Siblings of Adults With Schizophrenia: Expectations About Future Caregiving Roles

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Sibling expectations to provide future instrumental or emotional support for a brother or sister with schizophrenia when parents became disabled or died were examined. Data came from a sample of 137 siblings participating in a longitudinal study of aging families of adults with schizophrenia. Early socialization experiences, the quality of the sibling relationship, and personal caregiver gains propel siblings toward a future caregiving role, whereas geographic distance and beliefs about the controllability of psychiatric symptoms reduce expectations of future involvement.

Keywords: family caregiving, sibling relationships, schizophrenia, mental illness, caregiver gains

With the rise of deinstitutionalization in the 1960s, many persons with mental illness turned to their families for support because of the lack of adequate community-based services. Even today, with the presence of an array of community services, family members, in particular parents, are often required to step in to fill in the gaps in the service system. However, as parents age, their capacity to provide support diminishes and ultimately ends (Lefley, 1987). It is generally assumed that siblings will become the next generation of caregivers for adults with mental illness (Hatfield & Lefley, 2000; Horwitz, 1993; Wasow, 2000). However, little is known about the willingness of siblings to take on a future caregiving role or the factors that may propel or deter siblings from taking on this role in the future. In this study, we investigate two research questions: (1) To what extent do siblings expect to be involved in future caregiving tasks for a brother or sister with schizophrenia? (2) What factors influence sibling expectations for assuming a future caregiving role for a brother or sister?

This study extends our prior work on the role of siblings as future caregivers for adults with mental illness in three important ways. First, in our earlier work, the outcome was limited to whether or not siblings expect to take on a caregiving role as a product of the brother or sister with schizophrenia when parents became disabled or died were examined. Data came from a sample of 137 siblings participating in a longitudinal study of aging families of adults with schizophrenia. Early socialization experiences, the quality of the sibling relationship, and personal caregiver gains propel siblings toward a future caregiving role, whereas geographic distance and beliefs about the controllability of psychiatric symptoms reduce expectations of future involvement.

Second, we gathered data on a much richer array of factors that may influence the extent to which siblings expect to provide instrumental and emotional support to their brother or sister with mental illness when their parents are no longer able to assume a caregiving role. Third, whereas our earlier study focused on siblings of persons who had a broad range of serious mental illnesses (e.g., depression, bipolar disorder, and schizophrenia), in this study we narrowed our focus to one diagnostic group, those siblings of adults with schizophrenia. We limited our study to families of individuals with schizophrenia because of very high costs associated with the treatment of this disorder (U.S. Department of Health and Human Services, 1999). Indeed, the future public costs of care for persons with schizophrenia very much depend on the willingness of siblings of adults with schizophrenia to take on a caregiving role.

We have conceptualized the processes influencing whether or not siblings expect to take on a caregiving role as a product of various factors that either push siblings toward greater involvement or pull them away (Greenberg, Seltzer, Ormond, & Krauss, 1999). One set of push factors arises from differences in childhood socialization experiences, based on the sibling’s gender, the timing of the brother or sister’s diagnosis in the sibling’s own life course, and family values about caregiving. Regarding gender, Chodorow (1978) has argued that women are socialized at an early age to take on a caregiving role. Regarding timing, siblings of persons with schizophrenia vary greatly as to the timing in their own lives when their brother or sister’s illness first occurs. Some siblings were adults and living independently when their brother or sister became ill, whereas other siblings were children or adolescents at that time. Those who were still living in the parental home when the brother or sister was first diagnosed may be socialized to take on heavier family caregiving responsibilities than those who were adults and living elsewhere at the time of diagnosis (Marsh & Dickens, 1997). Finally, sibling involvement may be sustained by family values that emphasize responsibility or duty to the family
across the generations and over time (Horwitz, 1994; Jewell, 1999).

Another set of factors that may push the siblings toward the
caregiving role is the nature of the present relationship with the
sibling with schizophrenia. Several researchers have found that
siblings of adults with mental illness are more likely to be cur-
rently involved or more willing to be involved in the future when
they have a good quality of relationship with their brother or sister
(Greenberg et al., 1999; Horwitz, 1993; Horwitz, Tessler, Fisher,
& Gamache, 1992; Jewell & Stein, 2002), and when the sibling
relationship is characterized by reciprocity, with each sibling on
the giving and receiving end of exchanges of support (Horwitz,
1994; Horwitz, Reinhard, & Howell-White, 1996; Jewell & Stein,
2002).

Finally, there is a growing body of research indicating that in
facing the challenges of mental illness, the lives of many family
members are transformed in positive ways through the experience
(Dixon, 1997; Lukens, Thorning, & Lohr, 2004). In a study of
resiliency in families of persons with mental illness, Marsh and her
colleagues (1996) found that almost all (87.8%) of the 131 family
members sampled could describe one or more personal strengths
that they had developed as a result of coping with the challenges
of mental illness. These strengths took many forms, including
enhanced coping skills, a strengthening of family bonds, increased
personal competence, and a greater appreciation of the sibling’s
own life and well-being. Similarly, Greenberg, Seltzer, and Judge
(2000), in a study of 107 aging mothers living with an adult son or
daughter with mental illness, reported that many family members
could identify ways that their lives had been positively trans-
formed in the process of coping with mental illness, for example,
by becoming more sensitive to persons with disabilities, develop-
ing a greater appreciation of one’s inner strengths, making new
friends, and strengthening family bonds. We predict that such
gains would be reinforcing and strengthen expectations or inten-
tions for continuing involvement in the future.

Considerably less is known about the factors that may pull
siblings away from assuming a caregiving role in the future. One
pull factor that might limit sibling involvement is the severity of
the sibling’s illness. Understandably, siblings may be reluctant to
take on a future caregiving role when their brother or sister has a
high level of behavior problems. An additional factor that might
limit sibling involvement is the sibling’s view of the etiology of his
or her brother or sister’s mental illness. Greenley (1986) has
argued that in our society, individuals who are appraised as having
control over their behavior or illness are viewed as not deserving
of help. We would expect that siblings are less likely to assume a
future caregiving role if they perceive their brother or sister as
having control over his or her symptoms. A third set of pull factors
may arise because of various aspects of the sibling’s life that
would make involvement more difficult. These include competing
work/family demands, health problems, and geographic distance
from the home of the sibling with schizophrenia. Hatfield and
Lefley (2005) reported that approximately 60% of the siblings
surveyed mentioned that family demands and geographic distance
would make it difficult for them to be involved in the future care
of their brother or sister with mental illness.

Based on prior research and our conceptualization of push and
pull factors, we hypothesized that push factors, including gender,
the timing of the illness in the sibling’s life, a strong sense of
family duty, the quality of the relationship, reciprocity, and gains,
will be related to the expectation of greater future involvement,
and pull factors, including the adult’s behavior problems, the
sibling’s appraisal that his or her brother has control over his or her
symptoms, and personal and situational constraints, will be related
to the expectation of less future involvement.

We recognize that predicting individual expectations and behav-
iors is a very complex process. There is a very large literature
suggesting many other factors such as perceptions of control and
self-efficacy, moral obligations, and personal habits influence in-
dividual expectations and behaviors (e.g., Ajzen, 1991; Bandura,
1982; Eagly & Chaiken, 1993). However, we focused in this study
on a more limited set of factors predicting sibling expectations
because prior research suggests these are the most salient factors in
shaping the expectations of siblings about their future involvement
as caregivers to their siblings with mental illness (Greenberg et al.,
1999; Hatfield & Lefley, 2005).

Method

Sample

The data for this analysis comes from a longitudinal study of
aging families of adults with schizophrenia in Wisconsin. Families
met two criteria when initially recruited: the mother was age 55 or
older and the adult had a diagnosis of schizophrenia or schizoaf-
fective disorder. The majority of participants were recruited with
the assistance of the state or county agencies responsible for
providing services to persons with mental illness. All sample
members were volunteers. At the first wave of data collection, 301
mothers participated in an in-home interview and completed a set
of self-administered standardized measures. By the third wave of
the study, 17 mothers had died or became too ill to participate, 17
adult children with schizophrenia had died, 11 mothers refused to
participate, and we were unable to locate an additional 8 mothers,
reducing the sample to 248 mothers. In 7 of the 17 cases in which
the mother had died or become too ill to participate, the father or
a sibling had assumed a primary caregiving role and was asked to
participate as the primary respondent in the study. One father and
two siblings agreed to participate.

At the end of the third in-home interview, the 248 mothers and
1 father were asked to identify which of their other adult children
would be “most involved” in helping their son or daughter with
schizophrenia when the parent became disabled or died. Of the 249
parents approached, in 7 cases the adult with schizophrenia was the
only child, in 4 cases the “most involved” sibling also had schizo-
phrenia and was not eligible for the sibling study. Of the remaining
238 parents, 28 indicated that none of their other adult children
would be involved. For the 210 parents who indicated a sibling
would be involved, we described the sibling study and asked their
permission to contact the most involved (or only other) sibling to
request his or her permission to participate in a mail survey. One
hundred ninety-one parents gave us permission to contact the most
involved (or only other) sibling to participate. Of the remaining
hundred ninety-one parents, 30 had missing data on key variables and were removed from the analysis.
To examine nonresponse bias, we first examined if mothers who agreed to sibling contact differed on demographic variables from mothers who refused sibling contact. There were no significant differences in maternal age, education level, marital status, number of children, and whether the son or daughter with schizophrenia lived at home. Second, we compared the characteristics of siblings who refused to participate with those siblings who took part in the study, based on data from the mother’s interview. The two groups of siblings did not differ in age, gender, the likelihood of having a disability, or the amount of contact and level of closeness they shared with their brother or sister with schizophrenia. It was only in respect to marital status that the two groups differed. Siblings who participated were more likely to be married compared to siblings who refused to participate (75.2% vs. 55.6%, \( p < .05 \)).

As shown in Table 1, siblings who participated in the study had a mean age of 44.5 years. Over 50% were female and about 75% were married. Over half of the siblings graduated from college and more than 66% were employed full-time. The mean income for the siblings was about $47,500. Two-thirds of the siblings reported that they were in very good or excellent health.

The brothers and sisters with schizophrenia of these sibling respondents average 43.6 years of age, and 26.3% were female. Although 89.1% had graduated from high school, only 16.1% had gone on to graduate from college. Approximately 24.8% were working in competitive jobs, and the majority (73.5%) received services from community support programs.

**Measures**

Because individuals with schizophrenia require both instrumental assistance with daily living tasks and emotional support, we constructed two variables to capture these distinct dimensions of future involvement. Based on the objective burden scales developed by Tessler and Gamache (1994), siblings were asked to indicate on a four-point scale from 3 (definitely not) to 0 (definitely not) the likelihood that they would provide support to their brother or sister by listening to his or her problems and providing advice, inviting him/her to family celebrations and holidays, visiting regularly, including him/her in social events, and going out together to a movie or restaurant. These five items were summed to create an indicator of the amount of emotional support the sibling expected or intended to provide in the future (\( \alpha = .82 \)).

Three push factors (socialization experiences, nature of the current sibling relationship, and caregiving gains) and three pull factors (i.e., behavior problems, control attributions, and personal and situational constraints) were investigated as predictors of future instrumental and emotional support. Indicators of socialization experience included the sibling’s gender, a sense of family responsibility, and the timing of the mental illness in the life course of the sibling. Gender was coded as a dichotomous variable (0 = male, 1 = female). Family responsibility was operationalized by a single item asking respondents to indicate on a 5-point scale from 1 (strongly disagree) to 5 (strongly agree) the extent to which they agreed with the statement "I feel like it is my family duty to be involved with my brother/sister" (Jewell, 1999). The timing of the onset of the brother or sister’s mental health problems in the life of the sibling respondent was measured by a single item that asked respondents whether or not their brother or sister had mental health problems while they were growing up (0 = no, 1 = yes).

A second set of push factors were indicators of the nature of the current sibling relationship. The Positive Affect Index (Bengtson & Schrader, 1982) is a 10-item self-report measure used to evaluate the quality of the sibling relationship. The first five items assess how much the respondent has feelings of trust, intimacy, understanding, fairness, and respect toward the sibling with schizophrenia. The second five items rate the respondent’s perception of how much the brother or sister with schizophrenia has feelings of trust, intimacy, understanding, fairness, and respect for the respondent. Each item was rated on a 6-point scale ranging from 1 (not at all) to 6 (extremely) and summed to derive a total score. Bengtson and Schrader (1982) substantiated the construct validity of this measure in their original study (\( \alpha = .92 \)).

Another indicator of the current sibling relationship was the degree of reciprocity, which was calculated from the sibling’s responses to two sets of items. The first set asked the sibling to report how much (0 = none to 3 = a lot) help he or she provides currently to his or her sibling with schizophrenia in each of the following eight areas: household tasks, preparing meals, getting places, managing money, shopping, providing advice, companionship, and assistance during an illness. The sibling also was asked to indicate whether he or she received help from their sibling in these same eight areas. The degree of reciprocity was the sum of the number of areas in which the sibling respondent indicated he or she both provided to and received help from his or her brother/sister with schizophrenia at the current time.

The third set of push factors concerned the sense of gain and growth that the sibling might derive from coping with the challenges of mental illness. Pearlin, Mullan, Semple, and Skaff's

<table>
<thead>
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<th>Table 1</th>
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<td><strong>Background Characteristics of Sibling Respondents</strong></td>
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<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Siblings (( n = 137 ))</th>
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<tbody>
<tr>
<td>Age (mean years)</td>
<td>44.5</td>
</tr>
<tr>
<td>Gender (female)</td>
<td>56.2%</td>
</tr>
<tr>
<td>Marital status (married)</td>
<td>75.2%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>2.9%</td>
</tr>
<tr>
<td>High school graduate</td>
<td>16.8%</td>
</tr>
<tr>
<td>Some college</td>
<td>27.8%</td>
</tr>
<tr>
<td>College graduate</td>
<td>52.5%</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
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<tr>
<td>Full-time</td>
<td>66.4%</td>
</tr>
<tr>
<td>Mean annual income</td>
<td>$47,399</td>
</tr>
<tr>
<td>Self-reported health</td>
<td></td>
</tr>
<tr>
<td>Very good/excellent</td>
<td>63.5%</td>
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(1990) Personal Gains Scale, developed for a study of caregivers of adults with Alzheimer’s disease, was adapted for this study. The Personal Gains Scale consists of 10 statements identifying different benefits that family members might develop in the course of coping with a family member’s major illness (e.g., becoming more aware of one’s inner strengths, becoming closer to one’s family, and becoming more self-confident). For each item, siblings indicated on a four point scale, ranging from 0 (not at all) to 3 (very much), how much they had experienced this positive change as a result of coping with the challenges of their brother/sister’s mental illness. A total personal gains score was calculated by summing the responses to the 10 items (α = 94).

With respect to pull factors, the frequency of behavior problems was measured by a modified version of the Inventory for Client and Agency Planning (Bruininks, Hill, Weatherman, & Woodcock, 1986), later known as the Scales of Independent Behavior—Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996). The primary respondent in the study (typically the mother) rated the frequency (0 = not at all to 3 = a great deal) of eight behavior problems in the adult with schizophrenia: hurtful to oneself, unusual or repetitive behaviors, withdrawn or inattentive, behavior that is hurtful to others, destructive to property, disruptive, socially offensive behavior, and uncooperative behavior. A total score was calculated by summing the responses to the eight items (α = .71).

A second pull factor, the respondent’s belief about the amount of control the individual with schizophrenia had over his or her symptoms, was operationalized by the Control Attribution Scale (Greenley, 1986; Greenley, McKee, Stein, & Griffin-Francell, 1989). Respondents indicated their level of agreement (0 = strongly disagree to 3 = strongly agree) with each of five statements about the ability of their sibling with schizophrenia to control their symptoms. Sample items included “My brother/sister can make his or her strange thoughts and feels come and go at will,” and “My brother/sister could control most of his or her difficult behavior if he or she really wanted to” (α = .81).

The third pull factor was personal and situational constraints in the sibling’s life that might limit their future involvement with their brother or sister. Siblings rated on a four-point scale from 0 (not at all) to 4 (a great deal) the extent to which the following four factors would limit their future involvement: heavy work/school responsibilities, family demands, personal health problems, and health problems of other family members. The two items on work/school and family responsibilities were summed to derive an indicator of competing family/work demands. The two items on health problems were also summed to derive an indicator of health problems. A third situational factor, geographic distance from the home of the brother or sister with schizophrenia, was coded “1” if the sibling lived more than a half day drive from the home of his or her brother or sister with schizophrenia and “0” otherwise.

Finally, we included two control variables: the sibling’s age was coded in years and the sibling’s marital status was coded as 1 (currently married) or 0 (otherwise). A correlation matrix of the dependent and independent variables is given in Table 2.

Results

Our first research question examined the extent to which siblings of adults with schizophrenia expected to take on a future...
caring role. Table 3 shows the percentage of siblings who expected to help their brother or sister with schizophrenia with six aspects of instrumental support and five aspects of emotional support. As shown in Table 3, more than three fourths of the siblings reported that they “probably” or “definitely” expected to assist their sibling in the future if he or she became physically ill and approximately two thirds expected to help their brother or sister manage his or her money. A smaller but still substantial percent of siblings expected to assist their brother or sister with instrumental tasks that require a high level of contact, such as providing transportation, keeping appointments, helping with household chores, and monitoring medications (all over 40%).

Siblings were even more likely to expect to provide emotional support to their brother or sister with schizophrenia. Almost all the sibling respondents expected that they would “probably” or “definitely” listen to their siblings and provide advice, include the sibling in family holiday celebrations, and visit their sibling regularly (all over 85%). Over three fourths of the siblings reported that they would “probably” or “definitely” take their sibling to social events and go out to eat or to the movies. Thus, the majority of siblings expected to support their brother or sister with schizophrenia by assisting him or her with various daily living tasks, and an even higher percentage expected to remain involved through the sharing of social and family activities.

Our second research question investigated the factors that either push siblings toward greater involvement in the future or would pull them away from such involvement. We conducted separate regression analyses for the predictors of instrumental and emotional support to examine whether different sets of push and pull factors predicted the two types of involvement (see Table 4).

With respect to sibling expectations about providing instrumental support in the future, siblings who were married and younger (at the trend level) were more likely to expect that they would provide help to their sibling with schizophrenia with daily living tasks, such as household chores and transportation, when their parents are no longer able to assume a caregiving role.

Table 3
Sibling Expectations About Future Caregiving

<table>
<thead>
<tr>
<th>Type of future involvement</th>
<th>Instrumental support (%)</th>
<th>Emotional support</th>
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<tbody>
<tr>
<td>Instrumental support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helping during illness</td>
<td>83.2</td>
<td></td>
</tr>
<tr>
<td>Managing money</td>
<td>66.4</td>
<td></td>
</tr>
<tr>
<td>Helping with transportation</td>
<td>56.9</td>
<td></td>
</tr>
<tr>
<td>Keeping appointments</td>
<td>54.3</td>
<td></td>
</tr>
<tr>
<td>Helping with household chores</td>
<td>45.2</td>
<td></td>
</tr>
<tr>
<td>Monitoring medication</td>
<td>44.5</td>
<td></td>
</tr>
<tr>
<td>Emotional support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Listening to problems and provide advice</td>
<td>92.7</td>
<td></td>
</tr>
<tr>
<td>Including in family celebrations/holidays</td>
<td>92.7</td>
<td></td>
</tr>
<tr>
<td>Visiting regularly</td>
<td>86.9</td>
<td></td>
</tr>
<tr>
<td>Including in social event</td>
<td>80.3</td>
<td></td>
</tr>
<tr>
<td>Taking to a restaurant or movie</td>
<td>75.9</td>
<td></td>
</tr>
</tbody>
</table>

*Percent of siblings who indicated that they would “definitely” or “probably” provide this type of support.

Consistent with our hypothesis, push factors representing early socialization experiences were significantly related to future expectations of providing instrumental support. Siblings whose brother or sister developed mental health problems during the sibling’s childhood were more likely to expect to help their sibling with schizophrenia with a greater range of daily living tasks than those who were adults when their sibling became ill. Also, siblings who expressed a stronger sense of family responsibility to care for other family members were more likely to expect to be involved in providing future assistance with instrumental tasks. Although in the expected direction, the gender of the sibling was not a significant predictor of future expectations of providing instrumental support.

In addition, although the quality of the current sibling relationship was not related to the expectation of providing instrumental support in the future, the degree of reciprocity in the sibling relationship was related to instrumental support. Siblings who perceived greater reciprocity in the relationship expected to be more involved in providing their brother or sister with schizophrenia assistance with instrumental tasks than siblings who reported lower levels of reciprocity in the sibling relationship. Also, respondents who felt a greater sense of personal growth through the process of coping with their sibling’s illness were more likely to expect to provide instrumental support in the future than those who experienced fewer gains.

Regarding pull factors, counter to our hypothesis, there was a trend for siblings to express stronger expectations that they would assist their brother or sister with instrumental tasks in the future when their brother or sister was currently experiencing more severe behavior problems. As hypothesized, those who viewed their brother or sister as having more control over their symptoms viewed themselves as less likely to assist their brother or sister with daily living tasks in the future. Siblings expected to provide less future support with instrumental tasks when they lived more
than a half-day drive from their brother or sister’s home. Finally, neither competing work/family demands nor health problems were significantly related to expectations of providing instrumental support.

Next, we examined factors predictive of whether siblings expected to provide emotional support to their brother or sister with schizophrenia. As shown in Table 4, there was a trend for married siblings to report higher expectations that they would be a source of emotional support for their brother or sister with schizophrenia than siblings who were not currently married. With respect to the push factors, sisters and those with a stronger sense of responsibility to care for family members were significantly more likely to expect to remain emotionally supportive of their brother or sister. In addition, siblings who reported having a better quality of relationship with their brother or sister, those who perceived greater reciprocity in the relationship with their brother or sister, and those who realized greater personal gains from coping with their brother or sister’s illness were more likely to express the intention to provide emotional support to their brother or sister with schizophrenia in the future.

Regarding pull factors, only geographic distance to the home of the sibling with schizophrenia had an effect on future expectations of providing emotional support. Siblings who lived closer expressed greater confidence that they would provide their brother or sister with emotional support than those who lived at a distance.

Discussion

To summarize our findings, there were both similarities as well as differences in the factors predicting the extent to which siblings will be involved in providing two aspects of support—instrumental and emotional—to a brother or sister with schizophrenia in the future when parents are no longer able to assume a primary caregiving role. Siblings who were married, felt a stronger sense of responsibility to take care of family members, perceived the relationship with their brother or sister as being characterized by reciprocity, and who experienced gratifications or gains from the challenges of coping with mental illness were more likely to report that they would provide their brother or sister with schizophrenia with both instrumental and emotional support when their parent was no longer able to provide care. In addition, siblings who lived in relatively close proximity to their brother or sister expected to provide more instrumental and emotional support than siblings living at a distance.

Yet there were several differences in the predictors of instrumental versus emotional support. Siblings who were younger and who had been coping with their brother or sister’s condition since childhood were more likely to expect that they would assist their brother or sister with instrumental tasks. Also, siblings who perceived their brother or sister as not having control over their symptoms were more likely to express the intention of providing instrumental support in the future. There was a trend for siblings to expect to provide more instrumental support when the brother or sister had more behavior problems. In contrast, gender and the quality of the relationship were predictive of the provision of emotional support. Sisters and those with a high quality relationship were more likely to expect to offer emotional support to their brother or sister with schizophrenia than brothers and those with a poorer quality of relationship.

On a more fine-grained level, siblings are more likely to be involved with their sibling with schizophrenia in activities that require periodic but not sustained regular contact. Siblings were most likely to expect to help their brother or sister during an illness, invite him or her to participate in family holidays and celebrations, listen to his or her problems and provide advice, and visit him or her regularly, all of which involve only periodic contact. Siblings were less likely to expect to help with more hands-on and ongoing caregiving tasks such as household chores, medication monitoring, and transportation, all of which demand almost daily contact. Our findings about the future involvement of siblings are remarkably similar to those reported by Hatfield and Lefley (2005) who found that the great majority of siblings expected to provide emotional support but significantly fewer expected to provide instrumental caregiving support. Thus, on an optimistic note, our findings along with the results reported by Hatfield and Lefley (2005) do not suggest that adults with schizophrenia will be abandoned by their siblings, as siblings expect to remain involved in the life of their brother or sister with schizophrenia by helping with daily living tasks and through visits, family celebrations, and other shared social activities. On the other hand, our findings do not indicate that siblings are ready to take over the active hands-on caregiving role that many parents currently perform. Siblings will likely take on a more secondary caregiving role and depend on the mental health system to assume primary care.

Not surprisingly, socialization experiences have a powerful influence in determining whether a sibling expects to help a brother or sister with mental illness when parents are no longer able to be the primary caregivers. Having a strong sense of responsibility to care for family members was a significant predictor of expecting to provide both instrumental and emotional support in the future. Siblings who were children when their brother or sister became ill were more likely to expect to help their brother or sister with schizophrenia with daily activities. Sisters, many of whom grew up during the 1960s and 1970s when typically young girls were socialized to take on a caregiving role, were more likely than brothers to expect to be a source of emotional support to their brother or sister with schizophrenia. These findings point to the importance of studying the sibling relationship from a life course perspective in understanding the differential involvement of siblings in the lives of their brothers and sisters with mental illness.

The degree of reciprocity in the sibling relationship was a significant predictor both of future involvement with instrumental tasks and the provision of emotional support. This finding is consistent with the research of Horwitz (1994) who found that siblings reported a greater willingness to help a brother or sister with a mental illness when the relationship was characterized by reciprocity in the exchange of assistance. Although difficulty in maintaining reciprocal social interactions is a hallmark of schizophrenia, it is a skill that can be acquired through appropriate treatment. Considerable effort has been extended in developing social skills training programs to provide persons with schizophrenia the necessary skills to establish friendships and succeed in the workforce. Social skills training also might be a forum for focusing on family relationships and skill building that promotes greater reciprocity in these relationships. We recognize that some siblings may have low expectations concerning their brother or sister’s ability to reciprocate, and clinicians may need to work with these
siblings to encourage them to offer opportunities for their brother or sister with mental illness to make contributions to family life.

Whereas the quality of the sibling relationship had little effect on expectations about helping with daily living tasks, relationship quality had a strong effect in predicting expectations about future provision of emotional support. Quality of life research on adults with schizophrenia demonstrates that the receipt of emotional support is a powerful predictor of life satisfaction in persons with mental illness (Caron, Tempier, Mercier, & Leouffre, 1998; Yanos, Rosenfeld, & Horwitz, 2001). This speaks to the importance of working with adults with schizophrenia and their siblings today to strengthen these bonds of affection, as the quality of the current relationship helps form the sibling’s expectation about his or her future role as a source of emotional support for the brother or sister with schizophrenia.

Contrary to our hypothesis, we found that siblings expected to take on a more active caregiving role in the future when their brother or sister was experiencing more behavior problems. Research on normative sibling relationships in later life indicates that siblings turn to one another for assistance when other relationships are lost because of death, divorce, or geographic relocation (Bedford, 1998; Cicirelli, 1995). Because few persons with schizophrenia marry or have children, most siblings are aware that one day they may be called upon to assume a more active caregiving role when their parents are no longer able to continue in this role. Our findings suggest that sibling expectations about the degree of their future involvement are based in part on their brother or sister’s current functioning. If their brother or sister is functioning poorly now, siblings will likely project this into the future and see themselves as needing to be more involved than if their sibling is doing well and experiencing few behavior problems. Thus, sibling expectations about assuming a future caregiving role are influenced by the current functioning of their brother or sister with schizophrenia.

Limitations

Our study has several limitations. First, not all siblings volunteered to participate in the research, so participants might not be representative of the population of siblings of adults with disabilities. Second, we sampled only one sibling per family who was identified by the mother of the adult with schizophrenia as the sibling most likely to take on a future caregiving role. In some families, several siblings were expected to take on a future caregiving role and the mother was asked to select the sibling who would be “most involved.” Because children in families often have different roles, by sampling only one sibling per family we may have underestimated the range of support that may be available to adults with schizophrenia when their parents are no longer able to assume this role. Third, we did not collect data from the brother or sister with schizophrenia about how he or she felt about being the recipient of care from a sibling. As Hatfield and Lefley (2005) discuss, the involvement of a sibling is in part limited by the openness of the brother or sister to offers of help. Future research should not only assess the siblings’ expectations of providing help, but the perceptions of the one needing care.

Fourth, we focused on factors predicting the individual’s intentions to help in the future because of the relatively high correlation (in the .70 range) in other research between intentions and behavior (Fishbein et al., 2001). Yet many other factors might influence whether individuals enact a behavior such as whether the individual has the prerequisite skills and ability to perform the behavior, perceptions of control and self-efficacy to produce the desired outcomes, moral obligations to perform the behavior, habits, attitudes, and the emergence of unexpected events that alter an individual’s intention to act (e.g., Ajzen, 1991; Bandura, 1982; Eagly & Chaiken, 1993). Longitudinal research is needed on how these other factors along with behavioral intentions relate to the actual involvement of siblings in the lives of their brother or sister with mental illness after the parent’s death.

Implications for Practice and Research

The results of these analyses provide several implications for mental health practice and research. First, we found that siblings who perceived their brother or sister with schizophrenia as having control over his or her symptoms expected to be less involved in providing future assistance with daily living tasks than siblings who perceived their brother or sister’s symptoms as being beyond his or her control, as predicted by Greenley (1986). Siblings are often poorly informed about their brother or sister’s mental illness, its causes, and treatment (Judge, 1994). They may misinterpret their brother or sister’s symptoms as willful or manipulative because of misinformation or simply the lack of knowledge about mental illness. Psychoeducation programs appear to be in part effective by helping family members reframe their relative’s condition as an illness, beyond the individual’s control. Such programs also help family members to develop new perspectives about mental illness, which often promote feelings of personal growth (Chen & Greenberg, 2004). We found that siblings were more likely to expect to help their brother or sister with schizophrenia in the future when they reported higher levels of personal gains from their experience of coping with mental illness. Thus, psychoeducation programs targeted for siblings may not only have the benefit of helping them better understand their brother or sister’s symptoms, but also may strengthen their intention to help their sibling with mental illness in the future.

Second, although the majority of adults with schizophrenia had at least one sibling who expected to step in and assist the adult when their parents were no longer able to remain in a supportive role, we must not lose sight of the fact that some adults with schizophrenia, albeit a small percentage, do not have siblings to turn to when their parents become disabled or die. Approximately 10% of the mothers reported that none of their other adult children would be involved in the future, and another 5% of the sample had no siblings or only siblings who themselves had schizophrenia. These individuals not represented in this analysis may be at greatest risk because when their parents die or become disabled they may not have family to support them in a time of need. Mental health services will need to target these adults with schizophrenia who are without strong family supports.

Third, our findings are consistent with other research reporting that the involvement of siblings in the life of their brother or sister with mental illness is significantly influenced by the sibling’s perception of the quality of their current relationship (Greenberg et al., 1999; Horwitz, 1993, 1994; Jewell & Stein, 2002; Lukens, Thornig, & Lohrer, 2004). However, little is known about the factors that sustain the bonds of affection between siblings when
one sibling has a severe and persistent mental illness such as schizophrenia (Hatfield & Lefley, 2005). Future research is needed on the variables that promote high quality relationships between siblings when one sibling has schizophrenia.

Conclusion

In conclusion, during the past three decades, research on families of persons with schizophrenia has for the most part been research on parents, in particular mothers. This focus on mothers was understandable because they bore the major caregiving challenges stemming from deinstitutionalization and were scapegoated by many professionals as being responsible for causing their child’s condition. But today, these parents are in the retirement stage of life, and the focus is shifting to the future and the potential role of siblings as the next generation of caregivers. The findings of our study are encouraging and suggest that siblings are prepared to play a significant role in assisting their brother or sister with schizophrenia, and more importantly, to maintain family bonds through visits and holiday celebrations. However, there are several factors that may deter siblings, some of which might not be easily modified, such as geographic distance. Other factors, such as closeness and relationship reciprocity, may be responsive to interventions. Developing effective treatments and services to foster relationships between midlife siblings when one sibling has schizophrenia will require a more in-depth understanding and identification of those push and pull factors that can be modified through appropriate services and interventions.

References


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