In this chapter, we present the most recent research findings related to the causes, courses, and treatment of mental illness as a family stressor. We discuss topics relevant to families coping with mentally ill members in reference to the ABC-X model of family stress, and we use personal narratives throughout the chapter to illustrate the links between family issues and components of the ABC-X model. In addition, we adopt a family systems perspective, with a focus on the family system as the unit of analysis, in order to demonstrate how all family members interact as a system when the family is coping with one or more members who suffer from a mental disorder. Thus, from a systems perspective, we reformulate questions regarding cause, assessment of family resources, and treatment options within a family system framework (e.g., What do interaction patterns look like in families that contain members suffering from mental disorders? What are the most useful methods to ameliorate the burdens of families with mentally ill members? What is the most effective way to deliver community-based resources to families with mentally ill members?).

Family Stress Theory and Mental Illness

Maria is a 21-year-old college student who is living with her parents while she attends classes and works part-time at a local restaurant. Maria is the daughter of Josefina, who is an immigrant from Mexico, and of Robert, who is of
Mexican descent but was born in the United States. She has one older brother, George, who is 28 years old and who also lives with Maria and her parents. When Maria was a young girl, her mother was diagnosed with major depression. Subsequently, Maria had a difficult childhood, in part because her family coped unsuccessfully with her mother’s depressive symptoms. Recently, Maria has also been experiencing episodes of depression, but her parents have been unsupportive and critical during these times, claiming that Maria “just needs to snap out of it.” Robert is especially critical of Maria because he is ashamed that his daughter is not living up to the standards that he has set for her. He is uncomfortable when Maria attends any gatherings of their extended family because he finds her depressive symptoms to be embarrassing. Fortunately, George is very sympathetic toward his sister, and Maria has a close group of friends who offer her ongoing support and encouragement when she needs their help. Maria has also recently contacted a community-based support group for young women suffering from depression, and she plans to attend the group’s weekly meetings.

Unfortunately, Maria’s situation is not uncommon, and many of the issues that she is facing correspond with the elements of the ABC-X model. In addition, many of the topics that we discuss in this chapter can be illustrated through her story. For example, in the model, A refers to the stressor event, which is the family member’s mental illness. Thus we discuss below the numbers of individuals in the United States who are affected by mental illness, with particular emphasis on the demographic characteristics (e.g., gender, age, socioeconomic status, and ethnicity) associated with mental illness. Also related to the stressor event, we review the research related to the causes of mental illness, including genetic linkages, family environment contributions, and the combination of heredity and family relationships.

In the ABC-X model, B refers to the family’s perceptions and definitions of the family member’s mental illness. A very important issue we discuss in this chapter as an example of family perceptions is the notion of a subjective burden (i.e., a family member’s appraisal of the illness and/or the caregiving experience). For instance, a significant subjective burden for many families with mentally ill members involves the stigma attached to mental illness, both within the family and in society in general. We also review the literature pertaining to the concept of “expressed emotion,” illustrating how family members’ views of mental illness can translate into behaviors and attitudes that have direct impacts on the well-being of mentally ill family members.

The C element in the family stress theory model refers to available resources. In this chapter, we discuss family strengths and the positive outcomes that families can achieve by coping successfully with mental illness. We also discuss the community resources that exist for families coping with mental illness, such
as treatment programs (e.g., psychoeducation), community-based organizations (e.g., the National Alliance for the Mentally Ill), and social policy efforts.

Epidemiology of Mental Illness

Many families in the United States today are affected by the mental illness of one or more family members. Mental illness, which can be described as an abnormality in an individual's mood, cognition, emotion, behaviors, or integration of behaviors, is manifested through symptoms such as mood dysregulation, thought disturbances, and inappropriate anxiety. Mental illnesses are often classified into two groups: internalizing disorders and externalizing disorders. Internalizing disorders involve a major disturbance in moods and emotions, and may include symptoms such as anxiety, sadness, worry, and guilt (although the features of these disturbances can vary widely). The two main types of internalizing disorders are mood disorders and anxiety disorders. Externalizing disorders, in contrast, are characterized by aggressive, impulsive, and/or delinquent behaviors, and can include a range of mild to more severe acting-out behaviors. The two main types of externalizing disorders are disruptive behavior disorders and attention-deficit/hyperactivity disorders (McMahon & Estes, 1997; Zahn-Waxler, Klimes-Dougan, & Slattery, 2000).

Epidemiologists study disease patterns in given populations to determine how many people in those populations suffer from particular illnesses. Two terms from the field of epidemiology are used in estimates of the occurrence of mental illnesses in a population: incidence, which refers to new cases of particular mental illnesses that occur during a set period of time; and prevalence, which refers to new and existing cases of particular mental illnesses that have been observed during a set period or during one point in time (U.S. Department of Health and Human Services, 1999). Sometimes, however, it can be difficult to identify “cases.” For example, although an individual may experience particular symptoms, the duration and/or intensity of the symptoms may not reach the threshold necessary for a diagnosis of mental illness (Kupfer, First, & Regier, 2002). Nevertheless, using the information that is available about the incidence and prevalence of various mental illnesses, we can describe current patterns in the U.S. population.

Rates of Mental Illness in the U.S. Population

The National Institute of Mental Health’s Epidemiological Catchment Area study (Regier, Burke, & Burke, 1990) and, more recently, the National Comorbidity Survey (NCS) (Kessler et al., 1994) have supplied gross
estimates of the prevalence of mental disorders in the U.S. population. According to data from the NCS, in which more than 8,000 people between the ages of 15 and 54 were interviewed, nearly half of all respondents (44.2%) experienced a psychiatric disorder at least once in their lives (Kessler et al., 1994), and 29% indicated that they had experienced a mental disorder and/or addictive disorder within the past year. Specifically, these data show that in any given year, approximately 19% of adults in the U.S. population will have a mental disorder, 6% will have an addictive disorder, and 3% will experience both a mental disorder and an addictive disorder (Kessler et al., 1994). Translating these percentages into numbers, researchers have estimated that in 1998 nearly 44.3 million people in the United States had diagnosable mental disorders (Narrow, 1998).

Estimated mental illness prevalence rates among U.S. preschoolers, preadolescents, and adolescents are 12%, 15%, and 18%, respectively (National Institute of Mental Health, 1991; Roberts, Attkisson, & Rosenblatt, 1998). In addition, an even a larger percentage of children, nearly 20%, have mental disorders with at least mild functional impairment (Shaffer et al., 1996).

Gender

Several gender differences appear to be associated with vulnerability to mental illness. For example, data from the NCS indicate that women have higher prevalence rates for affective disorders and anxiety disorders, whereas men have higher rates for substance abuse (Kessler et al., 1994) and antisocial personality disorders (Regier et al., 1988). In fact, rates of depressive disorders (i.e., major depressive disorder, dysthymic disorder, and bipolar disorder) are twice as high for women (12%, or 12.4 million women) as they are for men (6.6%, or 6.4 million men) in the United States (Narrow, 1998). However, given the fact that men are more likely than women to self-medicate with alcohol and illicit drugs as a form of coping, some scholars have suggested that the rates of depression for males and females may actually be similar (Kessler et al., 1994). Also, although four times as many men die from suicide as do women, women attempt suicide two to three times more often than do men (Weissman et al., 1999).

Research also suggests that women are more likely than men to use the health care system to treat distress and dysfunction (Glied & Kofman, 1995); women are also more likely to utilize primary care providers and outpatient services. In contrast, men seek treatment through specialists and inpatient care. In addition, married women and unmarried men (single, widowed, or divorced) are more likely to experience mental disorders than are unmarried women (single, widowed, or divorced) and married men (Balcom & Healey,
1990; Gove, 1972). However, it should be noted that the terminology and theoretical frameworks that professionals use to describe individual and family functioning often pathologize the relational styles and coping strategies of women (Bograd, 1990).

Age

Data from the NCS suggest that the highest rates of mental illness are found in persons between 25 and 34 years of age, with prevalence declining at later ages (Kessler et al., 1994). However, between 15% and 25% of elderly Americans suffer from mental disorders (Cross-National Collaborative Group, 1992; Robins & Regier, 1991; Roybal, 1984), and some evidence suggests that individuals’ total number of physical and psychological complaints increases with advanced age (Brody & Kleban, 1983; Watson & Wright, 1984). For example, mental illness rates among individuals in nursing homes may be as high as 90% (Smyer, Shea, & Streit, 1994), but that may reflect families’ tendency to use nursing homes as “dumping grounds” for elderly family members.

Because American society has only recently begun to acknowledge the psychiatric impairment of youth (Mash & Barkley, 1996), mental illness among children and adolescents is a relatively new area of study. Reports indicate that rates of serious emotional disturbances among children and adolescents are between 9% and 13% (Friedman, 1996), suggesting that nearly 75 million children in the United States have mental disorders. In addition, researchers have suggested that rates of mental illness in the young vary among different age cohorts (preschoolers, preadolescents, and adolescents) (Roberts et al., 1998). One alarming statistic, however, shows that suicide rates among young adults are disproportionately high (Minino, Arias, Kochanek, Murphy, & Smith, 2002).

Ethnicity

Few large-scale studies have focused on mental illness among African Americans or Latinos, and no such studies have been conducted on Asian Americans or Native Americans. Hence the very limited information that is available concerning mental illness rates among ethnic minority groups in the United States is based on relatively small samples.

Although general mental illness rates are similar for ethnic groups and whites, several specific differences have been found. For example, compared with Caucasian youth, young Latinos report disproportionately higher rates of depression, anxiety, delinquency, and drug problems. Also, suicide rates
among African American teens increased by twice as much as rates among Caucasian teens between 1980 and 1995, yet suicide rates among Asian Americans of all ages tend to be substantially lower than the suicide rates for whites (U.S. Department of Health and Human Services, 1999).

Despite similar mental illness rates between ethnic minorities and whites, some scholars have suggested that ethnic minorities are overrepresented in certain high-need populations. For instance, African Americans, Latinos, and Native Americans make up a significant percentage of the homeless, incarcerated, and drug-addicted populations, all of which are at risk for a variety of mental health problems. In addition, high percentages of African American and Native American youth are in foster care, another group at risk for mental health problems. Also, high percentages of Latinos and Asian Americans are found in the populations of refugees and Vietnam War veterans, both of which groups are at risk for posttraumatic stress disorder (U.S. Department of Health and Human Services, 1999).

Socioeconomic Status

Studies have shown consistently that the rates of almost all mental disorders decline with increased education and income (Bruce, Takeuchi, & Leaf, 1991; Canino et al., 1987; Robins & Regier, 1991). However, socioeconomic status is more strongly related to anxiety disorders than to affective disorders. Specifically, the prevalence of anxiety disorders significantly increases with decreasing income levels, yet this negative relationship is not found between affective disorders and income. Hence lack of family resources and other characteristics often found among financially disadvantaged individuals (e.g., low level of employment, negative life events, poor nutrition, exposure to violence), especially children and adolescents, may contribute to increased apprehension and agitation, both of which are associated with anxiety disorders (Mash & Wolfe, 2003).

Historical View of Families and Mental Illness

Family experiences related to coping with mental illness have changed dramatically over the past several decades in the United States, and this historical evolution is largely related to how mentally ill family members are viewed in relation to the onset of their disorders. Marsh (1998) describes this evolution as occurring in three distinct phases. First, during the “institutional era,” prior to World War II, the majority of mentally ill persons resided in institutions; they were isolated from their families, and thus little
attention was paid to the family’s etiological role. The second phase, which lasted from the immediate postwar era into the mid-1980s, was characterized by the deinstitutionalization of the mentally ill, which typically resulted in mentally ill individuals’ returning home to live with their families. Concurrent with this residential shift, mental health professionals and the larger society began to shift the responsibility (often characterized as outright blame) for the development of mental illness onto families. Since the mid-1980s, a third phase has emerged in which families are actively involved with professionals in helping to ameliorate the impact of mental illness within the family. In this approach, the family is not held accountable for the onset of the family member’s illness; instead, the disorder is seen as arising from a combination of genetic factors and environmental influences (Rende & Plomin, 1993).

Much of our understanding of family stress and coping responses related to mental disorders has evolved from research conducted by family scientists and therapists who have either observed or directly intervened with families that included members with major mental disorders—usually schizophrenia (Broderick & Schrader, 1981; Hoffman, 1981; Nichols & Schwartz, 1991). Furthermore, much of the early research with such families focused on the mother’s role, usually in terms of how the mother’s illness may have contributed to her offspring’s dysfunction. For instance, in a review of the literature, Caplan and Hall-McCorquodale (1985) found that more than 70 forms of child psychopathology were attributed directly to mother-related variables. More recent research, however, has expanded to include examination of the father’s role (Phares & Compas, 1992) as well as the association between marital functioning and the development of psychopathology within families (Davila & Bradbury, 1998; Phares & Compas, 1992).

**Etiology of Mental Illness**

Antoine has been experiencing some very serious destructive and depressed thoughts lately, and he has even attempted suicide. His wife has recently become aware of his mental health issues, but she does not understand what is causing Antoine’s depression. She does know that Antoine’s father also experienced depression and engaged in an excessive amount of drinking and drug use throughout Antoine’s childhood and early adulthood. Also, Antoine recently lost his job and has been very worried about the family’s finances. In fact, without meaning to hurt Antoine, his wife has been putting a great deal of pressure on him to find a new job, as she is 7 months pregnant and worried about the hospital costs associated with the baby’s delivery. As a step toward staying away from self-medicating with alcohol as his father did, Antoine...
opened up to his wife one evening. He explained that he felt overwhelmed but did not believe that he could ask for help because “strong African American men do not need help” in fulfilling the role of head of the household. When his wife broached the subject of his recent suicide attempt, Antoine admitted that he still “just wanted to stop the stress” by taking a very large dose of medications and going to sleep.

It is difficult to discuss the etiology (i.e., the causes or origins) of mental disorders in family members without adopting a family-oriented perspective, as all family members are a part of the family system. Moreover, it is necessary to understand the role of at least one parent (mother and/or father) in an individual’s psychopathology, because even molecular, genetic-based research studies have at their core the implication of family heritage.

This present view is consistent with the biopsychosocial model of disease (Engel, 1977), which contends that the causes, courses, and outcomes of all illnesses are influenced by interactions among biological, psychological, and social factors. Thus multiple factors play roles in the etiology of mental illness, and the relative importance of the various factors differs among individuals and across the stages of the life span. In Antoine’s case, he may have inherited a predisposition for depression from his father, and he may have been influenced in his childhood both by his father’s depressive symptoms and by how his father “coped” with the manifestation of the symptoms through drug use. In addition, Antoine is currently experiencing stress caused by the loss of his job and anxiety stemming from his wife’s concern over the medical costs they face with the birth of their child. Antoine believes that a man should not appear weak in his role as head of the family, a belief that was most likely instilled in him by his family when he was a child. In sum, multiple factors have contributed to the destructive feelings that led Antoine to attempt suicide.

Research on the etiology of mental illness parallels this biopsychosocial framework, such that studies utilizing a family-oriented perspective on mental disorders can be organized into three categories: (a) studies that examine how the presence of a mental disorder in a parent puts his or her offspring at risk (genetic linkage research), (b) studies that assess the relationship between various family environmental factors and the subsequent mental health status of family members (family environment research), and (c) studies that attempt to examine the relationship of both genetic linkage and family environment to the development of mental disorders.

Genetic Linkage Research

Genetic linkage research usually explores the relationship between the presence of a mental disorder in one family member and the concurrent or
eventual manifestation of mental illness in other family members. Generally, researchers have used two types of study designs to examine this relationship: the “top-down” design, which involves the study of the children of mentally ill adults; and the “bottom-up” design, which looks at the adult relatives of children with mental disorders (Birmaher et al., 1996). Although these approaches are useful, they cannot clarify the unique contributions of genetic influences and family environmental influences. Therefore, researchers have implemented studies of twins and children who have been adopted to increase our understanding of how shared genes can cause mental illness among family members. For example, researchers often compare disorder rates among monozygotic twins (who share 100% of their genes) and dizygotic twins (who share only 50% of their genes) to evaluate the influence of heritability; if disorder rates are significantly higher among monozygotic twins, then heritability is deemed an important factor. Similarly, studies of adopted children generally compare adjustment/mental health similarity in twins who have been reared in separate environments. The results of twin and adoption studies suggest that genetic links are important elements in the onset of many different mental illnesses, such as personality disorders, mood disorders, autism, and substance abuse (Mash & Dozois, 1996). However, it is likely that the extent of genetic contributions may vary across specific disorders. For instance, in an extensive review of genetic studies on childhood and adolescent depression and anxiety, Eley (2001) found that genetics appears to account for one-third of the variance in childhood/adolescent anxiety and depression; however, heritability appears to be more significant for boys’ depression and for girls’ anxiety.

Pioneering efforts in molecular genetics indicate that it may be useful to examine particular genes or genetic markers for links to mental illness (Plomin, DeFries, Craig, & McGuffin, 2003). Recent genetic research has focused on the relationships between genetic markers and anxiety and depression (Collier, 2002; Eley, 2001), antisocial behavior (Eley, Lichtenstein, & Moffitt, 2003), and mood disorders (Goodwin & Ghaemi, 1999; Morley, Hall, & Carter, 2004).

Family Environment Research

A number of family environmental factors have been shown to be related to the development of mental disorders, including family stressors, numerous family relationship variables (e.g., conflict, support, and relationship quality), and expressed emotion. Researchers have found interrelationships among maternal physical and mental health, divorce, and parental death as well as typical, everyday stressors (Forehand, Biggar, & Kotchick, 1998;
Sheeber, Hops, & Davis, 2001; Weller, Weller, Fristad, & Bowes, 1991). For example, Forehand et al. (1998) found that half of the mothers in their sample of 285 families of adolescents (ages 11–15) reported experiencing two or more family stressors and that adolescents from those families with multiple stressors showed more depressive symptoms 6 years later compared with adolescents from less stressful family environments.

Family conflict, family support, and family members’ relationship quality also have been associated with youth reports of mental illness. For example, family conflict, parental hostility, and harsh discipline have been related to adolescents’ internalizing disorders. Specifically, one longitudinal study found that parent-adolescent disagreements during early adolescence predicted internalizing symptoms several years later among a sample of late adolescents (Reuter, Scaramella, Wallace, & Conger, 1999).

Also, the results of several studies suggest that family supportive behaviors are related to the mental health of children and adolescents (Cole & McPherson, 1993; Garber & Little, 1999; Garrison, Jackson, Marsteller, McKeown, & Addy, 1990). For instance, Sheeber, Hops, Alpert, Davis, and Andrews (1997) found that less supportive family environments and less facilitative behavior during problem-solving discussions were associated with adolescent depressive symptomatology. Studies that have examined family relationship quality have resulted in similar findings; for example, Puig-Antich et al. (1993) found that depressed adolescents reported poorer quality relationships with parents and siblings than did nondepressed adolescents, and Garber, Little, Hilsman, and Weaver (1998) found that poor family functioning mediated the relationship between maternal depression and adolescent suicide symptoms.

Research on Expressed Emotion

Lola is a middle-aged woman who has struggled with mild depression throughout her entire adult life, but recently she has been experiencing very severe depressive symptoms. In particular, Lola is often unable to get out of bed in the morning, and she is neglecting all of the household chores and the caretaking of her 15-year-old son. Hans, Lola’s husband of 30 years, has grown intolerant of her condition, and he frequently acts in a hostile and critical manner toward her. He claims that Lola is “just being lazy to avoid the housework,” and he believes that she is responsible for and in control of her symptoms. Lola, in turn, has become frustrated by Hans’s negative attitude and behaviors, and now she has begun to act hostile toward him as well.

The research on expressed emotion (EE; see Brown, Birley, & Wing, 1972; Brown, Monck, Carstairs, & Wing, 1962) has been very influential in
the movement toward a family-oriented perspective on mental disorders. In addition, the concept of EE fits within the description of the B element in the ABC-X model of family stress, such that EE represents an individual's perceptions. Specifically, the concept of EE comprises both (a) the level of emotional (over)involvement among family members and (b) the degree to which family members display critical attitudes toward and/or make hostile comments about the family member who has a mental disorder (Vaughn & Leff, 1976a, 1976b). Extensive research on EE has found that individuals suffering from a multitude of illnesses (e.g., schizophrenia, mood disorders, eating disorders, posttraumatic stress disorder, alcohol abuse, Alzheimer's disease, and personality disorders) who live with high-EE (i.e., overinvolved, critical, or hostile) family members are more likely to experience relapse (i.e., another episode of symptoms) than are persons with the same illnesses who live with low-EE family members (Barrowclough & Hooley, 2003; Wearden, Tarrier, Barrowclough, Zastowny, & Rawhill, 2000). Based on this information, it is likely that Lola will continue to suffer from depression, in part because of her husband's hostile attitude toward her illness.

Although by definition the EE construct involves family members' reactions to a mentally ill family member, recent research suggests that EE may reflect a bidirectional process (Scazufca & Kuipers, 1998; Wearden et al., 2000). In other words, instead of contributing to a family member's mental illness, critical and overprotective attitudes may represent the way in which some family members cope with the stress and burden of mental illness in the family. In addition, this form of family response must be considered in light of the patient's own behaviors (King, 1998). For instance, in a study of interactions between family members, Hooley and Richters (1995) found that negative communication exchanges were just as likely to be initiated by the patient as by the patient's parents. Consistent with these findings, Lola is responding to Hans's hostility with her own anger; thus the couple is likely to continue to engage in negative and harmful interactions.

Some researchers have attempted to gain a more complete understanding of exactly why EE is associated with psychiatric relapse. Barrowclough and Hooley (2003) note that growing evidence suggests that “high- and low-EE family members differ in the beliefs they hold about patients and the problem behaviors associated with the patient's illness” (p. 850) such that high-EE relatives tend to make internal, stable, controllable attributions about the abnormal behavior of a mentally ill family member, whereas low-EE family members perceive the individual's behavior to be out of his or her control and a product of the illness. Hence Hans's belief that Lola can control her
depressive symptoms reflects a high-EE attitude, which is likely to contribute to Lola’s continued struggle with depression.

One implication of these research findings is that it would be useful to educate family members regarding the severity and origins of the patient’s symptoms as a way of decreasing family EE levels. Lopez, Nelson, Snyder, and Minz (1999) contend that the goal of family treatment should be a “flexible attributional stance,” in which family members neither attribute all aspects of the patient’s behavior to factors beyond the patient’s control nor assume that the patient could easily control his or her symptoms. Thus the recognition that abnormal behaviors are distinct from the individual’s personality and largely out of that person’s control would increase the possibility that family members would act in a less critical fashion toward the patient (Fristad, Gavazzi, & Soldano, 1999). In Lola’s case, an intervention that educates Hans about Lola’s lack of control over many of her depressive symptoms would likely be a highly effective strategy for changing the couple’s problematic interactions.

Research Examining Both Genetic Linkage and Family Environment

As Hahlweg and Goldstein (1987) note, much of the current family-oriented research on mental disorders follows the vulnerability-stress model (also referred to as the diathesis-stress model), which is similar to the biopsychosocial model discussed above. Hahlweg and Goldstein state: “According to this model, a predisposition to a disorder, such as schizophrenia, is inherited and forms the basis for various indices of vulnerability to the disorder. This vulnerability is modified by all life events that increase or decrease the likelihood that a major psychiatric disorder, such as schizophrenia, will emerge in early adulthood” (p. 2). In other words, heredity can provide an individual with a predisposition to a mental illness, but the likelihood that the illness will manifest is largely determined by environmental and family influences.

Consistent with the vulnerability-stress model, Rende and Plomin (1995) contend that the most promising direction for future investigation is the examination of how heredity and environmental influences contribute—both separately and in interaction with one another—to the development of psychopathology. These authors outline important avenues for future research, including (a) the identification of genes and nonshared family environmental influences and (b) the examination of how an individual’s genetic predisposition can actively lead to the development of an at-risk family environment.
Assessment of Family Resources

Larry and Sharon Lusk are a middle-aged couple who have recently begun to care for Larry’s father, James, who has been diagnosed with Alzheimer’s disease. Since James first moved in with Larry and Sharon his condition has deteriorated rapidly, and he is now approaching the need for around-the-clock care. Larry and Sharon are struggling to pay for all of the medical treatment James needs, and the family is experiencing additional financial problems because Sharon had to quit her job to provide full-time care for her father-in-law. Other smaller adjustments the couple have had to make are also taking a toll. For instance, Larry has stopped hosting his Sunday-night poker games with friends because he is embarrassed by his father’s condition. Although Larry and Sharon have been unsuccessful in locating local programs and resources for families caring for elders with Alzheimer’s in their community, they have joined an online support group. Their search for resources on the Internet seems to have brought Larry and Sharon closer to each other. They have grown to understand that many other couples who have gone through similar hardships involving family caretaking have found their relationships strengthened as a result. In addition, Larry and Sharon have decided to organize a support group at their local hospital for other families in their community who are caring for family members with Alzheimer’s.

To understand and address the impacts of mental disorders on families, professionals must begin any intervention with a thorough assessment of family members’ strengths as well as their limitations. Specifically, mental health professionals must have a reliable and valid understanding of what family members have and do not have at their disposal in terms of skills and resources for coping with and adapting to a member who is mentally ill. For the Lusks, the stressors that are currently affecting the family include the financial burdens and daily tasks associated with caregiving; the stigma of the mental disorder, which has led Larry to reduce contact with his friends; and the lack of community resources available to help the family cope. However, as a result of their providing care for Larry’s father, Larry and Sharon have discovered several family strengths, such as the improved quality of their relationship and their ability to organize a local support group.

Each of the caregiving outcomes that the Lusk family is experiencing has been the focus of studies that have examined the stressors that families experience when they provide care to a mentally ill family member. These stressors typically are described as the “burdens” associated with having a family member suffering from a mental disorder. These burdens have been characterized as being of two types: subjective and objective (Hunt, 2003). Subjective burdens are those based in individuals’ perceptions about or appraisal of the
illness and/or the caregiving experience (Nijober, Triemstra, Tempelaar, Sanderman, & Van den Bos, 1999), whereas objective burdens are the observable and tangible stressors or costs related to caregiving and mental illness (Jones, 1996; Maurin & Boyd, 1990).

Objective burdens usually are measured in terms of economic hardships faced by a family, often calculated as the amount of money the illness has cost the family in outright payment or copayment for medical expenses as well as lost wages. Objective burdens also include many other tangible family costs related to the care and treatment of an ill member, such as the costs of providing transportation, food, clothing, and insurance.

The amount of subjective burden a caregiver experiences is related to his or her perceptions about the family member and the mental illness. Research has shown that caregivers who experience high levels of subjective burden are at greatest risk for negative health outcomes, such as depression (Nijober et al., 1999). One of the most severe subjective burdens that families with mentally ill members experience is the stigma attached to mental disorders; this psychological burden can lead to lower self-esteem levels, reduced social contacts, job loss, and family relationship difficulties (Fuchs, 1986; Leete, 1987; Mittleman, 1985; Wahl & Harman, 1989). Some researchers have suggested that the stigma is especially problematic for mothers who are suffering from severe mental illness because they often must be separated from their children, at least temporarily, to receive treatment, even though mothering remains an important role for them (Nicholson, Sweeney, & Geller, 1998; Savvidou, Bozikas, Hatzigeleki, & Karavatos, 2003). In addition, the mass media in the United States help to perpetuate negative public perceptions of mental illness by presenting inaccurate and stereotypical descriptions of individuals with mental disorders (Flynn, 1987). For example, in his book *Media Madness*, Wahl (1995) notes that mental illness is the form of disability most frequently portrayed in the contemporary media.

Some scholars have argued that research on family burden provides only half of the overall picture, in that it neglects the positive aspects and strengths found in families coping with mental illness (Doornbos, 1996; Hawley & DeHaan, 1996; Kramer, 1997; Morano, 2003; Walsh, 1996). One such strength is often referred to as resiliency in the family literature. Other positive concepts are also discussed in the literature on caregiving, such as caregiver esteem (the extent to which participating in caregiving enhances an individual’s self-esteem), uplifts of caregiving (caregiving events that evoke joy), caregiver satisfaction (benefits an individual receives as a result of his or her efforts at caregiving), caregiver gain (positive return
received as a result of caregiving), and meaning through caregiving (finding higher levels of meaning through the caregiving experience) (Hunt, 2003).

In a nationwide study, Marsh et al. (1996) asked 131 family members of patients with serious mental illness to respond to a set of open-ended questions concerning the development of personal, family, and patient resilience. They found that 99.2% of their respondents reported the presence of some form of personal resilience, 87.8% reported family resilience, and 75.6% reported patient resilience. Examples of the resilience dimensions the respondents mentioned included family support/bonding, insight and caregiving competencies, and gratification through advocacy initiatives for constructive changes in the mental health system.

Community-Based Resources

Therapy

The family therapy profession has greatly influenced the family-oriented perspective regarding major mental disorders. Some of the earliest writings in the field of family therapy blamed families, directly and indirectly, for “causing” mental disorders in family members. Blaming attitudes can be seen, for instance, in a particular school of family therapy known as the Milan model (Selvini Palazzoli, Boscolo, Cecchin, & Prata, 1978). A more recent version of the Milan model holds that much of the blame for mental disorders in individuals resides in the “dirty games” that family members play with each other in the course of their interactions (Selvini Palazzoli & Prata, 1989). From this perspective, therapeutic interventions are designed to disrupt unhealthy family interactions in order to eliminate symptoms of the mental disorder.

Such family pathology–based theories and therapies have been criticized for causing additional problems. Scholars have asserted that such negative outcomes stem from the therapist’s directly communicating to family members that they are “crazy making” and are to blame for the mental disorder (Goldstein, 1981) or from the therapist’s giving family members contradictory messages, to which, consequently, they are unable to respond (Lefley, 1989).

Psychoeducational Approach

Most family therapists have moved away from positions of blame. Examples of this trend can be found in the work of those who utilize a
psychoeducational approach when addressing mental disorders in a family context (McFarlane, 1991). A psychoeducational approach typically includes three elements: education, training in coping skills, and social support. The relative emphasis placed on each component varies, however (Marsh, 1998). Therapists using this approach encourage family members to learn all they can about the mental disorder, to become fully educated about the facts surrounding assessment and treatment. Nonblaming attributions about mental disorders and knowledge about the disorder’s symptoms, course, and treatment are thought to be indicators of the effectiveness of psychoeducational programming (see Gavazzi, Fristad, & Law, 1997). In contrast to therapeutic approaches, which are designed to eliminate particular disorders, a psychoeducational approach largely seeks to prevent the return of a disorder as well as to alleviate the pain and suffering of family members.

Researchers have documented the effectiveness of psychoeducational approaches in the treatment of adults who suffer from schizophrenia (Hogarty et al., 1991), depression (Holder & Anderson, 1990), bipolar disorder (Honig, Hofman, Rozendaal, & Dingemans, 1997), and any mood disorder (Clarkin, Haas, & Glick, 1988). Research concerning the use of psychoeducational programming with families of impaired children and adolescents indicates that it is successful in the treatment of mood disorders (Brent, Poling, McKain, & Baugher, 1993; Fristad, Gavazzi, Centolella, & Soldano, 1996; Fristad, Gavazzi, & Soldano, 1998; Fristad, Goldberg-Arnold, & Gavazzi, 2003).

Internet-Based Resources

Efforts to provide face-to-face support groups for families coping with mental illness have grown alongside the rapid expansion of Internet-based help options (Weinberg, Schmale, Uken, & Wessell, 1995). Online support groups appear to provide many of the same benefits as in-person resources (Bacon, Condon, & Fernsler, 2000) while offering the additional advantages of convenience and expediency (Salem, Bogar, & Reid, 1997). Given the recent estimate that approximately three-quarters of U.S. citizens with diagnosable mental disorders will never receive direct and necessary treatment (Norcross, 2000), Internet-based services may be the only resources available to many in need.

Some researchers have begun to examine the utility of online assistance for families with mentally ill members. For instance, Sisson and Fristad (2001) recently found that users of the Child and Adolescent Bipolar Foundation’s
Web site (at http://www.bpkids.org) typically identify themselves as white, female, married, and experiencing very high levels of stress related to having a son or daughter with early-onset bipolar disorder. Hellander, Sisson, and Fristad (2003) further note that these parents consistently report receiving a great deal of benefit from the resources available on that particular Web site.

Social Policy

In recent years, the most significant changes in Americans’ social attitudes toward mental illness and in policy-making decisions surrounding mental disorders have come about as the result of the work of grassroots organizations such as the National Alliance for the Mentally Ill (NAMI) and its related affiliates. NAMI has the dual focus of (a) advocating for patient (and family) rights and (b) providing general public education about mental disorders (Howe & Howe, 1987). A number of important issues have been brought to the forefront as a result of this organization’s efforts, including (a) the need to broaden the quality of mental health care, (b) the need to augment the public’s understanding of the treatment difficulties associated with dual diagnosis and involuntary hospitalization, and (c) the need to maximize outreach to other self-help organizations and advocacy groups.

Recently, NAMI has been involved in the development of educational programming about mental illness and increased advocacy efforts regarding more effective service delivery for mental health needs. NAMI now disseminates the Family to Family educational program, in which trained volunteers provide a 12-week course focusing on the treatment of mental illness and coping skills that are necessary for family members to participate effectively in treatment efforts. Additionally, NAMI has launched its Program of Assertive Community Treatment (PACT) Across America, a new advocacy initiative based on research findings and designed to endorse community-based treatment options.

Professional groups have also played a role in social policy efforts. In particular, the Group for the Advancement of Psychiatry has been heavily involved in educating both professional and lay audiences about critical issues associated with mental disorders and families. Perhaps most notable is a book published in cooperation with “Dear Abby” columnist Abigail Van Buren that covers many of the problems and concerns of families in the initial and advanced stages of dealing with family members diagnosed with mental disorders (Group for the Advancement of Psychiatry, 1986).
Future Directions

In this chapter we have applied concepts from the ABC-X model of family stress to organize our discussion of issues relevant to families coping with mentally ill family members. In particular, we have reviewed the characteristics of the stressor event (A, mental illness), such as demographic trends and potential causes of mental disorders. We have also presented examples of family perceptions (B) through our discussion of family burdens and family attitudes/behaviors exhibited by family members toward the mentally ill member. Finally, we have reviewed community resources (C) as we described current treatment approaches, supportive organizations, and policy initiatives aimed at improving family life. Although great strides have been made with regard to these issues since the first edition of Families and Change was published, scholars today need to put forth a clear and detailed agenda to guide further work in this area.

Based on our analysis of the present situation, we offer the following suggestions concerning future research and intervention efforts. First, scholars need to continue to focus on mental illness prevalence rates in the population—in particular, on how mental illness may have disproportionate impacts on those persons in greatest need of assistance (e.g., children and elders, men in families, socioeconomically disadvantaged families, members of minority groups). Similarly, it is important for professionals to develop more effective ways to deliver services and assistance to those groups most in need. Second, scholars need to identify strategies that will maximize family participation in community-based programs (Schock & Gavazzi, 2004) as well as techniques that will help researchers and practitioners to evaluate program effectiveness. Third, advances in technology will allow researchers to approximate more accurately the contribution of heredity to the development and continuance of mental illness. In tandem with such efforts, further research is needed on families’ utilization of Internet-based resources, and scholars should attend to policy concerns related to expansion of access to the Internet. Finally, on a larger scale, we must continue to work toward reducing the stigma attached to mental illness in American society.

Suggested Internet Resources

American Academy of Child and Adolescent Psychiatry: http://www.aacap.org

American Psychiatric Association: http://www.psych.org
American Psychological Association: http://www.apa.org
Child and Adolescent Bipolar Foundation: http://www.bpkids.org
Depression and Bipolar Support Alliance: http://www.dbsliance.org
Kristin Brooks Hope Center (organization devoted to suicide prevention): http://www.hopeline.com
National Alliance for the Mentally Ill: http://www.nami.org
National Foundation for Depressive Illness: http://www.depression.org
National Institute of Mental Health: http://www.nimh.nih.gov
National Mental Health Association: http://www.nmha.org/infoctr/factsheets/index.cfm
Suicide Prevention Action Network USA: http://www.spanusa.org

References


