Aging Families of Adults with Schizophrenia: Planning for the Future

A Compilation of Year One Study Findings

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History of the Study

Many persons with schizophrenia rely on their parents for support and help. As parents approach their aging years, they continue to grapple with many riveting and very difficult questions:

* Where is the best place for my son or daughter with schizophrenia to live now and in the future?
* How do I balance my child’s needs with my own needs and those of other family members?
* What plans should be made now to ensure my son or daughter’s future care when I am no longer able to continue in the role due to disability or death?

Even though these questions are frequently asked, very little systematic research has been conducted about the lives of aging parents of adults with schizophrenia, and the well-being of persons with schizophrenia when they can no longer turn to their parents as a primary source of support and help. It comes as no surprise, therefore, that there is much to be accomplished in the development of informed public policy and services for aging families of adults with schizophrenia.

Purpose of the Study

We have three main reasons for conducting this study.

* To identify the long-term toll that schizophrenia takes on parental well-being and family life. In the past, most studies about the families of people with mental illness have focused on the early stages of mental illness.

* To describe how families cope with the challenges of caring for an adult son or daughter with schizophrenia. We have a lot to learn from families like yours who have been coping with the illness for many years. Your insights may help younger parents who are earlier in this process.

* To document the type of services needed to help parents plan for their son or daughter’s future care. By virtue of your caregiving responsibilities and age, you and your adult child with mental illness have unique needs and concerns. We hope that the dissemination of our findings will improve the delivery and provision of mental health services to families and adults with schizophrenia.
In order to meet these research goals, we focus this study on five research questions:

* What roles do aging mothers and fathers take in the provision of care and support to their adult son or daughter with schizophrenia?

* What resources and services are most important in maintaining the well-being of parents?

* What mental health services are provided to adults with schizophrenia and what additional services will be needed when their parents are no longer able to provide care?

* What are the ways that adults with schizophrenia help their aging parents?

* How is the quality of life of adults with schizophrenia affected when their parents are no longer able to provide support?

Our study is longitudinal which means that we are hoping to interview participants on three different occasions over a five year period. In this report, we provide our preliminary findings. As we continue this study over the next three years, we will develop more complete answers.

**Recruiting Families for the Study**

We used several strategies to recruit families to participate in the study. First, we contacted professional staff from public agencies serving persons with mental illness in Wisconsin. They were very supportive and agreed to help us by distributing recruitment information to families that met our study’s criteria. We also successfully publicized the study with the help of the National Alliance for the Mentally Ill of Wisconsin (NAMI-Wisconsin) and its affiliates throughout the state. Finally, we promoted the study through newspaper articles. Many families contacted us after learning of the study through the media.

It has been very gratifying to see how willing families have been in sharing their experiences and we thank all of you for participating.
The Study Participants

* Mothers: 293 are participating
  * 23 have two children with schizophrenia; and 59 have another child with a
    major mental health problem including depression, bipolar disorder, and
    alcohol dependence
  * They range in age from 55-88 years, with an average age of 70
  * Over 45% of the women are currently caring for their child alone, with 16%
    being divorced or separated and 29% widowed; 53% are married and living
    with their spouse
  * About 88% are white; 11% are African-American; and 1% are Hispanic or
    Native American
  * 51% graduated from high school; 39% continued their education beyond high
    school; and 14% of the mothers have less than a high school diploma
  * 15% are employed full-time, 14% are currently employed in part-time jobs
  * Over 40% are or have been members of a support group, typically the
    National Alliance for the Mentally Ill

* Fathers: 106 are participating
  * 78% of the eligible fathers are participating
  * Fathers are an average one year older than their wives
  * Over 74% graduated from high school, and 43% continued their education
    beyond high school
  * 35% of the fathers are working full or part-time
  * 67% of the fathers reported being in good or excellent health

* Sons and Daughters with Mental Illness: 301 are participating
  * Data were collected about 301 adults with schizophrenia (8 mothers
    completed interviews about 2 of their children with schizophrenia)
  * 75% of the families have a son with mental illness, while 25% have a
    daughter with mental illness
  * The adults with mental illness range in age from 23 to 65 years; the average
    age is 42 years
  * Approximately 33% of the sons and daughters also have a problem with
    alcohol or drugs
  * 21% held a competitive job at the time of the interview while 14%
    participated in sheltered work or supportive employment activities
  * Over 60% have experienced some problem with the law or have been
    involved with the criminal justice system during the course of their illness
  * Over 40% have attempted suicide
  * 66% have one or more chronic health problems, with 33% having dental
    problems, 23% problems breathing, and 22% high blood pressure.
**Assistance Parents Provide to Their Sons and Daughters**

We asked a series of questions about the different kinds of help that the son or daughter needs and the ways that parents help. Approximately 75% of the mothers reported that their son and daughter requires help with money management and more than 60% reported that their adult child needs help managing their medications and doing household chores. About half of the adults with mental illness need at least some assistance with shopping, transportation, and keeping appointments.

Not surprisingly, mothers are the family member most likely to provide assistance with household chores and money management. Almost 70% of the mothers reported that they assist with household tasks such as cleaning, laundry, and cooking meals. Over half shop for their son or daughter and help them manage their money. They were least likely to be involved by supervising their son or daughter’s medication as most of the adults with schizophrenia took their medications as prescribed without reminding or prompting.

Many fathers remained actively involved in helping care for their sons and daughters with schizophrenia. In fact, in a few families, fathers had assumed the primary caregiving role for their son or daughter. Over half of the fathers reported helping their children “a lot” with at least one activity of daily living. Fathers are most involved in providing their sons and daughters with transportation, and approximately 40% help their children manage their money and keep medical and other appointments.

**Multiple Caregiving Responsibilities**

Approximately 13% of the mothers reported that they had other caregiving responsibilities in addition to those for their son or daughter. Most commonly, mothers are caring for another adult child with a disability, mental illness or alcoholism, or for an aging parent with an age-related disability. Only 3 wives reported that their husbands required care. Mothers with multiple caregiving responsibilities spend an average of 12 hours per week providing care to a second family member and have been doing so for an average of 12 years. Therefore, many mothers in our sample are not only providing primary care to their son or daughter with mental illness but another family member.
Care for Grandchildren

Forty-seven of the adults with schizophrenia have children of their own who range in age from 1 to 47 years old. Of these, 21 have one or more children 16 years of age or younger. In approximately half of these families, our respondents (the grandmothers) are very involved in providing care to the children of their son or daughter with schizophrenia. In four cases the grandchild lives with their grandparents and in three other cases, the grandparents provide 20 hours or more of child care per week.

The Emotional and Physical Toll of Caregiving

The mothers in our study reported high levels of caregiving burden. Mothers reported a level of burden similar to the level found in caregivers to persons with Alzheimer’s disease.

These mothers show remarkably positive psychological well-being despite the burdens of caregiving. The mothers, on average, reported relatively few depressive symptoms. Also, the mothers’ scores on our measures of anxiety, positive psychological well-being, and self-esteem were quite similar to their age peers in the general population.

Although the majority of mothers are in good mental health, they reported many physical health problems, suggesting that the toll of caregiving may have a “wear and tear” effect on physical rather than mental health. Mothers reported an average of 7 health problems such as shortness of breath, high blood pressure, stomach problems, and headaches. Approximately 60% of the mothers reported a general lack of energy, fatigue, and back pain, and 41% had high blood pressure. About a third rated their health as poor or fair whereas only 16% said that their health was excellent.

On the Positive Side

The mothers display remarkable resilience despite the hardships involved in caring for a child with mental illness. Over half of the women said that they had grown “very much” as a result of coping with their child’s illness and developed a greater inner strength. Whereas mental illness may create rifts in some families, about 80% of the mothers reported that they had become closer to their family as a result of coping with the challenge of mental illness.
In addition, we asked mothers about the ways that their son or daughter help them. Adult children living with their parents are much more likely to be helping their parents than those living apart from their parents. Of those living with their parents, about half help with yard work, snow shoveling, and other general outdoor tasks. Also, about 60% have cared for their parents during an illness. When the adult lives away from home, they are most likely to help their parents by providing companionship.

**Who Supports the Mother-Caregiver?**

We asked the women in this study about their informal support networks — family, friends, and other people who are important to them in their daily lives. The mothers’ friends and family tend to live close by and they have frequent contact with them. Mothers have an average of 3 close friends whom they have known an average of 25 years. The mothers, on average, listed four family members to whom they felt very close and could turn to for emotional support and help during illness. Women who are currently married reported high levels of marital satisfaction and felt supported by their husbands. Only 2% expressed dissatisfaction with the level of support they received from their family and friends.

**Future Planning**

Almost all the parents expressed concern about what will happen to their son or daughter when they, the parents, are no longer able to provide care and support. Over 60% worry that there will be no one available to provide support to their son or daughter in the future. Their greatest fear is that their son or daughter will end up on the street, the hospital, or jail, when they, the parents, are no longer around to support them.

Approximately 80% of the mothers have spoken to someone about their son or daughter’s future care. Mothers, if currently married, were most likely to have spoken to their husband, or otherwise to another adult child. About a third met with a lawyer to discuss their son or daughter’s future care. Only 20%, however, had discussed this with a mental health professional or a psychiatrist.

Siblings of the adult with mental illness were identified as the one most likely to take on a future caregiving role, with brothers as likely as sisters to take on this role. About 10% of the families thought that a professional would take on this role after the parents’ death. However, well over 40% of the parents reported that there was no one to take on the caregiving role after the parent’s death. About 70% of the mothers interviewed spoke of making plans for the future. Most
commonly, parents had set up a trust or made arrangement in their will for their son or daughter’s care upon their death. Parents face many obstacles in planning including the reluctance of their son or daughter to discuss the future. The greatest obstacle, however, is that parents lacked information about how to go about planning for their son or daughter’s future care. Since few mental health professionals had discussed future planning with them, many parents were unaware of what steps could be taken to plan for their child’s future care.

Future Housing Needs

We asked mothers about their son or daughter’s future housing needs. About half of the respondents believe that their son or daughter will be able to live independently in an apartment or house without any special supports. Other parents feel that their son or daughter will require a supported or supervised living situation. Many parents expressed the need for housing modeled after assisted living housing available for older adults. In an assisted living facility, individuals have separate apartments but meals are provided, and staff are available to supervise medications and general activities. Parents suggested that this housing option would offer their son or daughter privacy and a sense of independence, but at the same time provide the supports necessary for their child to live successfully in the community.

African American Families

To-date, 30 African American families have participated in our study. We found that these families are experiencing high levels of distress. African American mothers had elevated levels of depression, with 38% above the clinical cut-off score for depression. They also report significantly higher levels of caregiver burden and anxiety than European American families, and significantly lower levels of self-esteem. African American mothers have more health problems, with 57% rating their health as poor or fair compared to 26% of the European American mothers.

There are many reasons why caregiving has taken a particularly severe toll on African American families. The adult with schizophrenia is significantly more likely to be living with the mother. In African American families, 67% of the adults with schizophrenia live at home; this contrasts with 42% in the rest of the sample. Also, 37% of the African American adults with schizophrenia also have a diagnosis of mental retardation, in contrast to 13% in other families. African American families also had fewer financial resources. As we continue this study, we will further explore the reasons for these differences between the experiences of African American and European American families.

Quality of Life of Adults with Schizophrenia

Of the 301 adults with schizophrenia, 148 agreed to complete a questionnaire and
telephone interview. In one section of the questionnaire, they rated their satisfaction with various aspects of their lives. These individuals are most satisfied with their living situation and their family life. Overall, they express high levels of satisfaction with their family relationships, with 84% saying that they are satisfied or very satisfied with the quality of their relationships with family members. Only 5% express dissatisfaction with their family relationships. The adults are most dissatisfied with their social life and their financial situation. Approximately a third express dissatisfaction with the number of friends in their lives and 25% with their finances.

**What’s Next?**

We have learned a great deal from our interviews with families. But interviewing families only once does not provide the longer lens that is needed to understand the many challenges that families face in coping with schizophrenia. There has been virtually no research on how the experiences of families change over time. We are fortunate because the National Institute of Mental Health has provided us with funding to interview each family a second time. We very much hope that you will continue to participate in the study so that we can expand our understanding of the course of schizophrenia and the future service needs of persons with schizophrenia and their family members.