Future Involvement of Siblings in the Lives of Persons with Mental Illness

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ABSTRACT: Siblings are considered logical replacements for aging parental caregivers of persons with severe mental illness. For workshops on future planning conducted with 400 elderly parents, 60 siblings answered a survey regarding their future caregiving expectations, anticipated difficulties, and need for help. Nearly all expected to be involved, but were more likely to provide social and emotional support than the instrumental support offered by their parents. Nearly half indicated that the consumer's hostility and lack of cooperation were major barriers to effective care. It was suggested that siblings need education and help from professionals in assessing behaviors, interacting appropriately, and conferring control of their own lives to their ill relatives. For consumers, social skills and self-esteem training in psychiatric rehabilitation programs should address the area of sibling relationships and reciprocity. Such issues should be dealt with early, rather than later in the course of illness

KEY WORDS: mental illness; siblings; families; caregiving.

INTRODUCTION

As parents age and their ability to care for family members with serious mental illness diminishes, they look to other members of the family to assume caregiving responsibilities. Research indicates that few people with severe psychiatric disorders are likely to have spousal or other intimate relationships (Tsuang & Faraone, 1997). Therefore it is usually the next generation in the family of origin, i.e. siblings, who are expected to step forward and take over roles that parents once played.

How siblings respond to parental expectations for sibling caregiving and what involvement adult siblings actually have in the future life of a relative is not well known. There are few systematic studies on relationships between adult siblings when one sibling has a disability, nor do we know the implications of these relationships for future caregiving (Horwitz, 1993, 1994; Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997).

Greenberg, Seltzer, Orsmond, and Krauss (1999) compared current involvment and expectations of future caregiving of siblings with mental illness with siblings of people with mental retardation. They found that two-thirds of siblings of people with mental retardation expected to assume future caregiving responsibilities whereas only one-third of siblings of people with mental illness expected to do so. This study found that competing family or career responsibilities limited the expected involvment of siblings whereas the closeness of the family of origin led to greater expected involvement. The authors pointed out, however, that by the time caregiving was needed, the children of siblings could be grown and less a competing factor for their assumption of responsibility.

Beeler, Rosenthal, and Cohler (1999) interviewed older institutionalized patients and their families to determine the degree of contact these individuals had with other family members. Three-fourths of these patients had some form of family contact, with siblings being the most frequent. However, siblings had more contact with their family members when mothers were still living than when their mothers were deceased. Apparently mothers help to maintain support networks. This suggests that older psychiatric patients may be at risk for diminished family contact as mothers pass away.

The finding of less sibling support when parents are gone was not supported in a study by Horwitz (l993). Horwitz tested the hypothesis derived from a serial model of social support, that adult siblings will provide more support to brothers and sisters with mental illness when

parents are not available. This model assumes that in times of need, people depend upon those to whom they are most intimately related for support. The strongest relational bonds are between spouses and between parents and children. When people lack these relational bonds, which is often the case with people with serious mental illnesses, siblings are usually the next most intimate relation. Horwitz's (1993) study of 108 adult siblings of participants in a program for people with serious mental illness supports the serial model. The study finds that siblings provide more contact, intimacy, and help when parents are not living. However he notes that the kinds of support given, such as emotional support, gift giving, rides, or support during times of crisis are not especially demanding, so it cannot be concluded that sibling care fully substitutes for parental care. To further understand the conditions under which siblings are willing to give support, Horwitz (l994) examined how the sense of obligation, reciprocity, and the quality of interpersonal relationships affect whether siblings will play supportive roles to brothers and sisters with serious mental illness. The central finding of this study is the importance of reciprocity in creating bonds when one sibling has a mental illness. Siblings reported more willingness to help brothers and sisters who reciprocate through affection, gifts, and chores. Horwitz urges mental health professionals to become more aware of the important role that siblings can play over the life course and help their clients develop more reciprocal relations with their sibling.

Judge (1994) reviewed the literature on sibling relationships when one sibling had a serious mental illness and concluded that sibling relationships have the potential to provide important emotional support to the individual with serious mental illness through friendship behavior (approval, integration, and reciprocal relating), as opposed to "caretaking" or "rescuing". Judge concluded that while siblings had a positive role to play, there could be tension and conflict if the relationship is characterized as "caregiving".

Some research has shown considerable disparity between parents' preferences for siblings to serve as future caregivers and parents' expectations that they will do so (Pruchno, Patrick, & Burant, 1996; Smith, Hatfield & Miller, 2000). Prochno and colleagues found that while parents hoped for considerable sibling involvement in the future, many of them assumed that their siblings could not provide much direct care because of the demands on their own lives. Sometimes there had been no discussion between parents and adult offspring to clarify these issues.

These conclusions were evident in a study of 210 elderly caregivers (mean = 73.2 years), almost all parents of adults with severe mental illness, regarding their planning for the future (Hatfield & Lefley, 2000). The findings indicated that 63% of the sample had turned to the patient's siblings for help in planning the future, but about one-third were deemed not helpful. This figure is remarkably similar to the findings of Greenberg et al. (1999) when they contrasted future caregiving expectations of siblings or persons with mental illness vis a vis persons with mental retardation.

In the study by Hatfield and Lefley (2000), respondents' comments, freely offered on the survey protocols, elaborated on their anxieties. Even among those expecting siblings to assume some future role, their remarks reflected doubt and ambivalence about replacement caregiving by their other children. "Her brother is a prospective caregiver, but his health is bad." "My other son has a wife and teenage children. They are his first priority." "I expect my daughter to take over, but I don't think she really wants to." "His illness made it hard to bring friends home when they were growing up. They are not on good terms." And also, "I hate to impose this responsibility on my other children."

Assumption of caregiving also carries investments of time and money. A study of 156 adult siblings of persons with mental illness found that current caregivers incurred greater instrumental costs in terms of financial expenditures, time spent in care activities, and involvement in crisis situations than did siblings who were not involved as primary caregivers (Lohrer, Lukens & Thorning, in press).

Another factor is siblings' perception of services and support from the mental health system. In five focus group interviews, Lukens, Thorning, and Lohrer (2002), found that respondents varied in finding their mentally ill siblings as difficult and manipulative, but also reporting pleasure in their small successes. Some felt that their lives had been enriched by this experience. However, many reported negative experiences with the mental health system and difficulties in getting help. "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" (p. 361).

The issues and problems disclosed in the sibling literature seem to be fairly common across an array of geographic areas and convenience samples. However, there is little available on siblings as intended or actual caregivers. A survey was undertaken in what was an admittedly nonrepresentative sample of siblings. Many of them were the offspring of

parents who had been involved in workshops planning the future of their mentally ill adult children. These siblings were contacted through a newsletter of the National Alliance for the Mentally Ill (NAMI) of Maryland and were motivated enough to mail back a survey. Because of these factors, the following information is presented as a potentially "best case" example of the intentions of siblings regarding their future role.

SIBLINGS' INVOLVEMENT IN CAREGIVING: A POTENTIALLY "BEST CASE" EXAMPLE?

The role of siblings in the lives of a brother or sister with mental illness had been frequently discussed in NAMI Maryland's workshops on future planning. Many caregivers were unsure about reasonable expectations of their other children and how to communicate with them about the issue. To fill this gap in knowledge, a brief questionnaire focused specifically on issues related to siblings' expectations and attitudes about future caregiving was developed by NAMI Maryland and circulated through the NAMI newsletter.

Questions for the sibling survey grew out of 5 years work in training approximately 400 parental caregivers to develop future plans for their relative. The questions reflect concerns expressed by caregivers as to the role their well offspring might play in the future care and support of a family member with mental illness.

More specifically, the survey attempted to answer three major questions: (1) In what ways do siblings expect to be involved in the lives of a brother or sister with mental illness when parents are gone; (2) What issues and problems do siblings anticipate in this involvement; and (3) What kinds of help would siblings need to be successful with these responsibilities?

Sixty usable responses were received. Sibling respondents were predominantly female (77%), in their thirties and forties (70%), married (61%), and employed (81%). Eighty-seven percent had at least one parent still living.

The relatives with mental illness were males (69%), single (87%), and diagnosed with schizophrenia or bipolar disorders (83%). Thirty-three percent of them were living at home with 28% living elsewhere under family supervision. Only 23% were living in situations supported by the public system. These demographics are similar to those reported in a study of older parental caregivers conducted in Maryland and Florida (Hatfield & Lefley, 2000).

SIBLING EXPECTATIONS OF FUTURE CAREGIVING ROLES

Most siblings in this study expect to have some involvement in the life of the ill member. Only 8% said that they would not be involved at all. Their involvement was more likely to be in providing social support to their relative than in providing such instrumental help as housing, monitoring medication, or helping with household chores. Seventy-five percent of siblings said they would include their relative in social events and 49% would take him or her to restaurants, movies, etc. Forty-two percent expected to help with managing money and 40% to overseeing care of the individual in the community. Thirty- three percent expected to serve as a trustee. Fewer siblings (21%) expected to monitor medication or help with household chores (14%). Only one respondent expected to have the person live in his/her home.

Over one-fourth of siblings said that they did not know what their future involvement with a relative might be. Parents had never discussed the issue with them. When it had been discussed, parents and siblings were in close agreement 41% of the time.

Two-thirds of the siblings had brothers or sisters of which 30% had never discussed the issue of future care. When the issue had been discussed, about a fourth found themselves in general agreement with their siblings about future care, and an equal number reported conflict about the way help should be given, and how responsibilities would be shared.

DIFFICULTIES ANTICIPATED BY SIBLINGS

The most often mentioned difficulties in providing care were demands on siblings by their own families (61%) and the distances they lived from their relative (57%). Over a third (36%) of the siblings said that negative feelings about their relative's behaviors were barriers. Less frequent barriers to future care were work/school demands (29%), health problems of self or family (21%), lack of knowledge about mental illness (15%), and opposition to involvement by spouse or children (5%).

Several factors in their relative's life were expected by siblings to present difficulties: Hostility and lack of cooperation of the relative (45%), his or her unwillingness to use mental health services (41%), medication noncompliance (30%), and inability to keep housing (25%). Substance abuse (16%) and poor health (14%) seemed to be of lesser concern in this study.

Communication was a problem in some families. Over one-fourth of the parents had not talked to siblings about expectations for future care and 30% of siblings had not talked with each other about ways responsibilities might be shared.

NEED FOR HELP BY SIBLINGS

Forty-eight percent of siblings said that support groups for siblings with future caregiving responsibilities would be helpful and 46% felt that they would like printed material on mental illness and how to cope. In addition, 50% of siblings would like better understanding on the part of providers and parents about the stress for siblings and 41% felt their lives would be better if parents had training in making effective plans for the relative with mental illness.

DISCUSSION

Nearly all of the siblings in this study expect to be involved with their relative in the future, although many did not know what that involvement would be. They expected to provide emotional and social support more often than instrumental help. More of them expected to include relatives in outings and family events and to lesser, though significant extent, involve themselves in managing money and over-seeing care in the community. As was noted earlier, Horwitz (1994) also found that siblings expected to provide more social and emotional support and less instrumental help suggesting to him that sibling caregiving was not a full substitute for parental care. Some may believe that this is as things should be and that siblings should not expect to be a full substitute for parental care (Judge, 1994).

Siblings may believe that there are other ways to provide instrumental help. Perhaps the person with mental illness can learn to do more things for him or herself, services may be found in the public system, or they might be purchased. However it is hard to find a substitute for the emotional and social support of family members. In one study, parents rated socialization as a need most likely to be neglected when parents are gone (Hatfield & Lefley, 2000). They had visions of their relative living isolated existences with no one to care about them. It should be reassuring to parents to know that many siblings in this study expect to make emotional and social support a future priority.

Siblings most often mentioned that the demands of their own families would make it difficult to provide support and care to their disabled brother or sister. Several other studies noted these same competing demands on siblings' time and attention (Greenberg et al., l999; Pruchno et al., 1996; Smith et al., 2000). Later, as Greenberg and colleagues noted, these competing demands may lessen as the families of siblings grow up and leave home.

There were several factors in the disabled relatives' behavior that siblings felt would create barriers to help. Most frequently mentioned were the relatives' hostility and lack of cooperation. Little attention has been given to the nature of the relationship between the well and ill sibling and the effect of this relationship on future caregiving. Although mental illnesses are often accompanied by serious behavioral disturbances, not enough is known about ways to lessen the impact on other children in the family.

One of the challenges faced by siblings is determining how much control their relative has over his or her behavior. Siblings may have difficulty determining whether the behavior problems are intentional and manipulative or due to the illness. In the focus group sessions conducted by Lukens et al. (2002), siblings reported behavior that was "manipulative... enraging or mystifying" (p. 357) and claimed their relatives were able to dupe mental health professionals.

A Swedish study of siblings of patients with schizophrenia found "an emotional sibling bond characterized by feelings of love, sorrow, anger, envy, guilt and shame. The major categories linked to coping with the situation were avoidance, isolation, normalization, caregiving, and grieving." (Stalberg, Ekerwald, & Hultman, 2004, p. 445). Part of the siblings' response was a fear of their own genetic vulnerability. These mixed reactions showed a limited proclivity for caregiving, an ambivalence about an appropriate relationship with the ill sibling, and need for information about modes of genetic transmission and probabilities.

Siblings need to have the training to increase their understanding of the nature of mental illness, and to develop coping strategies in ways that avoid excessive conflict and anger (Seltzer et al., 1997). Judge (1994) found that many siblings felt confused and uncertain about how to help, how to interact with the person, and how to alleviate the distress of the ill family member. She said that it cannot be taken for granted that the education of the parents necessarily trickles down to the rest of the family. Service providers must offer help as siblings take on new responsibilities for the support and care of a relative with mental illness.

Some of the difficulties in relationships between the well and ill sibling may be longstanding. Research studies and individual accounts of the sibling experience reveal considerable pain and disruption to their lives by mental illness (Friedrich, Lively, & Buckwalter, 1999; Judge, 1994). Mental illness may take a significant toll on family relationships because of the behavioral problems which disrupt family life. Friederich et al. 1999 found that the disruption of household routine was the most disturbing to them. Lack of ability to deal with a precarious home environment caused siblings to distance themselves from the relative. The impact was greatest when the ill person lived at home.

It is apparent from this and other studies that more attention must be given to the factors that affect the quality of relationships between people with mental illnesses and their siblings. Some of the problems may be longstanding, arising from behavioral disturbances of an ill member at home, siblings' feelings of neglect when parents' attention is consumed by the needs of a troubled offspring, and excessive responsibilities demanded of younger siblings who have little understanding of mental illness. More must be done for parents to meet the needs of all family members. Practitioners must be prepared to help parents through these difficult times, and the educational and psychoeducational programs now available should include substantial material in their curriculum about siblings in the family.

Some of the difficulties in sibling relationships may also be due to a consumer's lack of social skills in relating to their families. Many people with the deficits of long-term mental illness may be obdurate and angry at the idea of being cared for by siblings who may be younger than themselves, and who usually have had more success in life. The self-esteem and social skills training of psychosocial rehabilitation programs rarely deal with the resentments that patients frequently feel toward relatives and friends whose lives have been more fulfilling than their own. Consumers must learn to judge themselves in terms of their own progress in overcoming barriers , rather than in comparison with others who do not have the same barriers. Psychiatric rehabilitation programs could do much more to teach consumers how to relate more effectively with their siblings. Consumers need to learn how to manage anger, how to show appreciation, and how to develop reciprocal relationships with their siblings.

Other difficulties in sibling relationships, as noted above, may be due to siblings' lack of understanding of mental illness and how it affects behavior and lack of skills in coping with inappropriate

behavior in ways that do not aggravate conflict and anger. Siblings in this study expressed a need for printed material and support groups to better prepare them to deal with the responsibilities they may inherit.

CONCLUSIONS

The findings reported here are based on what might be considered a best-case scenario of replacement caregiving when parents are gone. First, NAMI of Maryland had been conducting 5 years of training of approximately 400 parental caregivers regarding future planning for a relative with serious mental illness. Many of these parents expressed the intention to turn over caregiving to their other children when they were no longer able to fulfill this role. A survey was conducted by Maryland NAMI to learn the problems and needs of siblings, and the responses were sent in by siblings who were interested and motivated enough to participate.

It was found that these siblings expect to do less intensive caregiving than their parents had done. They expect to give more social and emotional support and less instrumental help to their relative. More instrumental help will be needed from community resources.

Nearly half of the siblings in this study perceived hostile and unco-operative behaviors as barriers to giving effective care to their rela-tives. Possible explanations for these negative behaviors are intertwined. They may be due to the psychological problems and/or lack of social skills of the relative. They could be due to the siblings' lack of understanding of mental illness and lack of coping skills that could prevent excessive tension and conflict in the relationship. Also, siblings may be carrying resentment and anger from the past that continues to distort their perceptions of present situations. Consumers may be resentful of dependency on their siblings. It is important for the future well-being of people with mental illness that these sources of negative feelings be addressed. Therapy and psychiatric rehabilitation can be useful to clients. Educational materials, seminars, and classes should be available to siblings and parents.

A parent's death is also a time of grieving for both consumers and siblings. For the consumer, the loss of both beloved parent and needed caregiver may evoke an intense emotional reaction that, without proper support, may lead to decompensation and rehospitalization. Siblings are also grieving the loss of their parent, with limited emotional energy

to assume a caregiving role. A parent's death may also be a particularly difficult time psychologically for sibling relationships, as childhood memories are exhumed and mixed feelings arise. Siblings may resent the years of attention devoted to their ill relative and the burdens imposed on their parents by the illness. They may feel that the illness hastened their death. This is a difficult period for adjusting to another caregiver and both consumers and siblings would benefit from professional help in making the transition. Lefley and Hatfield (1999) suggest that preparatory psychological work should begin much earlier, so that consumers are prepared for potential loss and can plan for a continuing support system. They also suggest that preparatory work, while the parents are still alive, may provide opportunities for consumers' growth as they themselves may fulfill caregiving responsibilities for aging or disabled parents and discover untapped strengths for greater independence.

Finally, it should be borne in mind that siblings who replace aging parents as caregivers may themselves be in late middle age. In contrasting aging caregivers in Alzheimer's disease and schizophrenia, Patterson, Semple, Shaw, Grant, and Jeste (1996) have noted that in schizophrenia there is greater unpredictability, feelings of less control, fewer caregiving resources, fewer support persons, repeated exposure to stress, more feelings of stigmatization, and potential avoidance and prejudicial behaviors from others. Lebowitz & Light (1996) have stated that the needs of aging caregivers of psychiatric patients may constitute a public healthcare concern or crisis. They state that well-designed studies show that the chronic stress of caregiving is associated not only with clinical depression but with actual alterations in biophysiology.

Overall, the literature suggests a strong need for mental health planning that provides continuous caregiving resources for consumers without families, or that can replace or supplement familial caregiving that may be both burdensome or ephemeral because of caregivers' age. The literature also suggests that as a matter of mental health policy, practitioners' attention to sibling relationships and concerns should occur at the beginning of illness, far earlier than the caregiving stage.

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