Sibling Perspectives on Schizophrenia and the Family

by Laina M. Gerace, Dorothy Camilleri, and Lioness Ayres

Abstract

Intensive audiotaped interviews with 14 adult siblings of schizophrenia patients were used to explore their experiences. Interviews focused on the ways adult siblings define and experience their sibling's mental illness and their participation in illness management. Cross-case analysis revealed that recognition of schizophrenia in a brother or sister was characterized by a pivotal, reorganizing event that redefined behavior previously viewed as difficult or different. Subjects' approach to the sibling's illness reflected three distinct patterns: collaborative, crisis-oriented, and detached. The impact of a mentally ill brother or sister on subjects' lives ranged from pervasive to discrete and was seen as emanating from the family and the sibling, but in different ways. These findings can help sensitize clinicians to the complex nature of sibling experiences as well as to the needs of siblings and their families.

While both family theorists and clinicians regard husband–wife and parent–child relationships as the most critical in family processes, sibling relationships are also important and are now recognized as a worthwhile area of study (Goetting 1986). Sibling relationships have several unique characteristics. They are of long duration, and they persist with varying degrees of intimacy or investment throughout the life cycle. Siblings share more fully than other family members in a common genetic and social heritage, early experiences in the family, and a common cultural milieu (Lamb and Sutton-Smith 1982). These factors, together with societal changes, such as increased geographic mobility, smaller family sizes, working parents, and the prevalence of single parent and blended families, have produced more interdependency and intensity in sibling relationships (Bank and Kahn 1982).

Goetting (1986) has analyzed the literature on sibling relationships using three developmental stages: childhood and adolescence, early and middle adulthood, and old age. Relationships among siblings are relatively intense during the childhood and adolescence phase, with siblings providing companionship, emotional support, and direct services for one another. In adulthood, sibling relationships become voluntary and less intense, but research suggests that they remain intact and supportive and are often reactivated around parental illness and decline. Even in old age, sibling relationships continue, though contact may become less frequent. Goetting (1986) points out that the most important tasks of siblingship throughout the life cycle are companionship, friendship, comfort, and affection.

Given the importance and enduring nature of sibling relationships over the life cycle, it is noteworthy that studies on family adaptation to illness have typically focused on parents or spouses and excluded siblings (Lobato et al. 1988). This exclusion holds in the area of schizophrenia as well; few studies have addressed the impact of a mentally ill brother or sister on siblings. Yet, over time, adult

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siblings often assume increasing responsibilities, both for their aging parents and for their mentally ill sibling (Samuels and Chase 1979). Furthermore, in spite of growing awareness that mental illness can impose an extensive burden on families (Fadden et al. 1987), studies have not examined how families define and participate in managing the illness or how they experience the impact on their lives. Siblings are not generally considered, even though clinical and lay literatures emphasize the confusion, disruption, and grief siblings experience when there is mental illness in the home (Bank and Kahn 1982; Bernheim et al. 1982; Dearth et al. 1986; Johnson 1988; Kahn and Lewis 1988).

Earlier studies on siblings typically focused on concordance for psychopathology and on communication deviance (Lidz et al. 1963; Pollack et al. 1969, 1970; Hoover and Franz 1972; Singer et al. 1978; DeLisi et al. 1987). Little attention has been paid to family accommodation to a mentally ill family member, particularly from the viewpoint of a sibling.

In mental illness, more than in other illnesses, the distinction between disease and illness is important. While disease frequently refers to physiological or structural alterations in the victims, illness concentrates on the subjective beliefs and experiences of all the individuals involved (Kleinman et al. 1987). Estroff (1989) defined schizophrenia as an “I am” illness, one that is known outwardly by others but also transforms the self inwardly. A serious mental illness such as schizophrenia is defined and experienced not only by the victim, but also by each family member. Smith (1991) describes her family’s experience of living with schizophrenia as “encumbered by a great sense of loss and frustration” (p. 690).

These family definitions and experiences are important because they can affect approaches to caring for the illness and thus can impact on illness outcome. Chesla (1989) found that parental care patterns were greatly influenced by parents’ understandings of and beliefs about schizophrenia. For example, parents who believed that mental illness has a strong biological basis were primarily concerned about chemical balance and medication management. On the other hand, parents who held a rational control, “mind-over-matter” stance on schizophrenia tended to stress the illogic of delusional thinking, often trying to persuade their child to give up these thoughts. Families’ understanding of schizophrenia is based on subjective experience. How adult siblings define and experience their sibling’s mental illness and how they participate in the sibling’s illness are the focus of this qualitative study of 14 sibling cases.

**Conceptual Framework and Study Design**

This study conceptualizes chronic illness or disability as having no single objective meaning that is shared by everyone (Knafl and Deatrick 1987). The inquiry was designed from a neutral perspective with as few preconceptions as possible. For example, the investigators assumed that dealing with a mentally ill brother or sister is not inherently positive or negative, that having a mentally ill sibling is not necessarily a “burden,” and that family environments are not necessarily “pathogenic” or characterized by deviant communication patterns.

A qualitative case study design was used to explore 14 siblings’ experiences with a mentally ill brother or sister. Subjects were adult volunteers (> 18 years of age) who were recruited (1) through psychoeducational workshops for families, sponsored by a major midwestern university hospital; (2) through advertising in the monthly newsletter of a self-help group; and (3) through other referrals. The subjects tended to be highly educated and reflected a variety of sibling relationships and ordinal positions. Twelve were in some way connected to a self-help group, either by membership in a support group or attendance at psychoeducational workshops. Table 1 summarizes demographic data about the subjects.

Subjects were selected according to two criteria. They had to have an ongoing connection with their mentally ill sibling, through regular visits, telephone calls, or participation in decisionmaking about the sibling’s care. In addition, the mentally ill sibling had to meet the following three criteria: (1) a history of at least three psychiatric hospitalizations for positive symptoms of schizophrenia (hallucinations, delusions, incoherence or loose association, inappropriate affect), (2) evidence of chronic impairment (decreased level of functioning, need for supervised living arrangements), and (3) ongoing psychiatric care (periodic assessments, continuing neuroleptic pharmacotherapy). The subjects provided a detailed description of their sibling’s symptom pattern. Mentally ill siblings’ ages ranged from 24 to 50 years (mean = 33); seven were male and seven female. The number of hospitalizations
Table 1. Characteristics of 14 adult sibling respondents

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<td>Sex</td>
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<td>Female</td>
<td>11</td>
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<td>Male</td>
<td>3</td>
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<td>Subject relationship to ill sibling</td>
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<td>Female with female sibling</td>
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<td>Female with male sibling</td>
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<td>Male with male sibling</td>
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<td>Male with female sibling</td>
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<td>Ordinal position</td>
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<td>Oldest</td>
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<td>Middle</td>
<td>9</td>
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<td>Youngest</td>
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<td>Range</td>
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<td>Mean</td>
<td>35</td>
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<td>Employment status</td>
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<td>Part-time</td>
<td>4</td>
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<tr>
<td>Full-time</td>
<td>7</td>
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<tr>
<td>Graduate student</td>
<td>3</td>
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<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>High school graduate</td>
<td>1</td>
</tr>
<tr>
<td>Some college</td>
<td>5</td>
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<tr>
<td>Undergraduate degree</td>
<td>2</td>
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<tr>
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<tr>
<td>Graduate degree</td>
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<tr>
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<td>Caucasian</td>
<td>13</td>
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ranged from 3 to more than 10.

Data were obtained through semistructured interviews designed to elicit each subject's perspective on the sibling's mental illness, the perceived impact of the illness on self and the family system, and the subject's perceived role in illness management. The interview guide was adapted from one used in a study of families of physically ill children (Knafl et al. 1993). Before data gathering, the instrument was pretested on two of the 14 subjects. All interviews were conducted by the primary investigator (L.M.G.) either in a research office or in the subject's home. Interviews averaged about 90 minutes each and were audiotaped and transcribed verbatim. Table 2 provides sample questions from major categories of the interview guide. The study was approved by the institutional review board of the university sponsoring the study.

Coding Procedures. Data were reduced with a two-stage coding system: content and thematic. First interviews were reviewed for actual content. Two coders, working independently, coded each transcript and met regularly to establish and refine coding categories. Disagreements about codes were resolved through discussion and consensus. Once each interview transcript was coded, The Ethnograph, a software program (Seidel et al. 1988), was used to store and retrieve coded data. Content codes were then reviewed for major themes that characterized this data set. On the basis of techniques described by Miles and Huberman (1984), summaries for each interview were arranged on a master grid according to the thematic codes developed for the study, with subject identification numbers along the left-hand side of the grid and code names along the top. The master grid facilitated a cross-case analysis for common themes and patterns for each research aim: (1) subject's definition of schizophrenia, (2) perceived role in caring for the sibling, and (3) perceived impact of the ill sibling on self and family.

Findings

Beyond Normalization: Pivotal Experiences. Subjects described their mentally ill siblings in one of two distinct ways: (1) a person who from early childhood was "always a little off, different, or not right"; or (2) a child who appeared normal but then had a "stormy" adolescence that eventually escalated into a psychotic episode.

Each subject was asked to talk about how he or she first came to recognize that the sibling had a mental illness. The following process of recognition was typical: First, the ill sibling was perceived by the family as "different" or "difficult" to varying degrees. The
Table 2. Sample questions from sibling interview guide

**The Illness:** I would like to start out by talking about the history of your brother/sister’s illness.
1. Please tell me about the time when you found out that (brother/sister) had schizophrenia.
   a. How did you first suspect something was wrong?
   b. What did the family do before going to a doctor?
   c. What was your reaction to finding out your brother/sister had a mental illness?
   d. What is your understanding of schizophrenia now?

**Managing:** I’m especially interested in finding out what you and your family do to manage your sibling’s condition. By manage I mean how you fit the illness into your life—everything from actual treatments or medications to dealing with the health care system or planning family activities.
1. Tell about your sibling’s medications, treatments, and daily functioning, and how they actually get carried out.
   a. What are the sibling’s responsibilities?
   b. What is your role in the management of your brother/sister’s illness?

**Impact:** Now I’d like to change topics one last time and ask you some questions about how having a sibling who has a chronic mental illness may affect your life and the lives of your family.
1. To what extent do you think your sibling deals with his/her condition?
2. What is the effect of your sibling’s condition on other family members?
3. How do you think you deal with having a brother/sister with a mental illness?
   a. What is difficult about being a sibling to a mentally ill brother/sister?
   b. In what ways does the sibling’s condition have an effect on your life?

family normalized these differences by strategies such as regarding the sibling as “spoiled” or “sensitive” or attributing the behavior to a difficult adolescence.

In most cases subjects perceived their parents as going to great extremes to incorporate as “normal” into daily family life what was later acknowledged as abnormal behavior. For example, in one case psychiatric help was not sought for 15 years, even though the sibling had failed out of college and had become completely isolated, deteriorated, and obsessively rigid. According to this subject, the parents told others that the sibling was “working on his college degree.” In some cases, the sibling recognized the problem before the parents did; for example, in one case the subject, not the parents, took her young adult brother for his first psychiatric evaluation. In describing her parents’ reactions to severe behavioral changes in her brother, this subject explained:

My parents aren’t real big about talking about things…. They just kind of had a wait and see approach whenever we had a problem…. You didn’t talk about any problems outside of the family circle, even to the extended family. It was very private. And they believed you had to listen to them and if you didn’t, you were punished for it.

Another subject explained that his brother’s behavior changed during his senior year in college. His brother had been a good student, but his grades deteriorated and he began to wander “day and night.” This subject said:

Usually when a person has a crisis, people rally and they talk and they get help. But nothing, nothing was done. None of us talked about it. No one did anything about it. And my brother just kept going, living in his room, and became more and more of a back closet case.

Eventually a pivotal event or set of circumstances altered the perception of the sibling as normal. Behaviors and personality traits that had been defined as normal, although difficult, were redefined as indicators of abnormality. Examples of such turning points include confirmation of a diagnosis by placing the sibling on antipsychotic medication or the occurrence of some dramatic, unacceptable outburst, such as violent behavior or paranoid, delusional thinking. For one subject, the pivotal event occurred when her brother began to “howl like a dog.” These florid outbursts painfully forced the mental illness into the family’s awareness. Such a pivotal redefinition of the meaning of the sibling’s behaviors occurred even in a case in which the mentally ill sibling had been in therapeutic schools since 2 years of age. It was the sibling’s
placement on antipsychotic medication (not simply methylphenidate) that led to the subject’s recognition that her brother had a mental illness.

In all cases, the recognition of a sibling’s mental illness was a bewildering and frightening experience, despite the presence of earlier indications. One subject said, “It was a mystery at the beginning.... A lot of tears, anger, a lot of frustrations.” Another subject explained:

I think the hardest thing is coping with it [schizophrenia] initially. When you have a cut finger or you need stitches, you know how to seek out medical help, but people are just so thrown by mental illness that it’s still kept in the dark. It’s a mystery to people and there is such a stigma still attached to it that people are just totally bewildered and don’t know what to do. People are prepared for disasters and catastrophes, but not how to deal with a relative who is mentally ill.

Many subjects saw themselves as paving the way to realistic illness recognition, as exemplified in this response:

I am the first one to begin to face the reality of this thing and it is not easy for me.... Both of my parents seem to be hopeless sort of, not really seeing a way out of the predicament and that things are only going to get worse. They don’t really lead lives for themselves....My mother feels cheated, and that’s because she hasn’t really accepted and embraced the whole thing in her life. Everything seems to be geared only toward J. [sister who has schizophrenia].

In addition to reconstructing the events surrounding illness recognition, subjects were asked by the investigator to explain schizophrenia. Subjects described their siblings’ mental illness in terms of brain disease or thinking disorder. All subjects saw schizophrenia as a complex disease deriving from the interaction of a variety of sources. Some, however, emphasized a genetic component, while others emphasized “bad parenting” and a “dysfunctional family.” Parental alcoholism was considered part of the cause by three subjects, and two other subjects mentioned drug abuse by their ill sibling as a contributing factor. Some subjects wondered about “character disorder”; others mentioned stress, depression, or low self-esteem. Several distinguished between mental illness and mental retardation by pointing out that their sibling was “not mentally slow.”

Some subjects expressed concern about how to explain schizophrenia, stressing that it takes time to accept the magnitude of the illness and its effect on the victim and the entire family. For example, one subject said:

I think I would explain schizophrenia differently depending on how long another family had been dealing with it. I don’t know if I would hit them with a lot of facts that I know right at the beginning, if this was the first time they were experiencing it. I think it needs to be a gradual process of acceptance. You don’t necessarily need to display a lot of pessimism with somebody who maybe for the first time has a relative with an acute psychotic break. I would tell someone maybe initially to be optimistic, and that there may be a good prognosis. I think if you are dealing with someone who is obviously chronic the picture is different and the way I would relate is different. You know, I may talk to them more about coping skills as opposed to trying to make them believe everything is fine and wonderful.

Some subjects emphasized that they, as the sibling of a brother or sister with schizophrenia, had become the expert. One subject jokingly remarked that he was “presently earning a Ph.D. in schizophrenia,” stating:

I am learning and educating myself because I don’t feel that doctors and nurses understand the need for the family to be a part of this whole thing. I am amazed at how little we know, period, and how relatively little information we have on schizophrenia.

Approaches to Illness Involvement. Each subject was asked to describe his or her participation in the management of the sibling’s illness. Subjects were asked questions about medication administration, activities of daily living, and contacts with health care providers around the care of the ill sibling. Three distinct patterns of involvement can be identified: collaborative, crisis-oriented, and detached. Seven subjects participated primarily in a collaborative approach, three took a crisis approach, and four had a detached approach. Three of the subjects reported some elements of combination approaches. For example, one subject worked mainly in a collaborative approach, but said she was “working hard to become more detached.”

Collaborative participation. This comprehensive, shared approach is characterized by active, ongoing working relationships with health care providers, other family members (especially parents), and the ill sibling. These subjects reported having consensually derived and understood roles with the sib-
ling, attempting to incorporate the ill sibling into regular routines, such as doing laundry and engaging in social or recreational activities. There is evidence of a planned approach to the care of the sibling. One subject, who appeared quite self-confident, explained:

My mother and I take turns [caring for sibling]. When one of us gets burned out the other one deals with it. When that one burns out the other one... and we talk about everything and discuss what we’re going to do, the alternatives and what our next step is going to be. We support each other.... And my husband is just as much a fighter for my sister as both my mom and me, and understands the situation. He has just been such a source of support. He has a relationship with my sister; he can go and talk, try to talk sense into her in situations when she is angry at my mother and me.

This subject’s mother also keeps a ledger on medications for the ill family member (who is frequently hospitalized) so that information is readily available to the health care system.

Subjects involved in collaborative approaches seem to be accepting of family members’ different responses to the sibling’s illness. In one case, for example, the subject seems to accept the difficulty her father has in setting limits on the ill sibling, stating that her father, who has a brother with schizophrenia, is “just overwhelmed with guilt” because of the possibility of genetic transmission and “just lets her do whatever she wants.”

Despite being part of a team approach to sibling involvement, these subjects experienced hardships and subjective distress over the illness. For example, one subject, a nurse who talked about a cooperative family approach to managing the illness of her sister, reported that she felt “more burdened [than other family members] to understand.” The target of her activities included support for her parents as well as her sibling. Another subject, who was supported by his parents and other siblings in involvement with his severely paranoid brother nevertheless reported that he “got saddled” with a lot of responsibility for his sibling.

Crisis-oriented involvement. This is a situation-specific approach to the sibling’s illness, with little or no carryover between situations. These families do not seem to have a plan until a difficult problem or unexpected event requires action. Subjects indicated that their involvement is sporadic and that their families fail to take charge of the ill sibling in the home. Consequently, these subjects see their role as helping to “calm the family down” and to problem solve when a disruptive event occurs. In all of these instances, the subjects portrayed the locus of authority as residing too much in the ill sibling, with the parents failing to act appropriately. Sibling noncompliance with the treatment plan was reported as problematic. For example, in two cases the ill sibling was seen as “ruling the family.” One sibling was described as “a 30-year-old brat” whose “rages and obsessional traits are very controlling.”

The crisis participation was graphically illustrated during a data-gathering interview in one subject’s home, when the subject’s father telephoned. The father needed help because the ill sibling was screaming and throwing dishes on the floor and the mother was crying. The subject dealt with the situation by getting each person on the telephone individually to resolve the outburst. He instructed his father to remove the sibling from the kitchen; he spoke soothingly to his mother and firmly to the ill sibling. The strain of this subject’s role became obvious to the researcher, when, after the call was completed, the subject cried openly, telling the investigator that such calls were “typical” and happened several times a week.

Detached approach. This approach is characterized by indirect involvement with the ill sibling and attempts to create distance between subjects and the ill siblings and sometimes their families. These subjects try to keep the ill sibling out of their daily life as much as possible and to diminish the sense of responsibility they feel for the sibling. It is difficult to determine from these subjects exactly how they perceive the family’s role with the ill sibling. Subjects who use this approach solve problems with housing placements, finances, and health care professionals on an as-needed basis without directly involving the ill sibling. They express feeling upset over the sibling’s behavior and annoyance or anger about the inconvenience of having to participate. For example, one subject said, “I end up doing all her financial planning. She doesn’t want to work at getting better. Why get better when she has everything she needs?”

Some subjects working at detachment also report that they are “working on” separation issues in psychotherapy. These subjects assumed indirect roles while simultaneously attempting to extricate themselves from the sibling’s life
and problems because of the cost to their own growth and well-being. For example, one subject explained about his psychotherapy:

Now I'm starting to feel that the anger and bitterness I had toward my brother because of what happened between us and the mental illness-how much I hurt myself because of how much I tried to give to the situation that was totally beyond me. Now that I'm getting on with my life and starting to put things together, that bitterness and resentment is lessening. I can remember more of the good things that happened between us. I can remember brotherly feelings again and feel softer. It has taken a lot of work [in psychotherapy] to do that, to get softer and to heal.

Another subject said she was in therapy because

I think about her [sister with schizophrenia] a lot. I'm probably too involved; sometimes it affects my work and I have a hard time concentrating. When studying, I tend to think about [sibling] and have a hard time getting through it. I'll start crying, thinking about her. I think I'm too sensitive. It affects me for a long time. After an upsetting phone call, I'll have a hard time switching gears to something else. I make too much of it.

Continuum of Illness Impact.
Subjects were asked to describe how the illness affects their lives, as well as the lives of their families and the ill sibling. Details were obtained about impact on daily life, goals, and relationships.

Descriptions of how mental illness affected subjects' lives range on a continuum from pervasive to discrete. Three general patterns of impact are apparent: pervasive impact, moderately pervasive impact, and discrete impact. Six subjects described a pattern of pervasive impact, six moderately pervasive, and two discrete.

Those subjects describing themselves as experiencing a pervasive impact reported that all areas of their lives are affected by the situation. The impact is experienced as general and negative, overshadowing much of their lives. Family descriptions offered by these subjects are consistent with what could be considered dysfunctional families, including severe alcoholism in one or both parents, unclear communication and interpersonal boundaries, or constant open conflict or abuse. The subject views the impact as generated by both the ill sibling and the family and affecting every part of his or her life. One subject said he had been "carrying a depression about home for years" and was in therapy because of "not emotionally accepting an abnormal family." Another subject noted that "everything [in the family] is focused on the sibling, no one lives his own life." In the most extreme cases of pervasive impact, the general notion was that the ill sibling compounded a bad situation, making things even harder. For example, one subject experienced his sibling's mental illness in his life as "double duty." He compared himself to a Vietnam veteran, stating that being raised in his family was like being in "a war zone." He explained, "But they weren't shooting bullets in my house. It wasn't bombs in that way, it was emotional and mental bullets."

The pattern of moderately pervasive impact was characterized as coming mainly from the ill sibling and the family. The sibling was seen as the focal problem with fallout for the family. The family impact was perceived as deriving from stress inherent in having an offspring with schizophrenia (as opposed to being a "dysfunctional" family). One subject, for example, in discussing her parents, said, "They are very sad about the damage that was done [by the mental illness]," adding that the family would have been "more joyous" if the sibling had not been mentally ill. Another subject described her sister's illness as "a cloud over your life. You're never totally exuberant...you always have a little bit of a heavy heart."

Subjects experiencing moderately pervasive impact generally felt that the family "needs my help" in managing the problem; they didn't feel that the family itself was the problem. Subjects often mediated between the family and the health care system. One subject said:

My parents would rather I talked with doctors because they feel I understand things better than they do. I always feel like I'm trying to explain things to my family and mediate things.

Another subject who assumed much of the responsibility for her brother, said:

My mother has just had problems all of her life. When I was 5 years old, she used to tell me about her problems. Now she calls me every day and tells me how her day has gone and what should I do? I never have a week where I can just—I always try to find time within my life, within my week where I can spend time with my brother and with my mother...I think I spend more time with my family than anybody I know.

In contrast, subjects describing a pattern of discrete impact had considerably different views about what areas of their lives were affected and what areas were not. The im-
pact was perceived as originating specifically from a problematic sibling. One subject said, “I think I was a little bit more of a loner than I would have been otherwise.”

One subject was surprisingly positive about the impact of his brother’s illness, noting that he developed more tolerance toward people who are different. He admired his brother for “surviving” severe bouts of paranoia, stating:

“I’ll tell you one thing that’s just remarkable about him [brother], the part that makes life so enriching. If I had to think of one word for him: he’s a survivor. He really is. He’s an incredible scraper. He survives. I don’t know how anybody can survive what he has gone through, I really can’t. A weaker person would have killed himself. But he is just an incredibly strong individual because he has really suffered through a lot.

Further, this subject spoke movingly about the impact of having a mentally ill brother, how it forced him to think differently about his own life and to make some crucial changes:

[His illness] had a dramatic impact on me from the standpoint that I stopped being a troublemaker. I stopped getting into fights. I turned from a mediocre student to really striving to do well in high school and I did. It was a dramatic change in the way I approached things.

The perception of subjects experiencing discrete impact is that the family was helpful in cushioning the subject and other siblings from the illness impact.

In addition to describing the impact of illness on themselves and their families, each subject also discussed the effect on the sibling. When talking about the ill sibling, subjects’ responses were heavy with descriptions of profound changes and loss—lost potential, appearance, relationships, and life opportunities. For some, it seemed like the lost personhood of the affected person. One subject expressed this theme:

The illness has affected her life in every way you can imagine...Before she was ill she was creative, she had friends, and we had fun together...and all of that is just gone...just blown with the wind, or whatever, because of her illness. It’s as if her growth stopped when the illness began.

Another subject said this about her brother:

He will just never be the same person he was before, and that’s very hard to deal with because for years and years you just remember your childhood and you remember how this person was and how normal he was. It’s so difficult to see him the way he is now. He’s just a completely different person. Even though there are good times when I can talk to him, he’s still not the same. He is not normal and not like he used to be. It’s hard.

Discussion

The significance of the findings from the sample studied is twofold. First, the findings identify areas of substantive interest for further investigation and support concepts, particularly normalization, that already appear in the literature. Second, the results provide sensitization about the needs of families of the mentally ill that should inform clinical practice with patients and families.

Through these moving accounts adult subjects who have siblings with schizophrenia reconstructed their experiences with the siblings to provide data about three general areas: (1) their definitions and recognition of their sibling as having schizophrenia, (2) their involvement in the sibling’s illness, and (3) their perceptions about the impact of the illness on their lives. The data in all areas suggest questions for further investigation.

For instance, the data lend support to the idea that normalization as a process is a frequent and strong occurrence in families. Normalization is a concept that has many of the same indicators as denial. The emphasis is cognitive, however: the individual or family acknowledges the presence of symptoms while minimizing or otherwise failing to recognize their significance (Knafl and Deatrick 1986). Normalization in this sample seemed to be more powerful or encompassing in some families than in others. Is this simply a matter of sibling perception? Or are there characteristics of the family that contribute to its strength? The florid outbursts that occurred in some families shattered illusions of normality for most subjects and their families, but the variability among families in tolerance levels for both florid and other atypical behaviors is not easily explained. Even the mentally ill sibling whose behavior led to his placement in a special school for treatment, although seen as troublesome, was regarded as basically normal until the change in his medications.

Normalization was insightfully described by Schwartz (1957) in her work on wives’ definitions of their mentally ill husbands. She portrayed wives as incorporating their husbands’ unusual behaviors “into a framework of normal social behavior...[which] supplies the rationale whereby behavior that is first seen as problematic can be transformed into that which is reasonable, or to what is expected under the circumstances” (p. 277). The sibling reports in this study
are congruent with Schwartz’s description. In both studies, families’ views arise from different assumptions and end with different implications for action than do the views of clinicians. Normalization reveals the lengths to which families go to tolerate abnormal behavior in their midst. While clinicians may view normalization as pathological denial, the process may, as suggested by Schwartz, serve useful functions for the family, such as justifying support for the ill person and motivating that person toward healthier behavior. Labeling a complicated social process as “denial” precludes a deeper understanding of families. Clinicians need to ask how family perspectives of the patient’s illness serve to help or hinder the adaptation of the patient and the family.

It is noteworthy that all subjects were readily able to produce definitions or explanations of schizophrenia and that the explanations were reasonably congruent with the subjects’ reported experiences. Subjects had obviously thought about the matter and had incorporated their perceptions of their family life into their understanding of the sibling’s illness. For instance, subjects who described their families as having considerable upheaval were also likely to include parental alcoholism or “bad parenting” as contributory. A clinical question arising from this finding is, when should or should not a subject’s perception be supported. Our data suggest that subjects’ perceptions typically had some basis from their past experiences. While clinicians should not take all perceptions as gospel, those interested in helping families to cope effectively would do well to explore the underlying reasons for the varying family perceptions.

The differences among the three approaches to participation in the sibling’s illness are noteworthy and raise important questions for clinicians: Is one approach clearly preferable? If so, how can families be encouraged to adopt it? What factors support the development of a particular approach, and what are the costs and benefits of each? Intuitively, the collaborative approach would seem desirable. It involves complementary efforts from all parties (health care providers, other family members, and the mentally ill sibling) in constructing well-understood roles, and the result is a sense of having the situation somewhat under control that was markedly absent in other approaches.

It may be that the collaborative approach distributes the burden of care more effectively over all participants in the situation but requires a degree of coordination and unity of purpose that is not always available in families or between families and health care providers. If this proves to be the case, a goal of treatment would be to place more emphasis on developing a team effort around common goals and commitment among providers, family members, and the patient.

In comparing the crisis and collaborative approaches, crisis involvement did not seem as satisfactory to the subjects reporting it. It is not clear, however, whether the crisis approach reflects primarily the impact of a volatile or unpredictable ill sibling or other characteristics of either the family or the subject. While the ill-sibling behaviors reported by the crisis approach subjects seemed quite difficult, equally difficult ill-sibling behaviors were reported by some collaborative approach subjects.

The families using the crisis approach, however, were less likely to have agreed on a course of action for the ill sibling’s care. Subjects whose illness participation descriptions were classified as detached seemed to be trying to carry out some responsibility toward their ill sibling or the family while simultaneously protecting themselves from overly stressful family situations. It was the impression of the investigators that these subjects were in a transitional state; they felt guilty about wanting to get away, yet impelled to do so for their own well-being. This finding points to a serious need for clinicians to include siblings in any family meetings and interventions. Providing information to siblings and alleviating guilt and unreasonable feelings of responsibility or powerlessness are especially important. Should siblings always be involved in caring for a mentally ill brother or sister? There may be times when a more detached role is appropriate and should be encouraged. On the other hand, better management skills may help the entire family to feel less stress and function more effectively.

It is not surprising that so many subjects described the illness of the sibling as having such a pervasive, dampening influence on the lives of everyone in the family. In other illnesses family members frequently cite some good that has come from the illness situation, such as drawing the family closer together, reordering and enriching their values, or simply valuing one another more. Judging from reports of these subjects, it is difficult to portray schizophrenia as a cloud with a silver lining of any kind. A therapeutic goal for clinicians to pursue with family mem-
bers may be to help them achieve a degree of equanimity and sense of accomplishment in making the best of a difficult situation. Current psychoeducational interventions may need to put more emphasis on stress management techniques for families.

Finally, a point can be made about probable biases in this study sample. Recruitment procedures favored having subjects who took an active role in their sibling’s illness situation. For these subjects, participating in a sibling’s illness was taken for granted. But they may not typify most family situations. It would be useful to know how many individuals detach themselves from their mentally ill siblings and to identify the circumstances that lead to this decision. It would also be useful to identify how this sample of actively involved siblings differs from those who are more detached with regard to the likelihood of having a dysfunctional family, sense of personal accomplishment, or close family ties with nonimpaired siblings. Ongoing research on family burden and psychoeducational programs should include siblings, both as sources of data and as targets for intervention.

References


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