How Siblings of Those with Severe Mental Illness Perceive Services and Support

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This study examines the complex and varied effects associated with having a brother or sister with a severe and persistent mental illness (SPMI) on the lives of adult siblings without chronic disability. Through five focus group interviews, 19 participants were asked to describe the impact that having a brother or sister with mental illness had on their lives. Codes and categories derived from the text of the transcribed interviews were grouped into broad themes. The respondents described the manifestations and challenges of contending with the SPMI of an adult sibling. They focused on gaps in services and communication with mental health providers, particularly with regard to timing of interventions and identifying readiness for treatment, as well as their own mental health needs. The article concludes with a discussion of the increased need for exchange of information and clarity of communication among family members and providers, following best practice guidelines that are well documented but not well implemented. (Journal of Psychiatric Practice 2002;8:354–364)

KEY WORDS: sibling caregivers, severe mental illness, consumer behaviors, family issues, family support

Much of the existing research on family response to severe and persistent mental illness (SPMI) has addressed the emotional responses and efforts at coping associated with the mental illness of an adult son or daughter.1–3 This literature is extensive and documents the intense and cumulative stress and burden that parent caregivers experience in trying to gather accurate information, obtain resources, monitor and advocate for care, and contend with the crises and symptomatic behavior of the loved one, while simultaneously mustering the resiliency to continue with their own lives.2, 4 Less attention has been focused on the impact of the SPMI of a brother or sister on well adult siblings. Available literature suggests that well siblings who assume caregiving responsibilities contend with burdens and stressors that are similar to those parent caregivers face, particularly regarding the impact on self and family and the effort to maintain equilibrium in the face of limited resources and competing responsibilities.5–11 These responsibilities are affected by personal and family dynamics and by the nature of the sibling relationship, including attachment, reciprocity, and ambivalence.5, 7 They vary in intensity throughout the life course and in response to changes in the illness and the availability of both formal and informal supports.5, 6, 8–11 Efforts to provide care and obtain services for an ill sibling are further complicated because societal norms regarding the line of obligation between siblings, as compared with parent caregivers, are ambiguous.12, 13 This ambiguity may interfere with the willingness of mental health providers to communicate directly with sibling caregivers.

As estimated 60%–75% of persons with SPMI reside with family, and up to 90% remain in close contact with family members at any given point in time.2 Families


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serve as the primary providers of community care and support for these individuals, and during periods when formal services are limited or nonexistent, they may provide the sole support. Co-resident status may contribute to the caregiving dynamic as well. Not surprisingly, when parents live with and supervise an adult child with illness, their level of experienced burden rises. However, this finding has not been replicated for siblings, who are less likely to share housing with the affected individual.

The extent of sibling involvement in this informal caregiving system has not been fully documented; however, it may be assumed that some siblings will eventually provide care and oversight to the family member with SPMI as parents age and die. Available research suggests that some siblings will be consistently involved over time, others will step forward during periods of crisis, while still others will withdraw altogether.

The literature is relatively sparse concerning sibling caregivers’ impressions of the dynamics and responsibilities involved in their relationships with their ill siblings. Findings from three qualitative studies indicated that involved siblings tended to feel patronized or marginalized in their interactions with professionals, or that information was simply withheld, purportedly for reasons of confidentiality. Some respondents described receiving mixed messages from professionals, which they described as a combination of subtle blaming combined with assurances that the mental illness was biologically determined. Sibling respondents also described being excluded from care planning and treatment efforts, on one hand, while at the same time, receiving direct requests for crisis placement and financial assistance, on the other.

Current best practices for persons with SPMI and their families clearly validate the importance of providing support and education to family caregivers, and evidence has been explicitly documented supporting the positive outcomes of such interventions for both the person who is ill and his or her family. Parental response to and demand for adequate services are well documented both in the professional and advocacy-based literature. However, such services have historically been limited or nonexistent and the availability of such services continues to be inadequate. An important step in developing and implementing a range of preventive strategies and proactive interventions for SPMI is to cultivate rather than alienate family resources and to identify and support both the unique and shared needs and contributions of different groups of caregivers and potential caregivers, including siblings as well as parents. To this end, it is critical to gain a more substantive understanding of how people are uniquely affected by having a brother or sister with SPMI, how they cope with the day-to-day efforts to support and monitor the needs of the affected sibling, and how they experience encounters with mental health professionals.

The goal of the research presented here was to use focus group methodology to obtain rich and detailed descriptions of both the barriers and supports available to involved sibling caregivers in different aspects of their lives to assist, monitor, and obtain services for a brother or sister with SPMI. In this article, we report on a series of five focus groups conducted with adult well siblings in late 1999 and early 2000. These focus groups were part of a multi-method study designed to describe the impact of illness on the lives of well siblings using both qualitative (i.e. focus groups and individual in-depth interviews) and quantitative (i.e. survey) methods, and are reported separately (see article by Lohrer et al., p. 365). The findings highlight the perspectives of the 19 focus group respondents as they reflected on their efforts, both in the present and over time, to grapple with the SPMI of their adult brothers or sisters, to obtain mental health services for their siblings, and to care for themselves. The participants were asked to consider both the positive and negative aspects of their experience as a means of trying to understand the demands, range of feeling, and unique concerns associated with this particular caregiving role.

**METHODS**

Focus group methodology was used to gather narrative information directly through open discussions among a group of adults who had shared the experience of a sibling’s mental illness and could corroborate or challenge each other’s perspectives. This approach gives participants the opportunity to contribute actively to the research process by allowing them to voice and develop ideas and thoughts in an open yet contained and safe environment, without the constraint of *a priori* or standardized measures. The focus group setting encourages interaction and discussion among participants and allows people to reflect together on the breadth and depth of their experiences and perceptions of a common set of circumstances, to respond to, support, or challenge the assumptions of others, and to extend understanding and clarity through exchange and documentation of ideas. Participants are given the opportunity to discuss a topic that they may shy away from in their day-
to-day lives, because of stigma, marginalization, or simply the lack of opportunity to discuss it.26

Sample
A convenience sample was identified, primarily through snowball sampling techniques.30 Mental health professionals were asked to distribute study brochures to eligible persons, and volunteers in turn distributed brochures to persons they knew. Information on the study was also introduced at local family support meetings and in local newspapers and advocacy newsletters. Nineteen individuals—16 women and 3 men—participated in the five focus groups; 16 were white, 2 were African-American, and 1 was Asian American. Ages ranged from 25 to 74 years (mean = 43 years). Fifteen held college degrees; two were high school graduates, and two had less than a high school degree. All worked full-time, and 10 worked in health or mental health services. Incomes ranged from $15,000 to over $100,000, with 5 participants earning less than $50,000, 8 earning between $50,000 and $75,000, and 6 earning over $75,000. Eight were members of family support groups, such as the National Alliance for the Mentally Ill (NAMI). Ten were primary caregivers for the sibling, 8 shared responsibility with a parent, and 1 shared responsibility with another sibling. None lived with the affected sibling. Of the siblings with mental illness, 5 were female and 14 were male. Their reported diagnoses included schizophrenia/schizoaffective disorder (13), bipolar disorder (4), and major depression (2). The duration of illness ranged from less than 5 years to over 40 years.

The characteristics and dynamics of the five focus groups differed somewhat. All were relatively small, and one group included only 2 people. We proceeded with this interview because the volunteers were eager and wished to continue. Three of the groups included only women. Except for two participants in one group, who were known to each other through their work situation, all of the participants were strangers.

Data Collection
Each focus group lasted approximately 2 hours and included 2–6 participants; each respondent participated in only one focus group. Following an approved Institutional Review Board protocol, all participants provided informed consent for participation and audiotaping and completed a brief demographic questionnaire. Each session was audiotaped. The participants were paid $10 in appreciation for their time and to cover transportation. After introductions and a review of study goals and confidentiality procedures, participants were asked to reflect briefly on the following question, using paper and pencil: “Describe how having a brother or sister with mental illness has affected different aspects of your life, either positively or negatively.” This question was used simply as a starting point for the group interviews and as a means of grounding the discussion.

The authors facilitated the groups, interjecting comments primarily to encourage participation and to maintain clarity and focus.31 At the end of each group, the facilitators reviewed and summarized the key points covered in the discussion. The participants uniformly expressed appreciation for the opportunity to share experiences.

Data Analysis
The audiotapes were transcribed verbatim, and segments checked at random against the tapes to ensure accuracy. Following procedures for grounded theory analysis,32, 33 content was examined inductively, using an iterative process of generating codes, grouping these into code clusters, and then reassessing and refining these using a system of constant comparison.32 The analysis was conducted in two stages, first using pencil and paper and then the computer program ATLAS-ti 4.0.34 The authors and a doctoral assistant independently coded each transcript by hand, tagging and coding sentences, sentence fragments, exchanges among participants, and the evolution of patterns and relationships among ideas. Discrepancies were reconciled through ongoing discussions among the authors. Transcripts and codes were then entered into ATLAS to further examine relationships and patterns and to organize code clusters according to overarching themes.35, 36

RESULTS
As the participants talked, their reflections ranged from the complex emotional impact on themselves and their families to the demands required to address the needs of the brother or sister with illness. The findings reported in this article are grouped into the following four types of issues:

- Reactions to the illness and the behaviors associated with it
Strategies for coping and attempts to intervene

Efforts to obtain services and contend with the “system”

Efforts to help themselves through support and advocacy groups.

Reactions to the Illness and the Behaviors Associated with It

As the respondents described their siblings, they zeroed in on aspects of the illness they found challenging. In all of the groups, the respondents specifically commented on the daily manifestations of mental illness that interfered with normal functioning. Some of these behaviors were described as manipulative, others as enraging or mystifying. As the following excerpts from the discussion indicate, the participants reported feeling particular frustration and anguish when they thought their siblings needed help, but the siblings easily convinced professionals otherwise:

It stuns me how my sister can dupe so many people—psychiatrists, therapists, social workers. She comes out of the doctor’s office and she’s like “Whew, I think I did a good job there, they don’t think I’m sick enough to be committed.”

I know the drill—emergency room, papers get filled out, they bring down the assessment team, they get the two consents [referring to consents from two physicians required to legally hospitalize a patient in some states], they check him in. The next day he gets a grip—he is very, very talented—and he signs himself out. When he doesn’t want care, he doesn’t want care. And then when you try to talk to the doctors about it, they are very resistant because he is an adult.

Their siblings’ seemingly uncanny ability to pull it together and manipulate a situation also affected the caregivers directly:

It’s scary to have a conversation with him sometimes. He is so good at it that, by the time he finishes, I feel like I am the sick person.

Another woman recalled a long period when both parents were ill and dying: What would always happen was that, whenever my mother or my father was gravely ill, my sister would slit her wrists or take three bottles of pills or do whatever and end up in the hospital too.

Several specific behaviors worried the respondents, specifically those that interfered with normal functioning and health. A sibling whose brother had become severely ill and debilitated in his 20s said sadly, He is very afraid. He just cannot do these day-to-day things.

Others zeroed in on bizarre behavior, a slovenly life style, and poor physical health:

Strategies for Coping and Attempts to Intervene

Participants in all of the groups described attempts to grapple with the elusive and very individual nature of mental illness in a manner that would be productive for their siblings. One sister observed, This is not like heart disease or something. I don’t find any two people that are the same with mental illness, even if they have the same diagnosis. And another participant responded, Yes, their personality customizes the disease.

These personality quirks added to the siblings’ frustration. The participants repeatedly commented on the search for a “window of opportunity,” that elusive point when the affected sibling might consider treatment. This involved first trying to build even a precarious relationship with the ill sibling—wheedling, cajoling, trying to engage the person in any way possible:
I left notes under the door, a couple of bucks here and there, and then, finally got him to speak to me through the door. Now he's been initiating get togethers once a month. So I feel like I'm building some trust. But it's very hard to reason with him—and the progress is so slow.

One sister described an ever vigilant waiting game: If I hear an opening, I exploit it the best I can. I heard an opening 6 months ago. But now I am just waiting.

This situation was echoed by a brother, who said, My ears are always open in case there is an opening for me to start talking about the stuff [referring to the need for treatment]. But I don't expect it. It would be a pleasant surprise.

Efforts to intervene were further hampered by what appeared to be denial of illness or lack of insight on the part of the ill sibling, but which some siblings also interpreted as refusal to participate in treatment or simply boredom.

She doesn't like being around “crazy” people, as she calls them. She doesn't think she has an illness.

She's in a supportive housing unit and she's supposed to go to a day program. She goes in body, but she doesn't get anything out of it.

Deciding whether to intervene, given the opportunity, and how to do so also seemed difficult: It's hard to determine what is the illness and what is the person, what she has control over and what she doesn't. What should I get mad about and what should I just let slide? What's acceptable and what's not acceptable? How do I deal with this in a positive way and how do I encourage him slowly, not too fast?

Sometimes efforts to help seemed counterproductive or served at best as a holding pattern until a new crisis or set of symptoms erupted; yet the siblings worried about the outcome if they did not intervene: Each passing day counts. The further they get out there, the harder it is to pull them back and get them back on track.

One woman who, together with her parents, worked tirelessly to help her ill brother described their efforts: There's always got to be something new. If he's interested in one of these projects, he does well, he looks happy, he laughs, he talks on his own initiative, he's witty, and smiles, you know, like a normal person. So to keep that going is always a concern, is always a focus. We're the treatment program.

But she also acknowledged their ongoing struggles with self-doubt regarding their level of involvement, wondering “Are we doing the right thing? Are we hurting or helping?”

At times the respondents felt that not intervening was problematic as well: We believed we were respecting his judgment, but, in hindsight, we may have made the wrong decision by not stepping in.

Several people referred to the unwillingness of parents to set limits or create expectations for their ill sibling. In one group, this led to further discussion about the wish to confront denial and lassitude in the ill sibling: My parents are afraid to say, “Why aren't you getting up and going to the hospital, why are you calling six times a day?” Everyone just babies her—“you're doing great, you've made so many accomplishments”—but life has to be more than just feeling good about yourself. I mean, she's not reaching her goals, there is no progress. She suckers all these people into believing that she's doing her best and trying her hardest, but she's not.

Others felt they couldn't really change the situation: We don't confront him any longer. If we found out about a cure, we would have to give it to him secretly and I would be too afraid to do that because one of his delusions is that people are trying to poison him.

The participants' hopelessness and emotional exhaustion regarding such situations were palpable: It's like beating your head up against the wall... there's really nothing you can do. You've been at this now for all these years, but [at this point the respondent hit an empty cup against the table], it is what it is. You can work around it. You can't make it better, but you can be grateful for when things are kind of stable, you can do certain things to make his life pleasant, to make your life more pleasant.

Another women echoed these feelings: It would be nice to find out about a cure, but I've given up on that—I'm just trying to have him be happy.

The respondents expressed resignation, anger, and hopelessness as well as a sincere wish for improvement: I can't make her better. You feel like you can do something—but you can't. If I could have done it, it would have been done... There are random stories about people who are able to be successful, but it's like a needle in a haystack. The majority of people with schizophrenia just never get better.

Efforts to Obtain Services and Contend with the “System”

Individual participants in the different focus groups were able to identify positive interactions with the mental health system, but these were largely expressed in isolated comments. For example, a woman whose immediate family included several persons with mental illness and who had contended with symptomatic behaviors over many years, said simply: I was grateful
when the state started stepping in. Another remembered the pivotal point when she finally found a psychiatrist who would really listen to me. A woman who had worked in the public mental health system over many years observed: From the doctors I've met, I think they really care.

However, the more prominent and consistent message was frustration associated with efforts even to make contact with mental health professionals. Overwhelmingly, the participants described insensitivity, lack of interest, and even overt hostility on the part of providers.

Some respondents zeroed in on past comments that still angered and haunted them many years later.

A middle aged woman recalled with incredulity an early interaction with a social worker: With my mother sitting beside me, she said, “Give it up—he’s not worth it. Take care of yourself.” I’d love to this day to have that women fired.

Bitterly sobbing, a woman in her 50s recalled, His first psychiatrist actually advised us just to stick him in an apartment in low cost housing and let him fend for himself—which I can’t believe, because, even without the mental illness, he would not have been able to do that because of his developmental problems.

Another woman in the same group reflected on a provider’s seeming naiveté regarding her brother’s denial and unwillingness to take medication: I remember one doctor, who I think was pretty good, said “I don’t understand the problem—it’s just a pill, he just has to take a pill.”

Several respondents expressed a wish to be validated and listened to: Everybody—that whole system of psychiatrists, psychologists, social workers, case managers—just pushed me off; no one kept me up to speed, no one listened to me when I said “My brother’s medication is too low.” They just released him and that was it.

In all of the groups, the siblings described their evolving anger and aggressiveness as they became increasingly disillusioned with the mental health system. One respondent said, For my brother, I’m an aggressive, assertive person. I’m not afraid to pull any string I can. I’d bribe a doctor if I thought it would cure him, I’d do anything. Another said, Faxing to psychiatrists has become my favorite thing—how to get right to them, underlined and in bold, “danger to self and others.”

Even when the respondents had gone to great lengths to seek hospitalization for their siblings, the impact seemed temporary at best. One sibling noted they’ll take the medicine when they’re there. Another added then they get out [of the hospital] and they won’t.

In all of the focus groups, individuals fretted about the vagaries of confidentiality with regard to the family, the ambiguous nature of the sibling relationship from the perspective of the provider, and how this added to their own sense of impotence as they tried to intervene on behalf of a brother or sister:

The medical profession is all set up around “I am your sister’s doctor—I’m not your mother’s doctor, I’m not your father’s doctor, I’m not your doctor.”

There’s the legal issue. The Family Medical Leave Act doesn’t apply to siblings. There’s no recognition that they’re our dependents.

You can’t get information and you don’t know how to act. I understand concerns about confidentiality and civil liberties, but you’re kind of operating in a vacuum.

One of my problems with the service system is, I’m not a parent, they don’t want to hear from me because I’m not her parent… even though I am the primary person here.

The frustration regarding this lack of communication was palpable:

You have to be clever to get anything out of the medical system. I’ve learned how to do it, but it doesn’t just naturally happen.

The social worker won’t help you. The doctor won’t help you. You’re constantly researching to find the cure that doesn’t exist.

Another woman described how she tried to stay abreast of her brother’s symptoms: At one point, I made my brother go to a doctor, but of course the doctor wouldn’t talk to me. So I got another doctor to find out what was going on.

Efforts to Help Themselves Through Support and Advocacy Groups

About half of the participants had been involved with some form of self-help group, particularly the National Alliance for the Mentally Ill (NAMI). This connection was generally associated with a positive experience and served as an emotional refuge. One woman observed: I always tell people that I’m glad I got to meet them, I’m just sorry about what brought us together. Another said, I am right at ease because everybody knows exactly where I’m coming from.

The personal support and education provided by NAMI seemed to be a lifesaver, but was still not enough at times:

It’s therapy for me. It gives me information to help my sibling. Information for me is support. The more I know about the disease, the calmer I am, the better able to deal
with it, the better I feel, the more I really believe I can help him. Even though I joined NAMI, and I started really learning and finding materials and meeting people, there was still a lot of it I have had to learn all by myself. I feel like I have earned a couple of degrees learning what I needed to learn and figuring out how to go about it and how to attack the system when it fails miserably. Reflecting on her own comments, this woman expressed a wish simply to have her plight acknowledged. If there was some understanding in the support groups that to some extent you are powerless to help, that would be constructive.

Another commented on the importance of recognizing that sibling caregivers have unique needs that are different from the needs of parents: In the sibling group, I was just amazed and so happy that there were people out there like us, people who had this problem and were dealing with it in a different way, other than coming in to save the day... and it was okay to acknowledge that you can’t make a difference. The other group I was in was mostly parents, and so maybe there was an age thing, because parental guilt and the whole thing is so much different from the sibling thing, there’s this obsession with the ill person. The group I am in now is more about the sibling, what’s going with you, what’s helping in your life, “Yes, you can tell me for days how your sister is doing, but how are you?”

**DISCUSSION**

**Summary of Sibling Concerns**

Many of the observations of this group of sibling caregivers will seem familiar to those who provide services to parents of adults with SPMI. Nonetheless, the bewilderment, vulnerability, and rising anger that these individuals expressed regarding both their ill brothers or sisters and the provider community are a major concern. Their thoughts challenge us to reflect carefully on the extent and quality of services provided to family caregivers and on the particular needs of siblings. Consideration of sibling caregivers will become even more critical as parent caregivers age.

The respondents in this study expressed consistent concern about obtaining more and better services for their ill siblings. Their frustrations were palpable, particularly as they struggled to sort out the differences between illness behavior and manipulation on the part of their siblings and lack of services and sheer insensitivity on the part of the provider system. They were quick to point out how the uncanny ability of an ill sibling to talk his or her way out of an opportunity for hospitalization or other treatment had stymied their own efforts to arrange for care and contributed to deteriorating functioning. Overall, they reported having difficulty discovering or comprehending 1) where and how to effectively communicate concern about changes they observed in the behavior or compliance of their siblings, 2) what a reviewing physician would consider a legitimate need for hospitalization, 3) how to proceed when a sibling successfully eluded hospitalization or other seemingly needed treatment, and 4) how to proceed when hospitalization was terminated without a well-defined care or transition plan.

Consistent with findings from earlier studies, the participants also expressed confusion about the role of confidentiality in provider communications with family members, a confusion that was further heightened by their nonparental role. Their anger and frustration was further heightened by the seeming inability or unwillingness of mental health providers simply to listen and consider the perspective of them or their parents.

These combined factors contributed to the chronic and cumulative stress that the focus group participants experienced in regard to their siblings’ illnesses. In the face of these challenges, they were cognizant of how difficult it was to maintain a semblance of normalcy and independence in their own lives and social relationships, while both helping their parents and attending to the chronic, unpredictable, and often overwhelming needs of their ill siblings. Overall, their observations highlight the efforts of the sibling respondents to intervene thoughtfully, given the precarious mental status of a brother or sister with SPMI, their ever present wish for more information, and their particular need for validation, receptiveness, and support from providers.

**How Siblings’ Concerns Differ From Those of Parents**

As the participants talked about their experiences with the mental illness of a brother or sister, they expressed concerns unique to their role as adult siblings. Being one step removed from the intense attachment that characterizes a parent-child relationship allowed them to stand back and assess the strengths and limitations of the individual with illness in a manner that a parent might find difficult or impossible. As siblings, they brought their own perspective on the complexity of symptoms, behaviors, and needs that the affected siblings displayed. They were willing to talk not only about
the difficulties they had encountered, but also about how the sibling with illness had enriched their lives. They took pleasure in the small successes of their siblings and wished to capitalize on these whenever possible. They also spoke poignantly about their own needs for support and attention as they struggled to maintain equilibrium in their own lives. They expressed particular appreciation for support groups that attended to the particular needs and concerns of siblings, as opposed to those of parents or other caregivers.

Need for Enhanced Professional Services

Some of the more successful family-oriented programs nationwide are support and advocacy programs such as NAMI that receive at least some portion of their funding from state offices of mental health. About half of the respondents in the focus groups belonged to such groups and greatly appreciated the support, information, and platform for advocacy and growth provided by such groups of peers and parents who face a common set of challenges. However, they repeatedly cited the need for consistent, reliable, and accessible contact with mental health professionals for themselves and their families, to enhance and complement the information and support provided by family sponsored services. From their perspective, family provided services are key components of comprehensive or “seamless” care, but professional services are critically needed as well and continue to be seriously lacking for siblings and other family members.

The complexities of mental illness can create situations in which the needs of the patient consumer are at odds with the needs of the family. In such circumstances, siblings, parents, and other primary caregivers need accurate and readily accessible information from mental health gatekeepers. As our respondents noted, family members have essential knowledge about subtle changes in their relative’s symptoms, behavior, compliance, and other personal patterns. At times, selective sharing and withholding of information both on the part of family and professionals may impede and disrupt communication. However, when a culture of mutual respect is present in the treatment process, family caregivers and providers together can identify recurring triggers and stressors and work to anticipate and avoid some of inevitable hurdles that occur during the crises or transitions that our respondents have described among their siblings. By fostering such partnerships, clinicians can create a safe arena for gathering and imparting information and interpreting professional decision-making processes fine tuned to the unique needs of the consumer. This process in turn builds on the strengths and differential resources and knowledge of individual family members.

For policymakers, administrators, and clinicians alike, creating such partnerships requires a shift in attitude, structure, and policy, to ensure that the input of siblings and other family members is actively sought and valued and that professional family services are adequately funded and supported across system levels.

Recent efforts to develop manualized educational and psychoeducational interventions to extend, consolidate, and update information for both mental health and primary care providers are critical and positive developments, and have been cited as best practices for families. As these approaches are integrated successfully into practice and their impact is evaluated and documented, the paradigm shift from a more exclusively medical model to a more collaborative, inclusive, and strengths-based model of family care and outreach should become increasingly feasible. Dixon et al. refer to this as a top-down, bottom-up paradigm shift, where siblings and other family members are welcomed and valued in mental health settings by professional, paraprofessional, and support staff, across administrative levels. As Marsh and her colleagues have emphasized, and as the siblings in this study remind us, the involvement of even one open, warm, and involved professional or provider can serve as a critical support for family members, grounding the services provided and creating a sense of hope.

Strengths and Limitations of the Study

In reviewing the results of this study, several limitations must be considered. The sample size was small and selected. More than half were mental health or other types of healthcare providers themselves, and all appeared to be quite well informed regarding SPMI. All were actively involved in the care of the sibling with illness, so that the study does not represent the perspectives of uninvolved sibling caregivers. The size of the focus groups was uneven, with one group limited to a two-way discussion. Finally, the participants were relatively privileged and came predominantly from white middle or upper middle class backgrounds.

In spite of these shortcomings, the dialogue and discussions provide insight into the complexities and cumulative stress associated with coping with the chronic mental illness of a brother or sister both on a
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day-to-day basis and over time. The experiences of this educated, savvy, and assertive group of individuals are instructive and shed light on some of the gaps in mental health services as perceived by sibling family members. If this group of involved sibling caregivers had trouble obtaining information and services, those with fewer resources or who are outside the dominant culture would undoubtedly find the process significantly more difficult and frustrating.

CONCLUSION

The findings presented here help guide our thinking as we develop strategies for providing more effective services and outreach to mental health consumers and their family caregivers. They underscore the need for services that are attuned not only to the person with the illness, but that also provide education, outreach, and preventive strategies targeting each member of the family, including siblings, as well as the entire family unit.

To develop such strategies, longitudinal studies are needed to track the concerns and resiliency of sibling and other family caregivers from diverse backgrounds as they face the mental illness of family members at different stages along the life course. Additional qualitative studies that explore diversity in culture and life course will add information as well. Qualitative studies would also help to delineate predictable transitions and changes in the evolution of SPMI and in its impact on the immediate family.

We also need to further explore timing and processing of information for siblings and other family members as they first recognize and cope with mental illness in the family, and after they have faced the cumulative stress of ongoing illness. Better understanding of how these changes are reflected differentially in response patterns among siblings, parents, and consumers should inform practice and programming for enhanced care and prevention.

A key element in devising effective community and family education and psychoeducational services regarding mental illness is determining when and how to present information in a manageable format that can be integrated and applied by individuals from a range of sociodemographic backgrounds and with different levels of service need. Implementing such programs demands a highly effective system of checks and balances regarding consumer care, family needs and input, confidentiality, and points of access for siblings and other informal caregivers with the formal provider system. Finetuning such services to reach those who have been angered or overlooked by the mental health system must inevitably be guided by creative and concerted professional strategies and knowledge.

Siblings are astute observers of illness behavior and are privy to an intimate level of knowledge that will contribute to high quality care and improved outcomes for consumers. Yet, based on the observations recently collected from the individuals in this study, there is a continuing lack of connection between identified best practices and resources for the family. Mental health professionals must find better ways to build collaborative teams that include and represent siblings and other family caregivers. As one study respondent observed, I don’t understand why there’s still a problem about the family. When people with mental illness are ill, they really can’t take care of their own fate. They need somebody who has their best interests at heart to make those decisions. You need to have the family involved.

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**Selected Readings for Caregivers**


