Abstract

Two surveys were undertaken to explore the impact of serious mental illness on adult siblings and children of people with mental illness. These family members reported a pervasive impact on their personal and interpersonal lives, both as young family members and as adults. The following topics are discussed: (a) the impact of the mental illness on childhood and adolescence; (b) the legacy for adulthood; (c) expressed concerns; (d) the process of coping and adaptation; (f) needs of siblings and children; (g) mental health problems among siblings and children; and (h) recommendations for siblings and
children and for professionals. Implications for professionals and for NAMI members are also considered.

Troubled Journey: Siblings and Children of People With Mental Illness

The past decade has witnessed dramatic change in the relationship between professionals and families of people with serious mental illness. A number of factors have influenced this transformation, including deinstitutionalization, which has resulted in a service delivery system that is as much family-based as community-based; new evidence regarding the biological substrate of serious mental illness; increasing recognition that families have legitimate needs and rights of their own that should be addressed by the mental health system; compelling documentation of the devastating impact of serious mental illness on families; greater recognition of their positive contributions and expertise; expanded knowledge of effective family-oriented intervention strategies; developments on the level of national policy and systems planning that mandate the involvement of consumers and families; and the consumer-advocacy movement, which has moved families into more assertive, informed, and involved roles.

The ascendent mode of family-professional relationships is now that of collaborative partnerships designed to build on the strengths and expertise of all parties; to respect the needs, desires, concerns, and priorities of families; to enable families to play an active role in decisions that affect them; and to establish mutual goals for treatment and rehabilitation. Until relatively recently, these constructive developments have had the greatest impact on parents of people with mental illness, who have become effective advocates for their children and, increasingly, full members of multidisciplinary treatment teams. At present, there is an effort to further explore the familial territory at the level of family subsystems. Although individual family members cannot be fully understood without reference to the family system, it is equally true that their lives as individuals have an integrity and legitimacy that cannot be reduced to their status as family members, and that their experiences and needs are likely to differ significantly as a result of their roles and relationships within the family (Marsh, 1992a).

The current research was undertaken to explore the roles of siblings and children of people with mental illness. Because of their developmental status, young family
members share a special vulnerability to the familial experience of mental illness. The disability of a family member can be viewed as an “energy sink” (Bubolz & Whiren, 1984) that consumes energy needed for normal development and that deflects these family members from their expected trajectory. Thus, the impact of mental illness depends on its timing in the life spans of the individual and the family and on the attributes of the illness itself (see Rolland, 1988). It would be expected, for example, that the mental illness of a close relative might undermine the acquisition of basic trust during infancy; the development of peer relationships and academic skills during childhood; and the establishment of a secure sense of identity during adolescence. A child who is confronted from birth with the mental illness of a primary caregiver may be vulnerable to all of these risks.

There are some valuable descriptions of the experiences of siblings and children in books written by and for family members (e.g., Dearth, Labenski, Mott, & Pelligrini, 1986; Garson, 1986; Vine, 1982; Walsh, 1985; Wasow, 1982; Wechsler, Schwartztol, & Wechsler, 1988), and by professionals (e.g., Bernheim & Lehman, 1985; Marsh, 1992a). There is also an expanding literature concerned specifically with siblings and children (e.g., Atkins, 1992; Brown, 1989; Carlisle, 1984; DeChillo, Matorin, & Hallahan, 1987; Dinner, 1989; Garmezy & Rutter, 1983; Gutman, 1989; Johnson, 1988). Of special value are the accounts of siblings and children themselves (e.g., Crosby, 1989; Moorman, 1992; Swados, 1991; Weisburd, 1992), and those that are empirically based (e.g., Horwitz, Tessler, Fisher, & Gamache, 1992; Goodman, 1987; Landeen et al., 1992; Riebschleger, 1991; Silverman, 1989). There have also been efforts to explore resilience among young family members who are coping with the mental illness of a relative (e.g., Anthony & Cohler, 1987; Beardslee & Podorefsky, 1988).

While this expanding literature offers many insights into the experiences and needs of young family members, there is a clear need for additional research designed to delineate their experiences more precisely, to explore the legacy of those experiences for their adult lives, and to elucidate their process of coping and adaptation. In turn, this knowledge can serve as the foundation for more effective and responsive services for siblings and children, both as young family members and as adults.

Method

Two surveys were conducted through the Siblings and Adult Children Network (SAC) of the National Alliance for the Mentally Ill (NAMI). The first survey included
60 subjects, consisting of siblings (n = 28), children (n = 19), and those who were both siblings and children (n = 13). Mean age of respondents was 37.6 years, with a range of 21 to 67 years. A majority were female (n = 47) and white (n = 55). All of their relatives were diagnosed as having a serious mental illness (most often schizophrenia), and almost one fourth (24.2 %) reported that more than one family member had mental illness, including extended family members. Reflecting the composition of the group, age of respondents at time of diagnosis ranged from birth to age 37 (mean age = 14.3). They had experienced the mental illness of a relative for an average of 23.1 years (range = 2 to 50 years).

The first survey consisted of both structured and open-ended questions. In addition to demographic data, structured questions were used to assess the relative importance of coping resources, ranging from 1 (“not helpful”) to 5 (“extremely helpful”), and of needs, ranging from 1 (“not important”) to 5 (“extremely important”). Open-ended questions probed the following: (a) the impact of their relative’s mental illness on their own childhood and adolescence; (b) the impact on their adult lives; (c) how they had been changed by the illness; (d) what had been most difficult and most helpful; (e) whether they had gone through stages as they adapted to the illness; (f) whether they had experienced mental health problems themselves; and (g) whether there had been any positive consequences of the illness. Respondents were also asked for suggestions for other family members and for professionals.

The second survey included 75 subjects; a majority were again female (77.6%) and white (91.3%). Mean age was 40.6 years, with a range of 21 to 77 years. Consistent with the characteristics of NAMI members as a whole (Flynn, 1992), their educational level was very high (86.2% had completed college or graduate school). In this survey, we asked adult siblings and children to rate their frequency of concern with 24 issues that had emerged in the first survey (see Table 1), ranging from 1 (“never”) to 5 (“always”). Respondents were also asked whether they had sought personal psychotherapy and, if so, whether it had been helpful, ranging from 1 (“not helpful) to 5 (“extremely helpful”). For both surveys, there was some missing data due to incomplete surveys and to the inapplicability of some questions concerning childhood among respondents whose exposure to mental illness commenced later in life.

Results

The surveys provided a rich array of data regarding the experiences, coping
resources, and needs of siblings and children. Results will be discussed in connection with the following topics: (a) the impact of the mental illness on childhood and adolescence; (b) the legacy for adulthood; (c) expressed concerns; (e) the process of coping and adaptation; (f) needs of siblings and children; (g) mental health problems among siblings and children; and (h) recommendations for other siblings and children and for professionals.

Impact on Childhood and Adolescence

Respondents who were dealing with the mental illness of a relative during their own childhood or adolescence reported a wide range of adverse consequences for themselves and their families. Some of the most important include the following: (a) disruption of normal development (e.g., absence of a model of normal development, difficulty determining which experiences were "normal" and which were not); (b) a subjective burden (e.g., intense feelings of grief and loss, empathic pain over the suffering of other family members); (c) an objective burden (e.g., need to deal with symptomatic behavior and illness-related crises, stigmatization); (d) altered roles and relationships (e.g., risk of "parentification" among children who assume responsibility for a parent with mental illness, "replacement child syndrome" among siblings who strive for perfectionism to spare their parents more anguish); (e) identity issues (e.g., fear of developing mental illness themselves, impaired sense of self); (f) personal risks (e.g., mental health problems themselves, especially depression and anxiety); (g) familial consequences (e.g., disruption and stress, retreat behind a facade of normalcy); (h) relationships outside the family (e.g., impaired peer relationships, social isolation and discomfort); and (i) school (e.g., poor school performance, superachievement at the expense of personal life).

"It's like a large cloud moved over all our heads and everyone was paralyzed for years."

"I became a perfect child to spare my parents more grief."

"The mental illness shaped my life--it revolved around her problems."

"I am a superachiever with a great big hole inside."

Legacy for Adulthood

Many negative sequelae were also reported for adulthood, including continuation of some of the difficulties experienced in childhood and adolescence, as well as the emergence of new concerns in later life. Some of the latter included the following: (a) the
personal legacy (e.g., impaired self-esteem and self-concept, arrested emotional
development, “emotional anesthesia”); (b) the interpersonal legacy (e.g., fear of rejection,
excessive concern with pleasing others); (c) problems related to intimacy, commitment,
and sexuality (e.g., avoidance of intimacy, inability to trust others); (d) marriage and
childrearing (e.g., concern about genetic risks for own children, difficulty balancing
responsibilities to families of origin and procreation); (e) caregiving responsibilities (e.g.,
intermittent or continuous caregiving, sense of lifetime responsibility); (f) balancing
family responsibilities and personal needs (e.g., sacrifice of personal life to meet family
needs, loss of family relationships in the quest for self-preservation); and (g) impact on
career (e.g., sense of unfulfilled potential, effect on career choice).

“I shut down emotionally some time in my youth and this carried into adulthood.”
“I feel like a perpetual outsider.”
“I still feel like that little girl who had to take care of everything herself.”
“Living with fear--fear that I would lose control and become ill, fear that my
children would have it, fear of the unexpected.”

Expressed Concerns

The open-ended questions allowed siblings and children to define their own reality
and to portray their experiences in their own words. Their responses provide compelling
testimony regarding the impact of mental illness on the lives of these family members
(see accompanying article). Complementing the experiential material, the second survey
provided empirical data regarding the relative importance of specific concerns, as
presented in Table 1.

Insert Table 1 about here

All of the items represent important concerns among adult siblings and children.
In fact, the empirical results do not begin to convey the anguish behind the numbers. For
example, one survey (returned too late to be included in the data analysis) included nine
items with ratings of “5+” (e.g., feelings of guilt: “5+++”). The following were the most
salient themes (in rank order): caregiving concerns, family disruption, trouble balancing
needs, own needs not met, grew up too fast, guilt, helplessness and hopelessness, need to
be perfect, poor self-esteem, and chronic sorrow. Over 50% of respondents reported
concern with all but one of these issues at least sometimes. The exception was fear of
mental illness (44.5%), an unsurprising finding in light of the age and educational level of
the sample. At this point in their lives, respondents were likely to be aware of the late
adolescent and early adulthood onset of serious mental illness; whatever their earlier
concerns, they are past the period of greatest risk.

In describing their experiences with mental illness, these family members
underscored the consequences of the illness for their own lives.

“I have spent the last 25 years trying to find confidence, love, acceptance. I am
extremely sensitive and weep easily. I avoid intimacy but crave it desperately.
I want more friends but fear to trust.”

“I learned to be fearful of everything in my environment and to devalue myself.
Inability to attach, to express emotions to others and to myself, and to trust.”

“I blame myself for anything that goes wrong, have trouble enjoying even the
simplest things in life.”

“For years I thought no one would really want me because I came from a
defective family. I still have a tendency to hold back in relationships for fear that I
will be abandoned or something unexpected will happen.”

Many of the concerns were shared by these family members, with relatively
consistent ratings across role and age at time of onset. For example, caregiving concerns
was cited by almost all respondents, with no significant differences as a function of either
family role or age at time of onset. For some items, however, there were differences
among siblings (n = 48), children (n = 15), and those who were both siblings and
children (n = 10). Based on analyses of variance, there were significant differences on
12 of the 24 items (and on average impact); all of these reflected higher ratings among
children (including those who were also siblings). Thus, as a group, children appear to
be more vulnerable to the consequences of a close relative’s mental illness than those
who are just siblings.

In addition, there were differences in ratings as a function of age at the onset of
their relative’s illness. There were significant differences on 12 of the 24 items (and on
average impact); 11 items received highest ratings by respondents who were age 10 or
younger at the time of onset (the remaining item received higher ratings by the two
younger groups). Thus, the younger the family member at the time of onset, the greater
the susceptibility to the adverse effects of mental illness. Reflecting the importance of
role and age at onset, family members who were both children and under age 11 at the
time of onset had higher ratings for the following expressed concerns: own needs not met, grew up too fast, need to be perfect, poor self-esteem, trust problems, intimacy problems, felt abandoned, identity problems, and depression.

“Where do you go when you need to revamp your whole life? I have basically a wasted life.”

“I feel I missed out on being a kid. Now I miss what I didn’t get, including friendships, sports, and learning to take better care of me.”

“I had a hard time moving away, felt guilty all the time. My mom still wants me to move home.”

“Before I went to a counselor, I did not realize I had suffered at all--I was numbed out, frozen.”

Coping and Adaptation

Respondents were asked to rate the relative value of a range of coping resources during the three developmental phases (to age 10, from age 11 to 20, over age 20). Results are presented in Table 2.

During each of the phases, respondents reported that their personal qualities were their most important resource. It is noteworthy, however, that no resource was rated as helpful during the first 10 years (all ratings fell in the “not helpful” and “somewhat helpful” ranges). In fact, aside from their personal qualities as adolescents, it is not until adulthood that siblings and children rate other coping resources as at least helpful. The absence of resources among the youngest family members is underscored by the differences in mean ratings for all resources (including “other”) to age 10 (mean rating = 1.70: “not helpful”), from age 11 to 20 (mean rating = 2.22: “somewhat helpful”), and over age 20 (mean rating = 3.26: “helpful”).

Several respondents cited additional resources that had been helpful, such as creative activity (e.g., painting, writing, theater); regular exercise; volunteer work; and geographic separation from their relative. When they were asked whether they had gone through a series of stages as they adapted to the mental illness of a relative, 91.2% of respondents answered affirmatively, frequently offering descriptions of the stages they had experienced during their own process of adaptation. They also shared personal
coping strategies.

“Learn about yourself and the impact of mental illness on your life.”

“Don’t keep the illness a secret--share with others you can trust.”

“Separate the relative from the illness and yourself from your relative.”

“Be compassionate, caring, and concerned, but take care of yourself.”

Because of the potential for a resilient response to stressful events, siblings and children were asked whether there were any positive consequences as a result of the mental illness. A large majority answered positively (86.7%). They cited the following benefits: (a) personal growth and development (e.g., increased tolerance, empathy, compassion, understanding); (b) better self-concept (e.g., greater strength, discipline, personal stability); (c) enhanced skills (e.g., effective coping skills); (d) significant contributions (e.g., assistance to other family members); (e) effective advocacy (e.g., reformation of the mental health system); (f) improved family and social life (e.g., special closeness among family members); (g) healthier perspective and priorities (e.g., knowledge of what is important); and (h) greater appreciation of life and mental health (e.g., more cognizant of blessings).

“It made me compassionate and understanding in my career.”

“It helped us to realize our abilities and talents, how precious life is.”

“Like the old aluminium foil ad, I am ‘oven-tempered for flexible strength.’”

“It helped us to get our priorities straight--no phoniness or concern for status.”

It is important to note, however, that these positive consequences never occurred in isolation; virtually all surveys attested to negative consequences.

**Needs of Siblings and Children**

Respondents were also asked to rate the relative importance of seven needs during the three developmental phases. Mean ratings for each of the needs are presented in Table 3.

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The number of subjects providing ratings varied for the three phases, since some respondents (particularly siblings) were not dealing with the mental illness of a family member until adolescence or adulthood. While there were some differences in rankings of needs during the three developmental phases, all of the needs received relatively high
ratings. Throughout childhood, adolescence, and adulthood, their most compelling needs were for satisfactory services for their relative, for working through their own reactions to the illness, for skills to cope with the illness, and for personal support (mean ratings for these needs fell in the “very important” range).

The need for information about mental illness and related issues received similarly high ratings during adolescence and adulthood. In contrast, there was less consensus regarding their need for meaningful involvement in treatment, which received the lowest overall rating (mean = 3.06: “important”). Some respondents rated that need as “extremely important”; others wanted no involvement (one wrote: “Give us a break.”). Some additional needs were also cited, including personal psychotherapy, validation of personal needs and plans, constructive relationships outside the family, and open communication within the family. The comments of respondents reflected all of these needs.

“Learn as much as you can.”
“Join a support group.”
“Learn to express your needs assertively.”
“Resolve your own issues and be sensitive to their impact on adult relationships.”

Personal Mental Health Problems

Many adult siblings and children reported personal mental health problems, primarily depression and anxiety. More than three-fourths (77.3%) had received personal psychotherapy. This high level undoubtedly reflects the anguish and demoralization experienced by family members of people who have serious mental illness. These family members reported a high level of satisfaction with therapy. A majority (62.7%) reported that therapy had been very or extremely helpful (mean rating = 3.6; only one respondent rated it as not helpful). Consistent with our findings regarding expressed concerns, the percentage of family members who sought psychotherapy varied with role (sibling = 77.1%, child = 80.0%, both roles = 90.0%), and with age at onset of relative’s illness (to age 10 = 90.0%, 11-20 = 76.9%, over 20 = 77.3%).

Thus, although the overall level of personal therapy is very high for all adult siblings and children, family members who are both siblings and children and who are under age 10 at the onset of illness are more likely to seek personal psychotherapy.

“It was hell living at home. My sister and I were abandoned emotionally for many years. I was so depressed and lonely. I even thought of suicide. My needs were
never important. I was in counseling for many years.”

“I’ve been in and out of therapy for depression. I’ve been looking for love in inappropriate people and ways, have a lot of trouble socially.”

“As a child I tried desperately not to have a problem because our family had so many. So I became perfectionistic, hid my fears and concerns and needs from everyone. I’ve probably always had a certain degree of depression as a result of my mother’s illness. When my father died, I suffered a major depression and went into therapy.”

“I’ve been in counseling for four years now. I’ve realized how her illness has hurt me—low self-esteem, relationship problems, etc. Only through therapy have I started to turn things around.”

Suggestions for Siblings and Children

Respondents were asked to make suggestions for other siblings and children. They offered a range of constructive suggestions. These included the following: (a) learn as much as possible (e.g., about mental illness, coping skills, community resources); (b) join an existing support group for siblings and adult children (e.g., for sharing, for advocacy); (c) begin a support group if none is available; (d) expand activities and relationships outside of the family; (e) do not let the mental illness of a relative take over your life; (f) locate a good therapist; (g) rid yourself of stigma; and (h) become active in education and advocacy efforts.

“Learn whatever you can about the illness, talk to others, don’t be ashamed, care for the ill relative without giving up your needs, and become active in teaching the world about mental illness.”

“I was helped by discovering NAMI. I’ve gained more information about mental illness through NAMI than I was ever given as a child or adolescent.”

“Learn to set limits, to say no, to live apart, and not to feel guilty about it.”

“I say positive affirmations every day—that I am worthy of the good things in life, of being loved.”

Suggestions for Professionals

Suggestions for professionals included the following: (a) become knowledgeable about the experiences and needs of all family members; (b) visit an existing family support group and a SAC support group if available; (c) form collaborative partnerships with family members; (d) include adult siblings and children as members of the treatment
team if they are interested and available; (e) avoid blaming and pathologizing family members; (f) address the needs of all family members as early as possible; (g) be available to answer their questions and respond to their concerns; (h) make referrals to existing support and advocacy groups; (i) assist families in achieving a balance that meets the needs of all family members; (j) offer services for family members in clinical settings; (k) serve as a resource and consultant to existing family support and advocacy groups.

"Be kind and considerate--have time for them. Encourage them to open up and be accepting of their feelings. Don't stigmatize or label. Don't look at them and treat them like they're ill also. Listen to them. Involve them. Treat them with dignity."

“The entire family system needs to be addressed. All family members are affected by a loved one’s mental illness.”

“Allow us to grieve. Take us seriously but help us to take ourselves less seriously. Don’t treat us like we’re crazy. Help us to love ourselves.”

“Be aware of our pain. I am angry at the doctors who blamed my parents, which hurt them as much as losing a daughter to mental illness.”

Discussion

Initially, it is important to note the limitations of the current sample, which is primarily middle class, middle aged, and white (reflecting the membership of NAMI). Thus, it is essential to replicate the present findings with other socioeconomic, ethnic, and age groups. For example, research should be undertaken with young children and adolescents who can offer a current perspective on their experiences rather than the retrospective accounts provided by adults, and with adult siblings and children who are not members of NAMI.

In spite of these limitations, results of the present investigation offer compelling evidence for the pervasive impact of mental illness on the lives of siblings and children, both as young family members and as adults. Indeed, from the moment that mental illness erupts in their families, their lives are transformed by this catastrophic event and their journeys deflected from the normal developmental course. Our results provide insight into the nature of this transformation, which affects all aspects of their personal, intrafamilial, and extrafamilial lives.

“I carry pain about my sister every day. I constantly battle low self-esteem and shame. Our family has lost a great deal to this illness.”
Adult siblings and children recounted many detrimental effects of the mental illness for their own lives as young family members. These included disruption of normal development; the experience of a powerful subjective and objective burden; distorted roles and relationships; impaired self-esteem and personal identity; personal mental health problems, especially depression and anxiety; familial disruption and stress; social isolation and discomfort; unsatisfactory peer relationships and academic performance; and a sense of having grown up too quickly.

“I lost a sense of knowing what I wanted, and how to set my own agenda, control my own life, choose relationships.”

These family members also reported a profound impact on their adult lives, which are affected by the continuing problems of their childhood and adolescence and by new concerns that emerge in adulthood. As adults, siblings and children reported a powerful personal legacy, including impaired self-esteem and self-concept, arrested emotional development, and a sense of unfulfilled potential. They also described a pervasive interpersonal legacy that affects all adult relationships and that undermines their capacity for intimacy, trust, and commitment. This interpersonal legacy may deter them from marriage, since over one-third (37.3%) had remained single, a higher proportion than the 10% that the Census Bureau estimates in 1992 will never marry. When they do marry, siblings and children report difficulty balancing the demands of their families of origin and procreation, and often fear that their own children will develop mental illness.

“I was afraid to have children because I had a fear that they would be mentally ill like my dad.”

Many of these concerns are shared by family members who are siblings, children, and both siblings and children, such as anxiety about caregiving for their ill relative. There are also differences among the three groups, who reported unique experiences and problems as well as shared concerns. For instance, siblings sometimes expressed resentment that the ill brother or sister had received so much attention. Based on our overall results, the most important variable appears to be age at onset of the relative’s illness. There are inherent risks for young children who are exposed to a primary caregiver whose reality contact is impaired and whose energy is depleted by the mental illness. There are also risks for siblings who are confronted during their early years with the ravaging aftereffects of the mental illness of a brother or sister.

Thus, it is not surprising that many adult siblings and children who were
confronted with mental illness during their first decade of life reported problems related to trust, identity, parentification, separation, intimacy, and affective blunting. These results are consistent with epigenetic stage-based conceptions of development, which assume that disruption during a particular developmental phase may undermine the resolution of the issues associated with that phase. The earlier exposure of children to this catastrophic event may result in a greater residue of “unfinished business” from childhood and a commensurate reduction in the energy available for adulthood.

“I lost my identity in relationships. Have only just begun to identify what I want, who I really am.”

The study also illuminated the process of coping and adaptation. Siblings and children reported that potential coping resources differed in usefulness during childhood, adolescence, and adulthood. Significantly, respondents did not find any resources helpful during childhood; during adolescence, they rated just their personal qualities as helpful. Only as adults are they able to make use of a number of coping resources, including their personal qualities, other NAMI members, a support group, friends, and professionals. Clearly, in spite of their greater vulnerability, young family members have fewer resources than adult siblings and children to assist them in coping with this cataclysmic event. In addition, from the perspective of professional practice, it is important to note that many respondents reported mental health problems themselves, primarily depression and anxiety. Many of these family members affirmed the value of personal psychotherapy, particularly individual therapy.

“My mother needed help and refused. So I was completely powerless and sank into depression. Because of her illness, I went into therapy. That helped me develop more healthily. That’s the only good result I can see coming out of this tragedy.”

Based on our surveys and on the general literature concerned with coping and adaptation, Table 4 summarizes a range of effective coping strategies.

Almost all respondents indicated that they had moved through a series of stages as they adapted to the mental illness of a relative. Their process of adaptation generally conforms to a three-stage structure similar to the one delineated by Rando (1984) in
connection with bereavement: (a) avoidance, which is characterized by feelings of shock, denial, and disbelief; (b) confrontation, which is characterized by intense feelings of grief and loss and by a range of negative emotions, including anger, guilt, and despair; and (c) resolution, which is characterized by understanding and acceptance of the mental illness and by reinvestment of energy in one’s own life. As is the case with the biological death of a relative, however, there is no single pattern of adaptation nor is there a universal and time-limited series of sequential stages (see Wortman & Silver, 1989). Furthermore, there is much evidence for the presence of “chronic sorrow” on a continuing basis (see Marsh, 1992a, for a discussion of these issues).

“It’s like someone close died--but there’s no closure. It’s never over.”

The study provided impressive evidence for resilience among siblings and children of people with mental illness. They reported many positive sequelae, including beneficial changes in self-concept and self-efficacy, in compassion and tolerance toward others, in contributions to society, in family relationships and social life, and in attitudes and priorities. Consistent with the literature concerned with familial stress (see Figley, 1989), it appears that a catastrophic stressor, such as mental illness, generally results in disintegration of existing modes of functioning, which in turn offers the opportunity for renewal and reintegration.

“I developed some exceptional coping skills: problem solving, soothing, getting along with difficult people, intellectual searching. I even learned to look inside myself and grow spiritually. And my siblings and I have a level of tolerance that is useful in our fast-changing society.”

As is the case in the present study, however, positive responses to stress often exist concurrently with a wide range of negative reactions and feelings. Indeed, virtually every survey offered cogent evidence for the anguish that accompanies the mental illness of a relative.

"Any increased sensitivity to others or any other 'side effects' would be traded in a eyeblink for a healthy relative."

Results of our surveys underscore the importance of a number of central needs among siblings and children, including their needs for information, for skills, for support, for services for their relative, for resolving their own reactions to the illness, for contact with other family members (especially other SAC members), and for maintaining the
integrity of their own lives. Some siblings and children expressed a need for meaningful involvement in the treatment of their relative; others preferred not to be involved. These needs remain important throughout childhood, adolescence, and adulthood, although there were some differences in relative importance of the needs. From a life span perspective, the stability of these needs provides a cornerstone for effective professional practice, since services can be designed to address the needs of siblings and children throughout their lives.

Implications for Professional Training and Practice

These results have a number of important implications for professional training and practice with siblings and children as young family members and as adults. The initial step involves cognitive restructuring, as professional practice is reformulated to focus on all members of the family and as service delivery systems are redesigned to meet their continuing needs. It is noteworthy that 80% of respondents indicated that professionals were not helpful until they reached adulthood. If the needs of these family members had been met as they were growing up, the adverse legacy for their adult lives might have been diminished.

In addition, graduate programs for mental health professionals should be modified to prepare clinicians to work effectively with all family members. For example, existing curricula should be expanded to incorporate the relevant literature concerned with family burden and needs, with the unique perspectives of siblings and children, and with new modes and models of professional practice with families. In addition, internships should offer professionals in training an opportunity to develop the skills and strategies necessary for collaboration with family members, including siblings and children, and for meeting their needs.

Finally, a range of services should be available to meet the needs of all family members from the moment of diagnosis. Services for siblings and children should include five general components: (a) a didactic component that provides information about mental illness and community resources; (b) a skills component that offers training in communication, conflict resolution, problem solving, assertiveness, behavioral management, and stress management; (c) an emotional component that provides opportunities for grieving, for sharing, and for mobilizing resources; (d) a family process component that focuses on the impact of mental illness on the family system, family subsystems, and individual family members; and (e) a social component that offers
support, reinforcement for normal developmental experiences and goals, constructive role models, and opportunities for advocacy.

There are two general forms of intervention: nonclinical and clinical. Nonclinical services are designed primarily to provide education and support. Examples include educational programs, support groups, and multimodal programs. See Table 5 for an example of an educational program for adolescent siblings and children.

Clinical services are designed to provide treatment for problems that are reactive to the mental illness of a relative or for more serious mental health problems that may have been precipitated or exacerbated by current stress. Clinical formats include individual, marital, family, and group therapy.

Researchers have consistently found that family members (primarily parents) perceive nonclinical services as the more valuable form of intervention (e.g., Hatfield, 1981; Lefley, 1987). These results have not yet been replicated with siblings and children, however, and SAC members who responded to our surveys cited the benefits of both nonclinical and clinical intervention. Thus, it is important to inform siblings and children of all available services and to assist them in making an informed choice regarding their use of specific services. Given the diversity among family members, it is likely that some will prefer nonclinical services, that others will choose a course of psychotherapy, and that still others will benefit from both forms of intervention.

Our overall results support the value of a multimodal approach to intervention designed to meet all the needs of siblings and children, and of a group format that provides contact with other family members. Groups can meet essential needs for information, skills, and support, and can be designed for school age, preadolescent, adolescent, and adult members. Such groups also offer opportunities to improve self-esteem and self-confidence, to develop a greater sense of mastery and control, to enhance social interaction, to reinforce normal patterns of growth and development, to provide assistance with peer relationships, and to encourage constructive long-term goals. While few resources are currently available for professionals who wish to work with siblings and children of people with mental illness (e.g., Dickens, undated), there are some resources concerned with professional practice with siblings who are dealing with other
forms of disability (e.g., Marsh, 1992b; Powell & Ogle, 1985).

Implications for NAMI

Results of this study also have important implications for NAMI, which was often cited by adult siblings and children as their most valuable resource. Most important, it is essential to reach out to young siblings and children as early as possible: to acknowledge their anguish, to address their needs, and to empower them in coping with this catastrophic event. Services should be responsive to their unique needs and concerns, to their developmental level, and to their changing needs throughout the life span.

Specific suggestions include increased support for siblings and children within NAMI and educational programs designed to sensitize families and professionals to the needs of young family members. Members of the SAC Network are particular suited for offering a corrective emotional experience for young siblings and children, for facilitating support groups, and for developing and implementing new initiatives for this population. For example, adult siblings and children might serve as mentors for young family members in a program similar to Big Brothers and Big Sisters.

References


children of people with mental illness.

Table 1

Expressed Concerns of Siblings and Children (n = 75)

<table>
<thead>
<tr>
<th>Expressed Concern</th>
<th>Mean Rating</th>
<th>Rating of 3 or higher</th>
</tr>
</thead>
</table>

Rating of 4 or 5

<table>
<thead>
<tr>
<th>Priority</th>
<th>Event</th>
<th>Average Rating</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Caregiving Concerns</td>
<td>3.83</td>
<td>94.4%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>62.0%</td>
</tr>
<tr>
<td>2.</td>
<td>Family Disruption</td>
<td>3.70</td>
<td>82.9%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>64.3%</td>
</tr>
<tr>
<td>3.</td>
<td>Trouble Balancing Needs</td>
<td>3.39</td>
<td>81.4%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>51.4%</td>
</tr>
<tr>
<td>4.</td>
<td>Own Needs Not Met</td>
<td>3.25</td>
<td>79.2%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>48.6%</td>
</tr>
<tr>
<td>5.</td>
<td>Grew Up Too Fast</td>
<td>3.25</td>
<td>66.7%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>51.4%</td>
</tr>
<tr>
<td>6.</td>
<td>Guilt</td>
<td>3.16</td>
<td>74.4%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>45.8%</td>
</tr>
<tr>
<td>7.</td>
<td>Helplessness and Hopelessness</td>
<td>3.12</td>
<td>75.3%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>35.6%</td>
</tr>
<tr>
<td>8.</td>
<td>Need to be Perfect</td>
<td>3.07</td>
<td>63.4%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>46.5%</td>
</tr>
<tr>
<td>9.</td>
<td>Poor Self-Esteem</td>
<td>3.04</td>
<td>75.0%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>34.7%</td>
</tr>
<tr>
<td>10.</td>
<td>Chronic Sorrow</td>
<td>3.03</td>
<td>63.9%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>38.9%</td>
</tr>
<tr>
<td>11.</td>
<td>Emotional Anesthesia</td>
<td>3.01</td>
<td>69.6%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>43.5%</td>
</tr>
<tr>
<td>12.</td>
<td>Trust Problems</td>
<td>3.01</td>
<td>68.6%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>40.0%</td>
</tr>
<tr>
<td>13.</td>
<td>Intimacy Problems</td>
<td>3.00</td>
<td>69.1%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>42.3%</td>
</tr>
<tr>
<td>14.</td>
<td>Unfulfilled Potential</td>
<td>2.93</td>
<td>64.3%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>35.7%</td>
</tr>
<tr>
<td>15.</td>
<td>Grief</td>
<td>2.87</td>
<td>63.4%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>28.2%</td>
</tr>
<tr>
<td>16.</td>
<td>Felt Abandoned</td>
<td>2.83</td>
<td>60.8%</td>
</tr>
</tbody>
</table>
Note. Rating scale: 1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = always.

Table 2

Coping Resources of Siblings and Children During Childhood, Adolescence, and Adulthood

(n = 60)
<table>
<thead>
<tr>
<th>Need</th>
<th>To age 10</th>
<th>Age 11-20</th>
<th>Over age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Information about mental illness, etc.</td>
<td>2.70</td>
<td>4.22</td>
<td>4.59</td>
</tr>
<tr>
<td>2. Skills for coping with the illness, etc.</td>
<td>3.39</td>
<td>4.33</td>
<td>4.48</td>
</tr>
<tr>
<td>4. Services for your relative</td>
<td>3.71</td>
<td>4.31</td>
<td>4.76</td>
</tr>
<tr>
<td>5. Meaningful involvement in your relative’s</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>treatment</td>
<td>2.22</td>
<td>3.20</td>
<td>3.77</td>
</tr>
<tr>
<td>6. Working through your own reactions to the</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>illness</td>
<td>3.64</td>
<td>4.33</td>
<td>4.33</td>
</tr>
<tr>
<td>7. Contact with other family members</td>
<td>3.50</td>
<td>3.72</td>
<td>3.87</td>
</tr>
<tr>
<td>8. Other</td>
<td>4.50</td>
<td>5.00</td>
<td>5.00</td>
</tr>
</tbody>
</table>

Note. Rating scale: 1 = not important, 2 = somewhat important, 3 = important, 4 = very important, 5 = extremely important.
Table 4

**Effective Coping Strategies**

Accept the mental illness and its consequences
Seek information about mental illness, services, and resources
Develop realistic expectations for all family members
Learn about the experiences of other siblings and children
Reframe to focus on personal and familial strengths
Develop communication, conflict resolution, and problem solving skills
Develop stress management skills
Learn to express your needs assertively
Develop strategies and skills for coping with your relative
Resolve your emotional burden
Employ mature defenses
Seek personal counseling when appropriate
Assume a constructive role in the family
Join an existing support group for siblings and adult children
Start a support group if none is available
Share feelings and coping strategies with other siblings and children
Expand activities and relationships and outlets outside the family
Strive to maintain a normal lifestyle
Learn to set limits
Do not let the mental illness of a relative take over your life
Establish collaborative relationships with professionals
Educate professionals about family experiences and needs
Become active in advocacy efforts

From Marsh and Dickens (in preparation).
<table>
<thead>
<tr>
<th>Week</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Nature and Purpose of Program</td>
</tr>
<tr>
<td></td>
<td>- Introductions; overview of educational program; description of agency program; written survey of needs and requests of family members</td>
</tr>
<tr>
<td>2</td>
<td>Mental Illness I</td>
</tr>
<tr>
<td></td>
<td>- Diagnosis; etiology; prognosis; symptoms</td>
</tr>
<tr>
<td>3</td>
<td>Mental Illness II</td>
</tr>
<tr>
<td></td>
<td>- Treatment; medication; diathesis-stress model</td>
</tr>
<tr>
<td>4</td>
<td>The Family Experience</td>
</tr>
<tr>
<td></td>
<td>- Family burden; family needs; life span issues; family roles and relationships; special concerns of siblings and children</td>
</tr>
<tr>
<td>5</td>
<td>Developmental Perspectives</td>
</tr>
<tr>
<td></td>
<td>- Normal child and adolescent development; peer relationships; separation</td>
</tr>
<tr>
<td>6</td>
<td>Stress, Coping, and Adaptation</td>
</tr>
<tr>
<td></td>
<td>- The general process; resources and strategies; increasing coping effectiveness</td>
</tr>
<tr>
<td>7</td>
<td>Enhancing Personal and Family Effectiveness I</td>
</tr>
<tr>
<td></td>
<td>- Behavior management; conflict resolution; communication; problem solving</td>
</tr>
<tr>
<td>8</td>
<td>Enhancing Personal and Family Effectiveness II</td>
</tr>
<tr>
<td></td>
<td>- Stress management; assertiveness; achieving a personal and family balance</td>
</tr>
<tr>
<td>9</td>
<td>Family-Professional Relationships</td>
</tr>
<tr>
<td>10</td>
<td>Services, Providers, and Resources</td>
</tr>
<tr>
<td></td>
<td>- Comprehensive system of community-based care; support groups</td>
</tr>
</tbody>
</table>

From Marsh and Dickens (in preparation).