or (b) withdraw from confrontation and accelerate the process of disengagement or even abandonment of the patient? Further, is there a “reciprocal Rosenthal effect” as a function of the family’s awareness of etiological theory? Many families are exposed to popular media articles on childrearing and assumptions of parental culpability when children are emotionally disabled. Do these theories generate varieties of intraputitive behavior that include fulfilling perceived negative expectancies of clinicians or researchers? Iatrogenic damage of some types of family theories has been discussed in the literature (Terken, 1983), but these empirical questions of self-stigmatization in familial response have yet to be addressed.

Clinicians With Mentally Ill Relatives

There is some evidence that the basic determinants of family burden, including stigma, generalize across populations regardless of level of sophistication or ease of access to the treatment system. In a study of 84 experienced mental health professionals with chronically mentally ill family members, Lefley (1987c) found that clinicians did not differ from lay family members in their assessments of the psychological burden of patients’ behaviors. Moreover, mental health professionals showed significant concordance with nonprofessional family members (Hatfield, 1979) in assigning priority to education on symptoms and medications, behavior management techniques, and involvement with a support group as the most important services that can be offered to families. Despite the fact that the respondents were predominantly involved in the practice of psychotherapy, they considered affiliation with a self-help group and residential separation from the patient more effective coping strategies than individual or family therapy. Most of these clinicians who had lived with the patient for many years and had observed the developmental and later course of illness questioned family pathogenesis. Siblings disputed this even more than parents (Lefley, 1985), suggesting that defensiveness about a putative role in etiology was not a major determinant of response. Some respondents expressed anger in their comments about the impact of the etiological theories of their early training and about the insensitivity of some colleagues to family pain. Yet, they were uncomfortable in discussing mental illness in the family with colleagues. Instructed to disregard personal reticence styles, only 26% of the sample indicated they would have no compunctions about talking openly about the situation, whereas another 26% expressed strong reluctance. More than 90% of the respondents reported that they frequently overheard colleagues make negative or disparaging remarks about family members. Yet, al-
most one third reported that although they generally disagreed they kept silent. Ambivalent about an appropriate role for a family member–clinician, the majority felt unable or unwilling to contribute information or expertise to successful treatment of the case. Overall, the group seemed uneasy about talking about their personal experiences or edifying colleagues. Although 72% had undergone personal psychotherapy to process the impact of their relative’s illness, in some cases there was an apparent reluctance to disclose fully their feelings of anger and cognitive dissonance to the therapist. Thus, for mental health professionals with seriously mentally ill relatives, family burden may be exacerbated by role conflict because of perceived stigma from colleagues or disturbing contradictions between experience and training.

**Changing Perspectives**

A number of converging historical events have generated a *zeitgeist* for more favorable attitudes, cognitions, and alliances between families and clinicians. New biogenetic research findings, a widening recognition of the dimensions of family burden, and the pragmatic needs of deinstitutionalization have led to a reconceptualization of family role in the mental health field. Depopulation of hospitals produces a need to reinvolve families as caregivers or support systems for long-term patients. Changes in levels of service funding require a grass-roots constituency for legislative advocacy at the state and federal levels. The remarkable growth and influence of the National Alliance for the Mentally Ill (NAMI) has been a propitious and timely development in this historical process. For the family members who comprise its base, the new organization has provided a vehicle for mutual support, information sharing, public education and advocacy, resource development, and investment in preventive research for future generations. For persons who have endured inordinate pain and distress, these are highly adaptive behaviors that must surely be confusing to professionals who are still reading an older literature on families of schizophrenics.

These developments have also paved the road for new and productive alliances between clinicians and families at both case-centered and societal levels. There are now mandates from regulatory agencies for family involvement in treatment and discharge planning. Increasingly, family members are being solicited to sit on advisory and governance boards, evaluate services, and participate in the mental health planning process. For the first time, both primary and secondary consumers are exercising some control over the services that affect their own lives. Family members are also sharing their experiences and expertise in clinical training and continuing education. In university programs throughout the nation, NAMI members have invited roles as lecturers, workshop conductors, discussants in grand rounds, and presenters at professional conferences. Clinical training grants from the National Institute of Mental Health have regularly required family and consumer input in developing curriculum materials on the seriously mentally ill patient.

This new collaborative model of clinician–family relationships has done much to desigmatize a formerly negatively valued group. It has also reoriented the thinking of many mental health professionals. Views of family pathogenesis are in many cases changing to admiration for coping strengths under conditions of great adversity. The new respect from service providers and the growing self-confidence of families in their own capabilities as educators, advocates, and survivors may do much to alleviate the stresses of family burden.

**REFERENCES**


