

Siblings' Coping Strategies and Mental Health Services: A National Study of Siblings of Persons With Schizophrenia

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Objective: This study examined the helpfulness of coping strategies and the relative importance of mental health services in coping with schizophrenia from the perspective of siblings. **Methods:** This article presents selected survey data from a national study of 746 respondents that investigated the impact of schizophrenia on siblings' lives. The authors developed the Friedrich-Lively Instrument to Assess the Impact of Schizophrenia on Siblings (FLIISS), a closed-ended questionnaire that included questions about coping strategies and mental health services. **Results:** Respondents identified services for the ill sibling, including symptom control, adequate housing, and long-term planning, as more important than direct services for themselves. The top-ranked coping strategies were education about schizophrenia, a supportive family, and seeing the ill sibling suffer less because symptoms were controlled. Understanding that families were not to blame for schizophrenia was the most helpful coping strategy for nearly three-fourths of siblings. Siblings had little contact with providers in the past; yet the majority of siblings wanted providers to be available to answer questions and clarify their role in future care. At the time of the study, respondents provided social support and helped with crises, but few coordinated the total care. **Conclusions:** Siblings identified multiple ways that providers can support and assist them in coping with the impact of schizophrenia. Education and support for siblings without schizophrenia and services for their ill siblings will become increasingly important for the well-being of siblings as they are faced with the responsibility of being the primary caregivers in the future. (*Psychiatric Services* 59:261-267, 2008)

Schizophrenia is a devastating illness, not only for the person who is ill but also for the entire family. Among the most vulnerable and most affected are siblings. As a consequence of unrelenting stress, multiple aspects of their lives are affected, including relationships, roles,

and health (1). Siblings often do not know how to cope with schizophrenia and its impact on their lives. Although the burden is costly for siblings, minimal attention has been paid to coping strategies and mental health services that could reduce the stress they experience.

The literature on coping with schizophrenia from the sibling's perspective is extremely limited. Only a few studies have focused on the resources that siblings of persons with schizophrenia need to manage the demands of the illness. Landeen and colleagues (2) developed a 14-item questionnaire and assessed the needs of 88 siblings for information, support, and practical skills. The results indicated a desire for more specific information about schizophrenia from providers. Another study of 11 siblings found that families had differing stages of readiness to receive information about the illness. For example, families who did not seek information appeared to be in denial (3). Gerace and colleagues (4) interviewed 14 adult siblings and distinguished three coping patterns: collaborative, crisis oriented, and detached. The collaborative siblings were actively involved with providers in caring for their sibling, whereas the detached siblings tried to keep the ill sibling out of their lives. In a recent study, Stalberg and colleagues (5) also examined coping patterns through interviews with 16 siblings. The major categories of coping were avoidance, isolation, normalization, caregiving, and grieving. Caregiving and isolation were viewed as similar to the patterns identified by Gerace and colleagues (4).

Some investigators examined the coping strategies and resources utilized both by siblings and offspring of persons with varying psychiatric diagnoses, including schizophrenia (6-8).

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Healthy and unhealthy coping skills of ten adult offspring and ten adult siblings of people with mental illness were identified by Kinsella and Anderson (8). Healthy skills included seeking support from family and friends, acquiring information, and having spiritual faith. Unhealthy coping consisted of withdrawing from the ill family member and addictive behaviors such as drug use.

Very little attention has focused on the role of mental health services in decreasing sibling stress. Nechmad and colleagues (9) pointed out that a limitation of current sibling research is the lack of recommendations for ways that health care providers can assist in relieving stress. In a study of 20 siblings of persons with mental illness, Riebschleger (10) reported that siblings recommended inclusion in client treatment, support, and education. Marsh and colleagues (7) assessed the relative importance of seven sibling needs and found that the most compelling needs were satisfactory services for their relative, working through reactions to the illness, skills for coping, and personal support.

Sibling studies have been limited by lack of sample homogeneity, reliance on qualitative data, and small samples. These limitations make it difficult to understand the efficacy of coping strategies and the relative importance of mental health services from the sibling perspective. Furthermore, in most studies there is no comprehensive framework that ties all aspects of the coping process together.

To investigate the impact of schizophrenia on siblings, we adapted the stress process model developed by Pearlin and colleagues (11) and developed a comprehensive questionnaire to assess each component of the model (12,13). According to Pearlin and colleagues, coping has protective functions that can be carried out in three ways: managing the situation giving rise to stress, managing the meaning of the situation to reduce threat, and managing the emotional distress created by the situation. Coping strategies represent some of the concrete things people do to deal with the problems they encounter. In addition to coping strate-

gies, social supports, such as family and friends, serve as resources for mediating stress (11,14). Mental health services can also be viewed as a resource in mitigating the impact of stressors (15).

There is a need for additional research that documents the sibling perspective on coping and mental health services. In turn, this knowledge can serve as the foundation for interventions aimed at relieving stress and increasing the well-being of siblings. This article presents selected survey data from a larger study that examined the impact of schizophrenia on siblings. The purpose of the study reported here was to examine the helpfulness of coping strategies and social supports as well as the relative importance of mental health services from the perspective of siblings of persons with schizophrenia.

Methods

Study sample

Siblings were eligible for the study if they were 18 years or older and had a sibling diagnosed as having schizophrenia. Siblings were recruited through three methods: first, questionnaires were sent to members of the Sibling and Adult Children Council of the National Alliance on Mental Illness (NAMI); second, an announcement of the study was included in the NAMI newsletter; and third, presidents of NAMI affiliates were asked to publicize the study at their meetings. Names and addresses of interested siblings were sent to the investigators. A total of 1,254 questionnaires were mailed, and 761 (61%) were returned. Thirty-nine states were represented in the sample. The dates of the study were July 1995 to May 1996. The study was approved by the University of Iowa's Human Subjects Committee, and informed consent was obtained from all respondents. [An appendix showing the respondents' state of residence is available as an online supplement at ps.psychiatryonline.org.]

Measures

The conceptual basis, construction, reliability, and construct validity of the Friedrich-Lively Instrument to

Assess the Impact of Schizophrenia on Siblings (FLIISS) have been described in earlier work (12,13). The coping and mental health services questions are part of the FLIISS and the focus of this study.

Helpfulness of coping strategies was measured by 22 items that asked siblings to rate the degree of helpfulness from 1, very helpful, to 4, harmful, and a rating of 5 indicates "did not use." Categories of strategies included management of the situation (five items), management of meaning (five items), management of distress (five items), social support (four items), and distancing (three items). Siblings also identified the degree of helpfulness of both informal and formal support from a 12-item list that included family, friends, and mental health providers.

Service needs were assessed with two sets of questions. First, siblings rated the relative importance of 11 needs at the present time from 1, very important, to 3, not important. This measure was an adaptation of the needs scale developed by Marsh and colleagues (7). Second, the relative importance of mental health services was assessed with 19 questions that included three categories of services: direct services for the ill sibling (nine items), information (six items), and support (four items). Siblings were asked to consider the importance of ways that health care professionals could assist them at the present time. Many of the top-ranked services were added at the suggestion of siblings during the pilot study.

Results

Sample characteristics

Respondents who answered less than 70% of the questions were not included in this study, leaving a sample of 746 siblings. Characteristics of respondents and ill siblings are exhibited in Table 1. A majority of the respondents were Caucasian, female, married, college educated, and employed. In contrast, most ill siblings were male, unmarried, and unemployed, and few had graduated from college. Ages for respondents and ill siblings ranged from 18 to 79 years.

Siblings had been ill an average of

19.4±10.6 years and had been hospitalized numerous times, including 214 (29%) who had been hospitalized more than ten times. Substance abuse and homelessness were prevalent among ill siblings. Although substance abuse was less common among respondents, one-sixth reported problems with drugs or alcohol and about one-tenth were diagnosed as having a mental illness other than schizophrenia.

The mean age of the siblings' parents was 66.9±8.8 years, and in 273 (37%) of the families one or both parents were deceased. About one-fifth of ill siblings were living with parents. Many respondents were members of NAMI and religious groups, whereas far fewer participated in Alcoholics or Narcotics Anonymous or counseling.

Coping strategies

Coping strategies and the proportion of respondents who used them are ranked in order of helpfulness in Table 2. Management of the illness situation through education and symptom control were some of the most helpful strategies. In contrast, spending time with the ill sibling (ranked 16) and talking with care providers (ranked 19) were very helpful to only about one-fourth of the siblings.

Strategies related to management of meaning were highly ranked. The most helpful strategy on the entire scale was "realize schizophrenia is a disease, and not anyone's fault." Accepting the illness and its consequences for the family was also very helpful to a majority of siblings. Family members were a very helpful source of social support to 423 siblings (58%). In addition, talking with others outside the family who had an ill relative was very helpful to 324 (44%).

Strategies for managing personal distress were ranked in the bottom third of those that were very helpful, except for exercise and physical activity (ranked 11). Distancing strategies, other than living in a location apart from the ill siblings (ranked 5), were the lowest ranked. Putting the siblings out of mind and having little to do with the ill siblings were the least helpful strategies.

Table 1

Characteristics of respondents and their siblings with schizophrenia^a

Characteristic	Respondents (N=746)		Ill siblings (N=746)	
	N	%	N	%
Female	548	74	243	33
Age (M±SD)	39.7±10.5		39.3±10.0	
Ethnic background				
Caucasian	711	95	709	95
African American	3	<	5	1
Hispanic	9	1	9	1
Asian	8	1	8	1
Native American	6	1	7	1
Other	9	1	8	1
Education				
High school or less	50	7	270	36
Some college	179	24	339	45
College graduate	515	69	137	18
Marital status				
Married	456	62	36	5
Widow, separated, or divorced	86	12	140	19
Never married	199	27	569	76
Employment status				
Competitive	617	85	97	13
Supportive	—	—	92	12
Unemployed	105	15	427	58
Other	—	—	122	17
Diagnosed mental illness other than schizophrenia	79	11	—	—
Drug or alcohol problem	118	16	250	34
Sibling ever homeless	—	—	186	25
Years sibling has been ill				
1–10	—	—	158	22
11–25	—	—	412	57
26–68	—	—	148	21
Number of hospitalizations				
0	—	—	26	4
1–4	—	—	281	38
5–10	—	—	209	29
>10	—	—	214	29
Parental status				
Age of parents (M±SD)	66.9±8.8		66.9±8.8	
Ill sibling lives with parents	—	—	157	21
One or both parents are deceased	273	37	273	37
Support services				
National Alliance on Mental Illness	337	53	—	—
Alcoholics or Narcotics Anonymous	36	6	—	—
Religious affiliation	245	39	—	—
Counseling	71	11	—	—

^a All data were not available for all respondents.

Support from individuals

The helpfulness of persons within the informal and formal support systems is listed in Table 3. A majority of siblings identified their family as very helpful, and about one-third of siblings viewed friends as very helpful. All providers ranked much lower in use and helpfulness. Many did not have any contact with mental health providers, ranging from 298 (41%) for psychiatrists to 406 (55%) for nurses.

Current needs and mental health services

The current needs of the siblings are displayed in Table 4. The number-one item was services for the ill person, not services for the respondent. Open communication in the family, emotional support, and information about the illness were next in importance. In contrast, the respondents assigned a much lower ranking to stress management skills,

Table 2Ranked order of coping strategies among 746 respondents with a sibling with schizophrenia^a

Rank and strategy	Category of coping	Very helpful		Slightly helpful		Not helpful		Did not use	
		N	%	N	%	N	%	N	%
1. Realize schizophrenia is a disease, not anyone's fault	Management of meaning	534	72	165	22	21	3	19	3
2. Read schizophrenia literature	Management of situation	431	58	230	31	23	3	56	8
3. Have supportive family	Social support	423	58	175	24	36	5	98	13
4. Seeing sibling suffer less because symptoms are controlled	Management of situation	401	55	210	29	46	6	79	11
5. Live apart from sibling	Distancing	395	54	177	24	64	9	97	13
6. Accept sibling's illness	Management of meaning	393	54	250	34	52	7	39	5
7. Learn what we are facing	Management of situation	368	50	241	33	44	6	80	11
8. Talk to others who have an ill family member	Social support	324	44	207	28	21	3	186	25
9. Accept that sibling will never recover	Management of meaning	309	42	246	34	121	17	56	8
10. Deal one day at a time	Management of meaning	298	41	267	36	75	10	95	13
11. Exercise, physical activity	Management of distress	276	38	210	29	62	8	187	25
12. Praying, spiritual activities	Management of meaning	272	37	239	32	61	8	166	23
13. Share concerns with friends	Social support	230	31	316	43	84	11	108	15
14. Engage in creative activity	Management of distress	209	29	158	22	81	11	285	39
15. Join support group, for example, National Alliance on Mental Illness	Social support	209	28	130	18	40	5	357	49
16. Spend time with ill sibling	Management of situation	197	27	299	41	181	25	53	7
17. Cry	Management of distress	196	27	253	34	134	18	153	21
18. Learn stress management	Management of distress	178	24	221	30	69	9	264	36
19. Talk with sibling's care providers	Management of situation	163	22	188	26	105	14	279	38
20. Keep personal journal	Management of distress	112	15	89	12	100	14	427	59
21. Put sibling out of my mind	Distancing	114	15	230	31	187	25	207	28
22. Have little to do with sibling	Distancing	51	7	124	17	265	36	297	40

^a All data were not available for all respondents.

individual counseling, and genetic counseling.

Table 5 lists the relative importance of mental health services in assisting the siblings. Similar to the current

needs shown in Table 4, many of the top-ranked items involved direct services for the ill sibling. The most highly ranked service was assistance with long-term planning for the ill sibling.

Other top-ranked services included monitoring symptoms of the illness and medications, identifying alternative living arrangements, coordinating community resources, providing help during suicide threats or attempts, and referring the ill sibling for vocational and psychosocial rehabilitation.

In Table 5, the availability of professionals to answer questions about the ill sibling was rated number one. A majority of siblings also wanted professionals to educate them about schizophrenia without blaming the family as well as to clarify their role in the ill sibling's future care. Support-related services were generally ranked lower than other services and included identifying support groups for families and providing individual or family counseling.

Discussion

One of the most striking findings in our study is that siblings identified services for the ill family member as

Table 3Helpfulness of individuals from the perspective of 746 respondents with a sibling with schizophrenia^a

Person	Very helpful		Slightly helpful		Not helpful		Did not use	
	N	%	N	%	N	%	N	%
Family member	402	54	233	32	98	13	7	1
Friend	242	33	311	42	102	14	88	12
Psychologist	120	16	145	20	150	20	322	44
Social worker	114	16	147	20	121	17	353	48
Psychiatrist	101	14	164	22	171	23	298	41
Coworker	68	9	202	27	178	24	294	40
Clergy	64	9	112	15	116	16	445	60
Nurse	58	8	145	20	129	18	406	55
Police officer	40	5	97	13	137	19	463	63
Family doctor	39	5	97	13	172	23	432	58
Lawyer	28	4	76	10	122	17	511	69
Other	68	28	14	6	16	7	145	59

^a All data were not available for all respondents.

Table 4Current needs of 746 respondents with a sibling with schizophrenia^a

Rank and strategy	Very important		Somewhat important		Not important	
	N	%	N	%	N	%
1. Services for ill sibling	578	79	114	16	43	6
2. Open communication in family	544	74	143	20	48	7
3. Emotional support from loved ones	471	64	187	25	80	11
4. Information about my sibling's illness	450	61	217	29	73	10
5. Relationships and activities outside the family	446	61	188	26	100	14
6. Coping skills for sibling's illness	404	55	243	33	89	12
7. Working through my reactions to sibling's illness	280	38	247	34	210	29
8. Involvement in treatment	251	34	316	43	167	23
9. Stress management	230	31	264	36	242	33
10. Counseling for self	168	23	209	28	361	49
11. Genetic counseling	127	17	189	26	417	57

^a All data were not available for all respondents.

more important than specific services for themselves. The ill siblings had a difficult time in the community. They had been ill an average of 19.4±10.6 years. Most had a history of multiple hospitalizations, about one-third had a history of substance abuse, and one-fourth had been homeless. These are all factors that significantly increased stress for siblings in this study (13). Community services are becoming

increasingly scarce, as indicated by greater numbers who are homeless and imprisoned (16). Lack of direct services has serious consequences for the ill person and the sibling. According to a sibling who has a 41-year-old sister with schizophrenia: "My ultimate concern is for my sibling who will die from poor living conditions, which are directly related to her illness. . . . I've been waiting almost two

years for her name to reach the top of a housing list. They tell me it will be about one more year! . . . If the illness were treated properly, the effect on the sibling would diminish."

Siblings identified symptom control for the ill siblings as one of the most helpful coping strategies as well as a top-ranked service. In previous work we found that siblings who reported more disturbing be-

Table 5Ranked order of importance of mental health services among 746 respondents with a sibling with schizophrenia^a

Rank and service	Category	Importance to well sibling							
		Very		Moderate		Mildly		Not important	
		N	%	N	%	N	%	N	%
1. Available to answer questions ^b	Information	506	69	135	19	50	7	40	6
2. Long-term care planning assistance ^b	Direct services	493	68	140	19	37	5	54	8
3. Monitor symptoms and medications ^b	Direct services	492	68	141	19	42	6	52	7
4. Education about schizophrenia	Information	453	62	166	23	53	7	54	7
5. Avoid blaming family ^b	Information	447	62	65	9	62	9	143	20
6. Alternative living arrangements	Direct services	444	62	100	14	58	8	116	16
7. Support for family during acute episodes ^b	Support	440	61	128	18	67	9	90	12
8. Coordinate community resources	Direct services	387	54	164	23	85	12	85	12
9. Help during suicide threats or attempts	Direct services	368	53	77	11	59	8	196	28
10. Vocational and physical rehabilitation sources	Direct services	376	52	164	23	82	11	95	13
11. Clarify well sibling's role in future care ^b	Information	371	51	162	22	87	12	103	14
12. Teach communication with ill sibling ^b	Information	368	51	146	20	92	13	116	16
13. Assistance with disruptive behavior	Direct services	343	48	156	22	84	12	137	19
14. Identify support groups for families	Support	325	45	167	23	107	15	125	17
15. Facilitate financial assistance	Direct services	322	45	147	20	98	14	153	21
16. Individual and family counseling	Support	298	41	177	24	118	16	135	19
17. Assistance with abusive behavior ^b	Direct services	291	41	120	17	100	14	198	28
18. Involve well sibling in treatment planning	Support	271	37	172	24	145	20	136	19
19. Identify temporary caregivers	Information	198	28	112	16	100	14	310	43

^a All data were not available for all respondents.^b Added by sibling suggestion during pilot study

havior of their ill relative had significantly more stress in multiple aspects of their lives (17). Symptoms and behaviors that were the most stressful for siblings included psychotic symptoms, noncompliance, and verbal aggression. These findings support Pearlin's (11) conceptualization of the importance and impact of primary stressors in his model that include illness symptoms that trigger multiple stress reactions. These findings also lend support to research in which the ill person's psychiatric symptoms and behavioral problems have been consistently observed to be strong predictors of family burden (18,19).

Nearly all of the siblings wanted service providers to assist with long-term planning for the ill sibling and clarify their role in future care. One of the greatest sources of stress for 612 siblings (82%) was "concern about who will take care of the ill sibling when parents no longer can." At the time of the study, respondents provided emotional and social support and helped with crises, but few coordinated the total care (20). About one in five ill siblings were living with aging parents, and in one-third of the families one or both parents were deceased. Future caregiving for persons with mental illness is emerging as a social problem for which few are prepared (21). Although siblings are considered the logical replacements for aging parents, it is unclear what their roles will be or how this will impact their lives (22). Hatfield and Lefley (23) reported that siblings were more likely to provide social and emotional support than the instrumental support offered by parents. Siblings are in a dilemma: spending time with ill siblings and living with them in the past has significantly increased their stress (13); however, having little to do with the ill sibling was the least helpful of all coping strategies. These findings underscore the importance of assisting siblings in the development of strategies that will maintain relationships with ill siblings and decrease stress.

Information about the sibling's illness and availability of providers to answer questions were top service

needs. Although clinical guidelines for the treatment of patients with schizophrenia recommend that providers share information with families and involve them in treatment, research indicates that collaboration is not part of routine clinical practice (24). Over the years, siblings have been left out of the treatment process and lack the knowledge and skills needed to manage the illness situation (8). A sibling wrote, "The worst problem our family has had, and repeatedly, is that during hospitalization (dozen or more) the doctors cannot share information about treatment with the family. My brother is considered an independent adult with privacy rights, even though he is dependent on family and community for support. We are neglected at this crucial time."

Understanding that no one in the family is to blame for causing schizophrenia was the most helpful coping strategy of all. In the past, about one-fourth of these siblings felt guilty because professionals blamed the family for the illness (20). Torrey (16) emphasized the importance of a no-blame strategy: "Developing the right attitude is the single most important thing an individual or family can do to survive schizophrenia. The right attitude evolves naturally once there is resolution of the twin monsters of schizophrenia—blame and shame." Accepting the illness is an important ingredient of the right attitude and was acknowledged as being very helpful to siblings in this study as well as earlier studies (7). Reading literature about schizophrenia helped put the illness in perspective and was also a top-ranked coping strategy.

It is no surprise that social support was a highly ranked coping strategy. Solomon and Draine (25) noted that social support was the strongest factor in their study in explaining adaptive coping among family members of persons with mental illness. Although their study found that friends and coworkers were helpful, the most helpful of all were family members and others outside their family who also had an ill relative. On the other hand, very few siblings found service providers to be help-

ful. Siblings with a diagnosed mental illness or substance abuse problems may be in need of more extensive counseling support from providers and referrals to support groups, such as Alcoholics Anonymous. When either of these problems was present, siblings experienced more stress in every measured aspect of their lives (13). Outside of the formal system of care, many siblings found support groups (NAMI) and religious groups to be valuable sources of support.

These findings cannot be generalized because NAMI was the main recruitment source, respondents were primarily college-educated siblings, and almost all respondents were Caucasian. However, these siblings can be considered "best case" examples of the needs of siblings and potential future caregivers.

Conclusions

Before development of the FLIIS, there were no comprehensive measures to assess the breadth and depth of coping strategies and mental health services helpful to siblings of persons with schizophrenia. These quantitative measures allowed siblings to prioritize needs and services, and the large sample strengthened the reliability of the findings. Siblings identified services for the ill family member, including symptom control, adequate housing, and long-term planning, as more important than specific services for themselves. However, in the future, siblings will be faced with the responsibility of being the primary caregiver. This role, combined with dwindling community services, will increase stress for siblings.

The challenge is clear—providers must advocate for adequate services for the ill person, include siblings in long-term planning, and help educate siblings about the illness. Additionally, providers should encourage siblings to seek social support from family, friends, and organizations such as NAMI or religious groups. Decreased stress can not only increase quality of life for siblings of persons with schizophrenia but also help siblings be better prepared to manage the demands of the illness.

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