At Issue:
Siblings of Patients With Schizophrenia: Sibling Bond, Coping Patterns, and Fear of Possible Schizophrenia Heredity

by Gabriella Stålberg, Hedvig Ekerwald, and Christina M. Hultman

Abstract

Siblings of schizophrenia patients are from the patient's perspective important support providers, but most studies on family burden have focused on the parental role. This study aims to develop a detailed analysis of the psychological aspects of having a sibling with schizophrenia. We did a qualitative study with audiotaped semistructured interviews of 16 siblings. The reliability of the inductive categorization of data was high. A unifying theme appeared to be an emotional sibling bond characterized by feelings of love, sorrow, anger, envy, guilt, and shame. The major categories linked to coping with the situation were avoidance, isolation, normalization, caregiving, and grieving. A third major theme consisted of a fear of possible schizophrenia heredity. The siblings described concerns about the impact of a family history of psychiatric illness, a fear of becoming mentally ill, and reflections about "bad genes." Our findings support earlier findings of coping patterns but complement them by providing a model that includes awareness of genetic vulnerability as an important part of siblings' subjective burden.

Keywords: Schizophrenia, siblings, coping, heredity, interviews.


Schizophrenia has a profound long-term impact on the lives of both schizophrenia patients and their families (Fadden et al. 1987; Solomon and Draine 1995). The main focus of studies in the field has been to understand the need for information and support in the family (Dixon et al. 1999, 2000) and how family intervention programs may optimize the recovery of the mentally ill family member (Pitschel-Walz et al. 2001). Most studies in the area have been conducted on parents and spouses and have largely excluded siblings. Sibling relationships are unique in that they are long-lasting and involve common social, genetic, and cultural heritage (Lamb and Sutton-Smith 1982). Furthermore, community-focused psychiatric care, independent living, and treatment that focus on the whole family may increase the importance of sibling relationships. Despite the need for greater understanding of sibling relationships and siblings’ experiences, only recently have efforts been made to systematically describe the emotional impact of being a schizophrenia patient's sibling (Nechmad et al. 2000).

Major findings from the few available studies of siblings' burden of care are that siblings provide more support when parents are not available (Horwitz 1993), with sisters generally providing more care than brothers (Greenberg et al. 1997). Moreover, evidence indicates that experiences of subjective burden seem to be related to younger age, higher education, and greater symptomatology of the ill sibling (Greenberg et al. 1997). Some authors suggest that the subjective experience of siblings is quite similar to that of parents in affected families (Greenberg et al. 1997; Magliano et al. 1999), while others argue that siblings' experience of the stressful situation is specific and may more easily allow physical or mental escape (Kinsella et al. 1996) and detachment (Gerace et al. 1993). Furthermore, healthy siblings seem to have specific needs that differ from those of other family members (Landeen et al. 1992). The emotional impact as mirrored in in-depth interviews or psychotherapy with schizophren-
nia patients' siblings involves feelings of guilt (Titelman 1991). Despite adversities, siblings also report personal qualities and strengths as a result of having grown up with schizophrenia in the family. Kinsella et al. (1996) reported independence, creativity, empathy, resiliency, assertiveness, and a broader spiritual perspective as potential strengths. These findings are consistent with other data showing that patients at all levels of symptomatology often make positive contributions to their families and are active reciprocal support providers (Horwitz et al. 1996); also, in an earlier study, we found a high association between frequent contact with siblings and good social integration as well as good outcome (Hultman et al. 1997). Moreover, because of an increasing awareness of genetic factors in schizophrenia research, siblings are of particular interest in the search for common vulnerability factors and early risk factors (Erlenmeyer-Kimling et al. 1997; Cardno et al. 2002).

Although there is growing evidence for complex schizophrenia heredity (Gottesman and Moldin 1997; Cardno et al. 1999) and many siblings come from multiply affected families (Fouldrin et al. 2001), it is hard to find studies investigating the siblings' perceptions and fears of possible schizophrenia susceptibility.

From our perspective, there are several problems connected to this field of research. In studies investigating siblings' perspectives it has been common to regard the family as a unit rather than separate it into distinct groups based on the different roles played. Moreover, relatives of people with different psychiatric diagnoses often participate in the same investigation. When studies have included mainly siblings of schizophrenia patients, the descriptions of siblings' characteristics (e.g., psychiatric symptoms) have often been poor. In addition, samples are often narrowed to mentally well siblings and to siblings with frequent contact with their ill relative.

This study seeks to help compensate for this dearth of research on the psychological aspects of being a schizophrenia patient's sibling. We conceptualize the character of the sibling relationship as central to understanding how schizophrenia affects siblings. The siblings' feelings, thoughts, and behavior are examined in an interview study based on the conventional sociological qualitative method of a close reading of the material. Using this psychological, qualitative approach, we aim to explore how schizophrenia patients' siblings perceive the sibling relationship and their role.

**Method**

**Participants.** We recruited 16 siblings of 14 schizophrenia patients participating in a research project at the Psychiatric Centre at Uppsala University Hospital (2 schizophrenia patients had 2 siblings each in the study). After patients gave their informed consent, siblings of patients with a schizophrenia or schizophrenia spectrum diagnosis (APA 1994) were contacted by telephone or mail. All approached siblings agreed to participate, but one sibling changed her mind when her sister got worse. To increase the transferability of findings, we did not exclude siblings with psychiatric symptoms or earlier psychiatric contact. Patient and sibling characteristics appear in tables 1 and 2.

<table>
<thead>
<tr>
<th>Table 1. Characteristics of 14 patients with schizophrenia</th>
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<tbody>
<tr>
<td><strong>Characteristic</strong></td>
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Note.—PANSS = Positive and Negative Syndrome Scale.

1 12 patients.
Table 2. Characteristics of 16 siblings of schizophrenia patients

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
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<tbody>
<tr>
<td>Age (yrs)</td>
<td></td>
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<tr>
<td>Mean</td>
<td>31</td>
</tr>
<tr>
<td>Range</td>
<td>16–55</td>
</tr>
<tr>
<td>Sex, n</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>8</td>
</tr>
<tr>
<td>Male</td>
<td>8</td>
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<tr>
<td>Family of origin size, n</td>
<td></td>
</tr>
<tr>
<td>2 children</td>
<td>8</td>
</tr>
<tr>
<td>3 children</td>
<td>5</td>
</tr>
<tr>
<td>7 children</td>
<td>1</td>
</tr>
<tr>
<td>Ordinal position, n</td>
<td></td>
</tr>
<tr>
<td>Oldest</td>
<td>4</td>
</tr>
<tr>
<td>Middle</td>
<td>3</td>
</tr>
<tr>
<td>Youngest</td>
<td>9</td>
</tr>
<tr>
<td>Sibling's relationship to the patient, n</td>
<td></td>
</tr>
<tr>
<td>Female with female sibling</td>
<td>4</td>
</tr>
<tr>
<td>Female with male sibling</td>
<td>4</td>
</tr>
<tr>
<td>Male with male sibling</td>
<td>4</td>
</tr>
<tr>
<td>Male with female sibling</td>
<td>4</td>
</tr>
<tr>
<td>Education (yrs)</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>13</td>
</tr>
<tr>
<td>Range</td>
<td>10–18</td>
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<tr>
<td>Estimated age at patient's onset of illness</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>21</td>
</tr>
<tr>
<td>Range</td>
<td>7–28</td>
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<tr>
<td>Contact with the patient, n</td>
<td></td>
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<tr>
<td>1–7 times weekly</td>
<td>6</td>
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<tr>
<td>1–4 times monthly</td>
<td>4</td>
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<tr>
<td>1–11 times yearly</td>
<td>4</td>
</tr>
<tr>
<td>Almost never</td>
<td>2</td>
</tr>
<tr>
<td>Have sought psychiatric help, n</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7</td>
</tr>
<tr>
<td>No</td>
<td>9</td>
</tr>
<tr>
<td>Psychiatric symptoms (PANSS)</td>
<td></td>
</tr>
<tr>
<td>Positive symptoms</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>9</td>
</tr>
<tr>
<td>Median</td>
<td>8</td>
</tr>
<tr>
<td>Range</td>
<td>7–17</td>
</tr>
<tr>
<td>Negative symptoms</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>9</td>
</tr>
<tr>
<td>Median</td>
<td>8</td>
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<tr>
<td>Range</td>
<td>7–11</td>
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<tr>
<td>General psychopathology</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>20</td>
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<tr>
<td>Median</td>
<td>18</td>
</tr>
<tr>
<td>Range</td>
<td>16–38</td>
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Note.—PANSS = Positive and Negative Syndrome Scale.

Measurement of Psychiatric Symptoms. Psychotic symptoms and general psychopathology were rated using the Positive and Negative Syndrome Scale (PANSS) for schizophrenia, a 30-item, 7-point rating scale (Kay et al. 1987). These ratings were based on a structured clinical interview performed by trained psychiatrists blind to other measures in the study. The PANSS was scored by summation of ratings across items with a potential range of 7 to 49 for the positive and negative scales and 16 to 112 for the general psychopathology scale.

The mean total number of symptoms for the patients in the present study was 57 (median = 54) and for their siblings 38 (median = 34). The normative mean and median values of PANSS (total) for 101 schizophrenia patients reported by Kay et al. (1987) were 77 and 74, respectively.

Interviews and Procedures. This study involved face-to-face semistructured interviews. We used the interview guide “Adult Sibling Response to Chronic Mental Illness” (Gerace et al. 1993), which elicits the participants’ perspective on their sibling’s psychiatric illness, the perceived impact of the illness on self and the family system, and the participants’ perceived role in illness management. The original version was translated from English to Swedish and shortened. Of the original 25 questions, we chose 15 that were related to the aim of the present study (appendix). In open questions we encouraged free expression of feelings, experiences, and reflections but followed the semistructured guide.

The first author conducted 11 interviews at the research clinic, 3 via telephone, and 2 in participants’ homes. The in-person interviews were audiotaped, then transcribed, and the telephone interviews were carefully transcribed as they happened. There was no time limit for the interviews, but all lasted between 45 and 90 minutes.

Data Analysis and Reliability Testing. The data analysis was guided by a variant of the inductive methodological school of grounded theory (Ekerwald and Johansson...
1989), characterized by close and repeated readings of the texts. First, each interview was openly coded. Second, codes from all interviews were studied and different themes were identified. Finally, major themes were explored by seeking elaboration and clarification from the texts.

To judge the coherence and reliability of themes and quotations, two psychologists (G.S. and C.D.) independently read the transcribed interviews and identified themes. They agreed on 12 of 13 themes (92%). As a second step, one psychologist (C.D.) categorized the interviews according to the major coping patterns identified for the siblings by the other psychologist (G.S.). The two psychologists gave exactly the same linking of each sibling to one of five coping patterns in 15 of 16 cases (94% agreement).

Results
The systematic organization and interpretation of the textual material resulted in three major themes (figure 1): (1) sibling bond, (2) coping patterns, and (3) fear of possible schizophrenia heredity. Illustrative excerpts related to each of these themes and their dimensions are presented.

Sibling Bond. The sibling bond has a central position in the analysis. We have chosen to name the relationship between the siblings the “sibling bond” because we want to stress the emotional transactions of the siblings (Bank and Kahn 1982). When describing the relationship, siblings spoke of many feelings and affectionate experiences. Reflecting in the narratives was a feeling of emotional involvement that we consequently described as the siblings’ feelings. In other words, we did not distinguish between feelings, emotions, or affects because we did not test for that distinction. Instead, the focus was on the siblings’ emotional experiences within the context of their sibling relationship. Love, sorrow, anger, envy, guilt, and shame were the primary feelings expressed.

Love and sorrow. The siblings expressed the feeling of sibling love and how this feeling affected them personally. There were three chief aspects. First, sibling love was described as something that facilitates the situation of having an ill sibling. A younger brother described what has made it easier for him to deal with the fact that his older sister has schizophrenia: “Despite everything, my sister and I have always had a pretty good relationship. She’s really kind and loves me so very much so it’s never been a problem.”

Second, love was described as a reason for helping and supporting the ill sibling. “Of course I have a responsibility for my sister. This is because she’s my only sister and I love her and we have all these shared memories and experiences together.” It was natural for this person to help her sister with practical things, and the love seemed to be a strong force in motivating the sibling to help her ill sister.

Third, sibling love was related to sorrow. Siblings were sad that their sibling was mentally ill, and the sorrow they expressed can be described as a feeling of loss and empathy with the sibling’s suffering and pain. “Somehow I’ve lost my sister the way she was before and I think I won’t get her back,” explained one sibling. It is as if the earlier relationship had gone forever and the siblings had to discover a new kind of relationship. Some siblings felt their schizophrenia sibling’s own pain caused by the mental illness, and their empathy gave rise to feelings of sorrow: “It’s the sorrow that is the hardest—that someone you love so much has to suffer so much.”

Anger and envy. Siblings in the study expressed anger and envy, both directly and indirectly. Anger and envy are two emotions not always allowed to be felt, but neverthe-
less they are important for the understanding of the sibling's emotional experiences. One younger brother's anger emerged when reflecting on how the behavior of his sister affected his mother: "Yes, it's hell. She gets beaten if she doesn't stop. She's incredibly mean to our mother and she sure as hell doesn't deserve that." Feelings of anger can also be interpreted as connected with feelings of sorrow, as this brother noted that there is "a certain amount of dejection all the time."

Envy, common in sibling relationships, can become yet more complicated when psychosis enhances the differences between the siblings. The envy is mutual, but interviewees expressed the ill sibling's envy more explicitly. Speaking of an ill sibling, one interviewee remarked: "Well, the thing is that, in a way, he can't have the same ambitions as I have. I think he finds this pretty tough. I think he's pretty envious that I do well you know, both in private life and at work." A different interviewee explained, "I know that he's smart . . . but he thinks I'm really smart and really good at everything and so on; he's envious of me." This brother pointed to the dilemma that siblings often differ in skills, a difference that promotes strong feelings of rivalry and can create other feelings, including guilt.

We also found indications of the participating siblings' envy, although they were hard to tease out from the text. Siblings seemed to not really allow themselves to talk about their own envy. The well siblings' envy was expressed implicitly, for example in terms of possible advantages of being ill, as demonstrated in the following excerpt: "Another advantage is this thing with bills. If he doesn't bother to pay the rent no one accuses him, and he doesn't care. He doesn't feel bad about this. There are no 'have to' situations in his life."

Guilt and shame. Guilt about being healthy was reflected in the siblings' personal accounts. They often wondered why their sibling became ill while they remained healthy. One sister said that she thought that she, not her older brother, should have been the one with psychosis because he was the more talented of the two. Another sibling noted the following: "Yes, you can think about why he got ill and I didn't, although we come from the same place." Closely connected to feelings of guilt about the sibling who did not become ill are thoughts and feelings about the family's contribution to the mental illness. One sibling described it like this: "I thought and wondered if I had anything to do with why it's like this and wondered if anyone in the family caused this illness." Feelings of guilt also revolved around the healthy siblings' seldom visiting the ill sibling or not helping him or her as much as they felt they should.

For many siblings, the feeling of shame seemed to be connected to the attitudes of other people toward mental illness and its social stigma. Generally, siblings had experienced other people's lack of understanding about having a mentally ill family member. One sister reported that the hardest thing about being a sibling to a person with psychosis was "when people talk crap about it or distance themselves from it." Well siblings also make comparisons between having a mental illness and having a physical illness. One sibling with a mother with schizophrenia touched upon this topic when explaining how she would like others to view her family: "It would have been different if we would not have had a psychiatric illness in the family but a physical thing, you know, some physical disease. I would just like them to look at us as though we were an ordinary family." This quotation is an example of how shame and longing for normality are linked to the sibling's experiences.

Many siblings found it difficult to handle questions posed by people about their sibling's illness. One interpretation of this difficulty was based on the narratives of well sibling uncertainty about whether the ill sibling really wanted the well sibling to be open about the illness. Another interpretation was based on the fear of the possible consequences of being open: "Some might be ashamed of it and thus don't dare do anything because of the fear it will come out in the open and that you will be labeled." This statement shows an ambivalence concerning the sibling's illness because it is unclear whether this brother was reflecting upon the risk that his ill sibling would feel ashamed or whether it was he who was ashamed of having a mentally ill sibling. These feelings of shame become even stronger because of the social stigma of mental illness. However, some siblings reported having positive experiences with telling others about their sibling's illness: getting an empathetic response, sharing similar experiences, and no longer feeling totally alone in having a mentally ill sibling.

We found strong indications that siblings' worries about other people's attitudes became more pronounced when they had an extended family history of psychiatric illness as well as a mentally ill sibling. One sibling with a mentally ill mother described this dilemma in the following way: "All the time when I was growing up . . . it was shameful to talk about one's family; you didn't want to reveal anything . . . I never mentioned my mother to anyone . . . that was closed off from the public." The complex feelings of shame can be described as an intricate combination of feeling ashamed about having mental illness running in the family and feeling strong respect for the ill sibling's integrity.

Coping Patterns. The second theme was siblings' coping patterns, which were a subtext in the whole narrative of the sibling and in sibling responses to specific questions.
about the way they dealt with the situation. Coping can be defined as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus and Folkman 1984, p. 141). According to Lazarus and Folkman, this is a process-oriented rather than trait-oriented definition that limits coping to conditions of psychological stress. We have made pragmatic use of their concept, not fully adhering to the process element in the definition. In our analysis, it is not possible to differentiate between statements describing processlike coping and traitlike coping, as the questions were not designed for that purpose. We also ran the risk of getting a quite insensitive description of the siblings' coping patterns when using the concept too narrowly. Nevertheless, for clarity, it has been a useful instrument in our analysis.

We found that the siblings expressed five coping patterns: avoidance, isolation, normalization, caregiving, and grieving. Many of the siblings described several patterns, but in all cases one pattern was dominant. The coping patterns were influenced in different ways by factors such as time, gender, sibling order, and frequency of interaction. These and other possible confounding factors were not included in our analysis. We focused exclusively on what siblings did to deal with having a mentally ill sibling, and what thoughts and feelings they were coping with, and we tried to interpret why a certain coping pattern was applied.

Avoidance. Avoidance is described here as a pattern of cognitive and physical avoidance. This pattern mainly involves trying to cope with feelings of confusion and sadness. Our interpretation is that the major reason for applying an avoidance coping pattern is to protect one's own health.

An example of cognitive avoidance is given in the following quote: "If I keep myself busy the whole time, I keep my mind on that, but if I stop . . . then maybe I'll think about that and that might be difficult." Later in the same interview, this brother told us that one of the hardest things about being a sibling to a mentally ill person was the difficulty in understanding the way his ill sister thought, which affected how he communicated with her. This may have been one reason why he avoided thinking about her illness.

Another sibling used physical avoidance and was cognizant of her choice to live far away from her brother: "I'd like to see him more, but it's hard because I get so sad." The strong emotional reaction she had when with him forced her to flee from these situations. She also told us about the necessity for a well sibling to go on living his or her own life instead of being deeply negatively affected by the situation. One sister, mostly applying a combination of cognitive and physical avoidance, explained how she encouraged her mentally ill brother to use cognitive avoidance when worried because it worked for her.

Isolation. The second coping pattern involves the psychological dampening of bad experiences in an effort to create distance between oneself and the situation and manage feelings of anger and frustration. Our interpretation is that these feelings become insurmountable if this dampening strategy is not used.

There are some similarities between the coping patterns isolation and avoidance. Both create emotional distance, but in isolation the siblings are more emotionally close to each other compared with the avoidance pattern. Therefore, isolation can be regarded as a more passive way of coping as compared with the active coping pattern of avoidance.

Although she often gets angry with her sister, one sibling had this to say about her ill sibling: "You can't get angry with her as with others. I give her more freedom. You have to take her with a pinch of salt and just let it be." Later in the interview, she explained that this was a way of coping that had evolved over a long time and had proved to "be the best in the long run." Describing strong feelings of irritation over his sister's behavior, another sibling remarked: "No, I didn't react in any special way . . . She's been tricky on and off for such a long time that . . . it didn't make any difference." A reasonable interpretation of this statement was that he preferred to isolate himself emotionally from the situation in order not to become overwhelmed by his strong feelings on the matter.

Another example of coping by dampening the experience of having a mentally ill sibling involved making it impersonal: "I could reason that I shouldn't take it personally. It's not the end of the world." Both this participant and a second compared being a sibling to being a parent. "I think it's easier to be a sibling than a parent," the participant reasoned. "You can sort of disconnect it more and focus on your own life."

Normalization. Normalization includes making comparisons between the ill sibling's present state and somebody else's or the ill sibling's earlier mental condition, and through such comparisons, conceptualizing the behavior of the sibling as normal. The siblings primarily apply this strategy to handle ambivalence about what is normal (well/ill), where the coping mechanism moves along a complex continuum between the two endpoints denial and acceptance of the sibling's illness. Our interpretation is that this pattern is neutralizing the social stigma of psychiatric illness and that it reduces stigma.

Concerning the first characteristic, denial or ignoring the illness, one brother whose sister had been ill nearly as
long as he could remember noted: "To me it was completely natural since my sister had it. I lived with it and it felt kind of natural that she had it." Another brother who used the normalization coping pattern stressed the necessity of accepting the sibling’s state: "I accept him as he is. He’s allowed to check the stove ten times for instance." Perhaps the fact that this brother had psychotic symptoms himself made it easier for him to handle his brother’s illness. He had this to add about living with schizophrenia: "It’s possible to live a good life despite having schizophrenia; that is, it is good once you’ve accepted your life situation."

When using this coping pattern, the siblings often expressed ambivalent thoughts about what is normal. Sometimes comparisons were made between the sibling’s actual mental state and earlier states of illness, or others’ mental state. For example, one sibling tried to normalize his brother’s psychotic symptoms by describing how he experiences his brother’s illness: "You have a psychosis . . . and the mental state is affected because the chemistry of the brain is upset a little. It’s like that with everyone more or less, but with him it’s more.”

Caregiving. Siblings are often emotionally and practically engaged in the ill sibling’s everyday life. They are also often keen on maintaining contact with the sibling. Caregiving helps many siblings to deal with feelings of inadequacy and guilt, which is one plausible reason for coping in this way.

One of the siblings who copes with her brother’s illness through caregiving emphasized the importance of helping her brother: "I try to be there and help him as much as I can. I’m at hand and he knows that." Feelings of inadequacy are closely linked to a strong involvement in the ill sibling’s daily life as well as in care. One sister expressed feelings of inadequacy when asked what was the most difficult aspect about being a sibling to a mentally ill person: "I feel that I am inadequate when it comes to dealing with my brother’s illness."

Another way to engage in the sibling’s everyday life is to report the importance of daily contacts: "To keep in touch I feel is important. At least I’ve tried to see my sister as much as possible and to do things we did before she became ill." In this group of siblings, feelings of inadequacy seemed to be ubiquitous in that these siblings discussed improving the frequency of contacts, even when they already saw their ill sibling quite often.

Grieving. The most prominent feature of grieving is siblings’ powerful sympathy or empathetic feeling of the ill siblings’ burden of having schizophrenia. This feeling results in a grieving process. Our interpretation is that grieving is a way to process the loss of the earlier sibling relationship and to seek emotional balance in the involvement and care of the ill sibling. There are similarities between the pattern of grieving and caregiving, such as a desire to be emotionally close to the ill sibling and a strong involvement in his or her everyday life. However, in comparison with grieving, we have found caregiving to be a more active coping style.

Concerning this empathetic feeling more generally, an acute reaction of sorrow seems to accompany empathy. One sibling whose brother had been ill for only 1.5 years noted: "It sort of hurts on the inside. Why should it happen to him? I was very sad, and there was actually a lot of crying there for a while." However, grief and its consequences could also be felt by siblings whose brother’s or sister’s illness had been known for a longer time. Several of the siblings who used a grieving strategy described themselves as sensitive because they easily burst into tears: "I’m very sensitive and I usually cry easily, even when watching TV programs and films." We found that siblings who used grieving as a coping mechanism struggled to attain emotional balance between being involved in the care of the ill sibling and trying to live a life of their own. One sister touched upon this issue when asked to give advice to other siblings: "Try to find some sort of balance, which for me means not taking on too much yourself.”

Fear of Possible Schizophrenia Heredity. Thus far, we have presented two of the three themes, the sibling bond and the well siblings’ coping patterns. Our third theme is fear of possible schizophrenia heredity. We found that thoughts and feelings about an earlier experience of psychiatric illness in the family and about possible schizophrenia heredity were activated when the sibling’s psychosis first appeared. An earlier family history of mental illness complicated the siblings’ experiences; expressions of this were particularly conspicuous when the sibling sought explanations of the illness. However, concerns about heredity were also expressed even when no earlier family history of psychosis was evident.

Impact of a family history of psychiatric illness. Ten of the siblings had a family history of mental illness, and five of these had grown up with a mentally ill parent (table 2). Thus, they shared a remarkably heavy psychiatric heredity. However, siblings with and without a family history expressed fear that they would also be diagnosed with schizophrenia. We found that beliefs about the etiology of schizophrenia seemed to be influenced by psychiatric family history. Siblings with an additional relative who had a psychiatric illness tended to be more aware of the possible heredity of schizophrenia: "There is a certain heredity, or more correctly, you inherit a sensitivity for
the illness, the psychiatric illness.” They also tended to stress a combination of biological and environmental factors as causing the illness. In contrast, siblings who do not have a family history of psychiatric illness attached greater importance to environmental factors: “It could be anything, such as tragic events, childhood, anything.”

**Fear of becoming mentally ill.** Half of the 16 participants expressed the fear of becoming mentally ill themselves. Six of these siblings had a family history of mental illness (two had psychiatrically ill parents, two had both a parent and another relative with psychiatric illness, and two had other mentally ill relatives). Those with a family history of alcohol did not express fear of heredity and did not relate alcoholism to heredity for psychiatric illness.

The siblings with a mentally ill parent made the most direct statements concerning the fear of becoming mentally ill: “Of course one doubted oneself and was really scared because it’s a nightmare and it used to be like that before he got ill, that you could end up like your mother. Thus, that’s what has definitely been the hardest thing.” Another sibling with a mentally ill mother expressed similar experiences: “It was difficult . . . because it can be hereditary . . . you worry a lot about getting it yourself.” However, it is important to note that fear was also expressed by siblings who lacked a family history of psychiatric illness: “I don’t know if the diagnosis had been made then, but it was tough when he was hospitalized. I felt a strong concern about getting ill myself and I was fairly paranoid about it.”

The fear of possible schizophrenia heredity, in combination with earlier experiences of psychiatric care, has affected some siblings’ tendency to seek help when needed. For example, one sister told us that she once turned to a psychiatrist when feeling depressed because she was very worried about developing schizophrenia herself. She felt a strong need for a specialist to evaluate her symptoms and to tell her whether she was mentally ill. She felt relieved when she was told that her feelings were normal considering the unique circumstances and that she was not mentally ill.

Another sibling reacted conversely when having problems with symptoms of anxiety hysteria. His reason for not turning to psychiatric care for help was earlier negative experiences: “My experience of psychiatric care is something I’d rather forget and . . . they are the ones filling [my mother] up with lots of medications and . . . they haven’t helped her—rather the contrary.” In conclusion, an earlier history of psychiatric illness in the family has a strong and contradictory influence on the healthy siblings’ relationship to psychiatric care.

**Reflections about “bad genes.”** Siblings who have mental illness in their family seem to struggle with thoughts about who brought the “bad genes” into the family. When the sibling has a mentally ill parent, these thoughts are part of a complex pattern of wanting to protect the ill parent from guilt. In other words, siblings want to protect the source of the “bad genes.” The combination of wanting to be strong for the parent’s sake and at the same time worrying about their own mental health is sometimes hard to cope with effectively. Some mentally ill parents have reflected on their possible genetic contribution to the sibling’s illness: “Yes . . . my Mum felt guilty since she is ill and that she’d sort of given my sister bad genes so she got ill.” The guilt is omnipresent and affects the sibling. One effect of these thoughts can be that the siblings try to protect the ill parent from feeling more guilty by keeping the parent outside any discussions about the illness of the sibling: “We kept my Mum out of it and I don’t know when she found out but it was a long time later. She’s ill and shouldn’t have to . . . take on that too.”

Another relevant aspect about bad genes is worries that siblings have about passing them on to their children, that is, the risk of being a carrier of “bad genes” and thus the cause of mental illness. This was the case for a man with a mentally ill grandmother and brother: “Yes, about this thing being hereditary—I had understood that. I got worried about my kids. That was my first thought.”

**Discussion**

The main finding in our study is that a brother’s or sister’s schizophrenia profoundly affects his or her siblings emotionally and psychologically. Our qualitative approach had both limitations and strengths. We chose a qualitative methodology to facilitate the emergence of the siblings’ whole experiences, and the semistructured interview guide, earlier used by Gerace et al. (1993), formed a base for our inductive reasoning and identification of major themes. The method proved to be useful to cover the richness of the material, and we believe that the thematic analysis illuminates existing and important concerns in the target population. We cannot, however, fully exclude interviewer bias and selective coding and analysis of the data. To reduce this bias, we used audiorecruited interviews and two reliability analyses. We found high concordance in the major themes between the interviewer and a second rater and high consistency in main coping patterns, both of which indicate reliable findings.

We are also cognizant of the limitations of small sample size and nonrandom recruitment of participants. It is well known that it is hard to recruit siblings with good or poor/little contact with the patient. The procedure of first asking the patients for permission to contact their sibling may have biased the results toward siblings with more
frequent or good contact. However, the current sample covered a diverse group, including participants who did not have regular contact with their ill sibling (e.g., several of the participants reported having relational problems when they occasionally met their ill sibling). Many studies in the field have relied on self-selection of participants from family support groups and family organizations, a sampling procedure that possibly creates a much stronger bias toward siblings engaged in the patient’s care. Moreover, schizophrenia is an illness with gross variations of psychiatric symptoms and grade of functioning, depending on the phase of the illness. It is also commonly known that patient symptoms often become less prominent over time. This phenomenon might affect the experience of having an ill sibling. The large age span among the participating siblings makes our sample comparable with the population of all siblings. The phase effect, though, should make a longitudinal study preferable to our cross-sectional design.

The major psychological experiences linked to having a mentally ill sibling were a strong sibling bond with mixed feelings of love and sorrow, anger and envy, and guilt and shame. The preexisting sibling bond seems to be the context in which the siblings’ experiences and affectionate responses evolved when the psychosis debuted in the family. Our findings suggest that strong feelings develop because of the character of the emotional tie between the siblings. We found that feelings of love made the situation of having a mentally ill sibling easier to handle. This powerful, positive feeling of affection was also a reason to support the patient and was strongly connected to feelings of sorrow. Several studies have reported siblings’ emotional reactions (Landeen et al. 1992; Nechmad et al. 2000), and other studies have found similar reactions in parents (Tennakoon et al. 2000; Teschinsky 2000). However, owing to different family roles, there seem to be qualitative differences in evoked feelings. For example, studies on parents’ emotional reactions when a child has schizophrenia emphasize experiences of lifelong mothering and feelings of disruption, loss, and grief (Ryan 1993; Davis and Schultz 1997). Concerning the experiences associated with lifelong mothering, this is an important difference when compared with siblings’ experiences. In our study, several siblings mentioned that although it is hard to be a sibling to someone with schizophrenia, they believe it would be even harder to be a parent to someone with schizophrenia. The literature on adult siblings also indicates that siblings’ obligations are less explicit and not as demanding as parents’ obligations. Although some literature discusses the “voluntariness of the sibling tie” (Connidis 1992), we believe that the siblings’ responsibility changes when the parents are not available (Horwitz 1993). Our findings suggest that siblings (perhaps because of the sibling bond) want to help their ill sibling.

Moreover, there seem to be differences between being an offspring and being a sibling (Kinsella et al. 1996), possibly because most of the offspring are young at the onset of their parent’s mental illness and quite affected by a caregiver’s mental condition. Some of our study’s results may be confounded by the fact that some subjects were not only siblings but offspring of people with schizophrenia.

The emotional burden reported by the siblings in the present study is comparable to earlier findings about siblings’ subjective burden (Nechmad et al. 2000). The feelings of shame seem to be especially hard to bear and are related to stigma (“the mark of shame”). The burden of social stigma faced by schizophrenia patients’ siblings has been found in other studies as well (Teschinsky 2000). Based on our findings that the participants believed it would be easier if the sibling had a physical disease, we suggest that the shame is more prominent in families with schizophrenia. However, research has shown similarities between siblings with a brother or sister with schizophrenia and siblings with a brother or sister with a physical impairment (Lefley 1987; Friedrich et al. 1999). There are studies showing that siblings with a brother or sister with a physical disease appear to be more likely than their peers to experience psychological adjustment problems (Prizant et al. 1997). Other studies have found the opposite pattern—that is, that the majority of the siblings did not appear to have adjustment problems (Taylor et al. 2001). Furthermore, siblings of children with other psychiatric disabilities also develop coping strategies and are an important source of support for the ill sibling (Prizant et al. 1997; Dellve et al. 2000).

In conclusion, all family members are affected when a child gets a psychosis, but because of different family roles the emotional reactions are different. The siblings seem to have a more voluntary role compared to the parents and are not as dependent on the ill family member as the offspring. However, the strong emotions described in our study suggest that the power of the sibling bond might be underestimated. The specificity of the sibling bond in schizophrenia compared to having a brother or sister with a physical disease is still unclear.

The strong emotions expressed by the siblings in this study appeared to increase the siblings’ need and search for adaptive coping styles. All five coping patterns were about thoughts, feelings, and behaviors related to the highly stressful situation. The five coping patterns can be classified into three groups: (1) avoidance and isolation, (2) normalization, and (3) caregiving and grieving. Isolation and grieving seem to be passive variants of
avoidance and caregiving, respectively. Siblings with a main coping style of avoidance and isolation can be regarded as “detached” siblings, while siblings with a coping style of caregiving and grieving can be regarded as “involved” siblings. Normalization is probably the most neutral pattern. We suggest that these five coping patterns form a continuum from “distant” to “close” with regard to the sibling bond. The order of coping patterns would thus be avoidance, isolation, normalization, grieving, and caregiving. According to this relational continuum, normalization is the coping pattern most in balance with the actual circumstances. However, our analysis allows us to make only tentative suggestions concerning a correlation between these aspects of the sibling bond and a specific coping pattern, and hence no general conclusions can be drawn. Our reflection should be seen as purely hypothetical but worthy of further examination.

Comparisons with other studies show both similarities and differences in siblings’ coping strategies. Gerace et al. (1993) found three distinct patterns: collaborative participation, crisis-oriented approach, and detached approach. Collaborative participation has similar characteristics as caregiving in our analysis. The detached approach describes the siblings’ attempt to create distance between themselves and the ill sibling and is therefore similar to our avoidance and isolation coping patterns. There are no similarities between the crisis-oriented pattern and the coping pattern normalization. Normalization was one of the major findings reported in Gerace et al.’s study, but that was in the context of the siblings’ definitions of the ill sibling’s illness. We suggest that a continuum of denial to acceptance characterizes normalization and that this might be related to the siblings’ defense mechanisms as well as their cognitive strategies. The concept of normalization can be described as consisting of the same indicators as denial but with a cognitive emphasis (Gerace et al. 1993). Closely connected to this description is the siblings’ desire to have others regard their family as “normal” despite having a mentally ill sister or brother. This is expressed in relation to not only how they cope but also how they would like others to describe their family. Stein and Wemmerus (2001) have written about relatives’ search for a normal life in schizophrenia and the devastating experience of the loss of a “normal life,” an observation in good accordance with our findings (Stein and Wemmerus 2001).

Kinsella et al. (1996) reported the following eight dimensions of coping skills in siblings who have a brother or sister with mental illness: constructive escape, seeking support, objectifying the illness, acquiring information, spiritual faith, internalization of emotions or unhealthy escapes, self-censoring behavior, and self-isolation. Among the coping patterns found in our study, avoidance is similar to their “constructive escape,” normalization has similar features to “objectifying the illness” and isolation is similar to Kinsella et al.’s description of “internalization of emotions or unhealthy escape.” Noteworthy is that Kinsella et al. (1996) differentiate between positive and negative coping. If we apply this distinction to our results, it can be hypothesized that it is healthier to have an active form like avoidance than a more passive form like isolation. One explanation of the differences between patterns of coping might be related to the use of different definitions of coping. Siblings’ coping patterns have been examined numerous times within a theoretical framework of mastering psychological stress (Webb et al. 1998; Friedrich et al. 1999). We applied a cognitive-phenomenological perspective on coping (Folkman and Lazarus 1980). Some studies are not as explicit in their conceptualization of coping, or they have used a definition different from ours.

Our study clearly illustrates that siblings struggle with their own fear of possible schizophrenia heredity. We think this important theme influences the sibling relationship. Siblings worry that if schizophrenia etiology is related to genetics and shared familial factors, as well as environmental and psychosocial factors, the siblings may develop it too. The siblings’ thoughts and opinions about heredity seem to be connected with difficult feelings of guilt because the siblings are mentally well. This sense of guilt expressed by the siblings is very likely unique to the role of sibling.

The siblings’ reflections about possible heredity factors were especially salient in their responses to queries about the etiology of schizophrenia. The heavy family history of psychiatric problems in our sample might have influenced the development of coping patterns and beliefs. Research has found a correlation between family attributions and subjective burden and stigma (Greenley 1986; Greenberg et al. 1997). However, the more specific impact of the siblings’ reflections on family history of psychiatric illnesses is still unknown. An earlier confrontation in the siblings’ life with information about the possible hereditary nature of the illness might have resulted in a completely different coping pattern. Fear of becoming mentally ill could also be related to lack of information about schizophrenia and lack of emotional support from family, friends, or caregivers. It might be interesting to explore whether there is a specific kind of coping connected to beliefs about schizophrenia etiology, namely “coping with heredity.”

The siblings’ fear of becoming mentally ill themselves is noteworthy. In the literature this has mostly been approached from a psychoanalytical perspective (Titelman 1991). Surprisingly, the devastating fear indicated by our participants’ stories has not been the main
focus of earlier investigations despite today’s extensive genetic schizophrenia research. Nevertheless, there are studies about invulnerability that describe how high-risk children manage to avoid psychopathology by successful adaptation and the increased use of coping skills (Anthony 1974; Kinsella et al. 1996). These studies mainly focus on the well siblings’ strengths rather than their fear of susceptibility to psychiatric illness. The uncertainty about the complex issue of schizophrenia heredity makes the area of risk perception difficult to study, both ethically and psychologically. We speculate that some of the siblings’ negative attitudes toward health care could be related to an experienced fear of schizophrenia heredity and activation of earlier negative experiences of psychiatric care. This issue merits further attention.

Future work on siblings of schizophrenia patients will need to consider the reciprocal aspects of the sibling relationship. For example, Magliano et al. (1999) reported correlations between key relatives and other relatives regarding adoption of emotion-focused strategies in schizophrenia and interpreted this in terms of their likely dissemination from one family member to another. In the long run, the adoption of emotion-focused coping can have a negative impact on the ill family member as well. Folkman and Lazarus also emphasized the transactional aspects of coping: “The person and the environment are seen in an ongoing relationship of reciprocal action, each affecting and in turn being affected by the other” (Folkman and Lazarus 1980, p. 223). Thus, to attain a fuller understanding of the siblings’ coping and the specificity of the sibling bond in schizophrenia, it would be preferable to also explore the affected siblings’ experiences of the sibling relationship.

Even though this study has the relationship between schizophrenia patients and their siblings as a main focus, it generated many indications of the siblings’ need for attention, support, and understanding within the family and from the health care system. For many siblings, participation in our research interview was the first opportunity they had had to talk about schizophrenia in the family. An open dialogue within the family might be facilitated by professional help to well siblings early in the illness and counteract the development of coping strategies like avoidance and isolation. Our results point to a need for both offering explanatory facts in psychoeducational support groups and building an understanding dialogue with the patient concerning mutual experiences.

References


Appendix. Adult Sibling Response to Chronic Mental Illness Interview Guide (Adapted from Gerace et al. 1993 and Knafl et al. 1993)

Swedish translation and preparation by Gabriella Stålberg and Christina M. Hultman, Department of Neuroscience, Psychiatry Ulleråker, Uppsala University Hospital, 1998
The reason for this interview is to learn more about your feelings and ideas in relation to having a brother/sister with chronic mental illness. I'm interested in hearing how you and your family manage things, and what your experience has been like. I'd like to ask you about your brother/sister and your family.

A. 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 a mental illness.
      a. How did you first suspect something was wrong?
      b. What was your reaction to finding out your brother/sister had (condition)?
      c. What is your understanding of (condition) now? If a person at the clinic asked you to explain (mental illness) to them, what would you tell them about its cause, symptoms, treatment, course/prognosis?
   2. I'm interested in the course of your (brother/sister's) condition.
      a. What stands out in your mind as major "turning points" or events (e.g., number of hospitalizations, behavioral changes in level of functioning)?
      b. What is currently being done to treat your brother/sister's condition (e.g., medications, other therapies)?
      c. What do you expect in terms of changes in his/her condition during the next year? In the more distant future?
   3. What were you told about your brother/sister's condition?
      a. After you found out about your brother/sister's condition, what was discussed in the family about:
         1. Origin/course
         2. Treatment
         3. Restrictions
         4. Expectations of brother/sister

B. MANAGING: Now I'd like to change topics a bit. 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 outings. Let's start out talking about the medical treatment or medications.
   1. We've talked a bit about what your sibling's medications, treatments, and daily functioning are; now tell me how they actually get carried out.
      a. What are the siblings' responsibilities?
2. Are there past contacts with doctors or nurses that stand out in your mind? Tell me about these.
   a. What kind of advice have you received from doctors and nurses about how to relate to your sibling?
   b. What advice would you give to doctors and nurses about how to take care of families like yours?
      1. How to take care of the mentally ill siblings?
      2. How to treat the family?
3. What things have made it easier for you as a sibling to manage? For example:
   a. What friends have made it easier to manage?
   b. What professionals have made it easier to manage?
   c. What social services or institutions have made it easier to manage?
4. What things have made it more difficult for you as a sibling to manage?
   a. What friends have made it more difficult?
   b. What professionals have made it more difficult?
   c. What social services or institutions have made it more difficult?
5. What advice would you have for others in your situation?

C. ASSESSMENT OF 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. Let's start by talking about (sibling).
1. How well do you think you deal with having a sibling with a chronic illness?
   a. What is your reason for this? Examples.
   b. Would you like to deal differently with this? How?
   c. What is difficult about being a sibling to a mentally ill family member?
2. In what ways does (sibling's) conditions have an effect on your life? For example:
   a. Initial impact
   b. Daily routine
   c. Vacations/family outings
   d. Your own activities/free time
   e. Financial situation and outlook
   f. Long-term plans/goals
   g. Relationships
      1. Spouse
      2. Extended family
      3. Friends
3. How would you like others to view or describe your family?
4. What is the effect of your sibling's condition on his/her own life? For example: (his/her)
   a. Personality
   b. School/work performance
   c. Interest/activities
   d. Relationships with peers
   e. What about having a chronic mental illness is hard for your brother/sister?
   f. What might your brother/sister see as advantages of having a chronic mental illness?
5. What is the effect of your sibling's condition on your other family members (family of origin; own nuclear family)? For example, effects on:
   a. Personality/mood
   b. School/work performance
   c. Interests/activities
   d. Relationships with peers
6. To what extent do you think your other siblings' lives have been changed because of (brother/sister's) condition?
7. Thank you very much. Those were all my questions. Are there additional comments you would like to make? What kind of an experience has this interview been?