Aging Families of Adults with Schizophrenia: Planning for the Future

A Profile of Adults with Schizophrenia

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History of the Study

This study is funded by the National Institute of Mental Health to understand the needs of adults with schizophrenia and their families as they grow older. We know relatively little about the health and well-being of adults with schizophrenia as they enter middle-age. Therefore, it comes as no surprise that there is much to be accomplished in the development of informed public policy and services for adults with schizophrenia as they age.

Purpose of this Report

Our study is longitudinal, which means that we are interviewing consumers on three different occasions (every 18 months) over a five-year period in order to understand how their needs change over time. During the past three years, 120 consumers have participated in our study in both the first and second data collections. We are currently in the process of asking consumers to complete a questionnaire for a third time. In this report, we provide our findings on changes that have occurred in the lives of consumers who have participated in our study at the first two time periods which we refer to as Time 1 and Time 2 throughout this report. As we continue our study over the next year, we will develop a more complete understanding of how the experiences of consumers change as they grow older.

Who Are the Consumers Who Have Participated?

- 120 participated in the first two time periods of our study.
- Average age is 41 years.
- 74% are male.
- 89% are white, 8% are African American, and 3% Hispanic or Native American.
- 44% live with their parent(s).
- Approximately 90% are high school graduates and of these, 19% went on to graduate from college.
- 43% work in either a competitive job or supportive employment, working between 15-20 hours per week.
- Over 90% are receiving mental health services, mostly from a community support program or an outpatient mental health program.
Physical Health

One of the most unexpected and important findings from our interviews thus far is the high prevalence of health problems in adults with schizophrenia.

Approximately 33% of the consumers reported that their health was poor or fair, and 20% reported that their health had deteriorated over the past 18 months. Figure 1 compares the health problems reported by the 120 consumers to the rates of health problems in the general Wisconsin population from a recent survey by the Center for Disease Control of 25-54 year old individuals. As shown, consumers were about five times as likely to have diabetes as their age peers in the general population and about 1.5 times as likely to have high blood pressure. A greater percent of consumers also had high cholesterol while there were small differences in the rates of asthma.

**Figure 1: Health Problems of Adults with Schizophrenia Compared to Their Age Peers**

Dental and hearing problems were common, with about half of the consumers reporting dental or hearing problems. Many consumers commented on having great difficulty finding dental care. In the words of one consumer:

*There needs to be more dentists who take medical assistance, I have a really good psychiatrist but can’t find a good dentist.*

Almost all consumers reported problems managing their weight. Approximately two-thirds of the consumers were overweight. Many consumers expressed frustration with weight gain caused by medications.
I wish there were new medications available so people didn’t have to gain so much weight. I gained 50 pounds since taking Zyprexa.

The meds make me gain weight and feel tired and lazy.

Many consumers tried to control their weight gain through exercise. About half of the consumers exercised regularly, typically walking or bicycling. However, 43% of the consumers report having difficulty walking one block or more, or climbing a few flights of stairs.

**Mental Health**

At each time period, we asked consumers to report how much they experience various symptoms associated with schizophrenia such as hearing voices, feeling controlled by others, and believing that others are aware of their thoughts. We also asked questions about their mood. Figure 2 shows the percent of consumers in the sample who reported experiencing a particular symptom a “great deal” or a “medium amount” at Time 1 and Time 2. It should be noted that the differences between the Time 1 and Time 2 bar graphs represent group level changes in the number of consumers in the study who reported experiencing the symptom, and may not necessarily reflect the degree of change within individuals in their symptom levels.

Our study results suggest that the symptoms of schizophrenia remain relatively stable over time. About 25% of the consumers reported hearing voices at the first interview and this dropped to about 20% by the second interview. Very few consumers (less than 10%) reported feeling like they wanted to harm someone. The most common symptom was nervousness. Almost half of the consumers reported feeling nervous at both time periods.

**Figure 2: Psychiatric Symptoms Experienced by Adults with Schizophrenia**
Employment

At our first interview, only 44 of the 120 adults with schizophrenia were employed, and worked an average of 15-20 hours per week. At the second interview, 46 consumers were working, but these were not necessarily the same people.

Even though the total number of consumers who were working changed little over the 18-month period, there was a lot of individual change. Eight consumers who were working at the first interview were no longer working at the second interview. Twenty-five consumers either found jobs or experienced a job change between the first and second interview. Thus, many consumers were in and out of the work force or moved from one job to another over a relatively short period of time.

Part of the reason that fewer consumers worked was because of the discrimination they faced in the labor market. In the words of one consumer:

*It can be difficult finding a job if they know you have a mental illness. I’m open about my illness. It can be hard because people don’t understand mental illness and so they treat you differently.*

Social Activities

Persons with schizophrenia participate in a variety of activities during the week. For participants in the study the most frequent social activities were going to a restaurant and spending time with friend. About 50% of the consumers attended church weekly and a similar proportion worked on a hobby.

[Figure 3: Participation in Social Activities]

- Go to a Restaurant
- Spent Time with a Friend
- Go to Church
- Work on a Hobby

Time 1 vs. Time 2
Receipt of Mental Health Services

We asked consumers about the kinds of services that they were currently receiving and their level of satisfaction. As shown in Figure 4, consumers were most likely to receive individual counseling or therapy and assistance with medication. About a quarter of the adults reported that they received job or educational training. Although in recent years there has been an emphasis on vocational services, less than 4 in 10 consumers reported receiving help finding a job at Time 2.

Figure 4: Percent Receiving Different Types of Mental Health Services

Overall, consumers reported high levels of satisfaction with the services they received. Over 80% liked the services that they received, found them conveniently located, and felt that the services they needed were available. They also reported feeling comfortable asking the mental health staff questions about their treatment, and thought that they were able to see a psychiatrist when they needed. Consumers were least satisfied with their ability to reach someone at night, with over 50% reporting difficulty reaching a staff member after regular business hours.
Discrimination Experienced by Persons with Schizophrenia

At the second visit, we asked adults with schizophrenia to report on their experiences of being discriminated against in different areas of their lives because of their mental illness. As shown in Figure 5, about 80% reported that they had been treated with less courtesy and respect because of their illness. About 64% had received poorer service than other people at a restaurant or store and 63% reported that other people appeared to be afraid of them because of their illness. Approximately one-third felt that they had been denied a job because of their mental health problems, and about one-quarter reported that they had been hassled by the police. Our data clearly indicate that persons with schizophrenia are often the targets of daily acts of discrimination.

Many consumers commented on their experiences with discrimination they faced when in public. In the words of one consumer:

*When things are going good, sometimes I forget that I have a mental illness. But when I go out in public, people always remind me of it. I go to church and dress like a normal person but people dislike me for my nervous behavior. I would take computer class, but I won’t because I would stick out like a sore thumb.*
Another consumer shared:

*We are humans and make mistakes (sometimes more than others), but we’re also smart in other areas of our lives. We want to be respected like other people and not just ignored or thought of as dumb because we don’t open up as much as other people.*

**Quality of Life**

At each visit, we asked consumers to answer questions about their satisfaction with various aspects of their lives. What may appear to be a contradiction (given the many difficulties they face in the social and occupational realm and their experiences with discrimination) is that the greater majority of adults with schizophrenia in our study report being satisfied with various aspects of their lives. Figure 6 shows that the consumers are most satisfied with their living situation, family relationships, and access to health care. This speaks to their ability to maintain a positive outlook despite the difficulties many face in coping with their illness.

![Figure 6: Life Satisfaction of Adults with Schizophrenia](chart.png)
Although the majority of adults reported high levels of quality of life, there are many individuals who continue to experience considerable distress. This is evident by the fact that over the 18-month period, about 20% of the consumers threatened to hurt themselves, and about 8% attempted to hurt themselves. Also, about 20% of the participants reported that they felt lonely and hopeless about the future. Here are a few comments from consumers who continue to struggle:

*I try to hide my negative feelings and actions because I’m afraid people will say I’m sick. I do not want to see my social worker or psychiatrist often because if I do, I feel sick. I like to pretend I am well. I started drinking recently to feel good.*

*I appreciate the care I receive. I just wish that I would feel better. It’s a poor way to go through life this way.*

*I am normal but not “normal” enough. I feel very isolated because of this. I wish and I hope that I can find a support group that will address this issue.*

*I try to hide my negative feelings and actions because I am afraid people will say I am sick.*

*It’s a day-to-day struggle. It’s not fun. I get delusions and hallucinations once in a while and wake up and wonder what’s going to happen. I try so hard to get myself together. I do things everyday and try to go to the clubhouse.*

Although we find the majority of adults with schizophrenia report being satisfied with their lives, we must not forget that there are still many who do not share this good fortune.
Consumers As Resources to their Families

Over the years, the emphasis of research has been on the burden of coping with a relative who has a mental illness. However, many persons with mental illness make valuable contributions to their families, especially as their parents age and experience physical declines. We asked consumers about the ways that they helped their parents. For the most part, the amount of help consumers provided their parents remained relatively stable over the 18-month period. As shown in Figure 7 below, at both time periods approximately 60% of the consumers reported helping their parents during an illness and approximately 40% helped with indoor tasks. However, there was a small decline (59% to 50%) in the percent of consumers who reported helping their parents with outdoor tasks.

It should be noted that consumers who lived with their families were more likely to help their parents. For instance, approximately 60% or more of the consumers who lived with their parents reported helping with indoor or outdoor household chores, and shopping. In comparison, about 30% or less of the consumers who lived away from their parents reported providing help with these tasks.

Figure 7: Assistance Provided by Consumers
Worries about the Future

Many consumers expressed worrying about the future when their parents would no longer be available as a source of support. During our first data collection period, about 50% of consumers reported that they worried a lot about the future. Consumers reported worrying less by the second period of data collection. At Time 2, about 33% of the consumers worried a lot about the future.

Many consumers worry about being able to pay bills, being alone, and not having others to turn to for support. Here are some worries about the future shared by the consumers:

- About missing my mom and what it will do to my mental health.
- About keeping friendships going, socializing with neighbors and friends, and maintaining my church membership.
- Being able to hold down a job when my parents are gone.
- That I might do something crazy without my parents providing support.
- That I won’t be able to take care of myself and will be all alone.
- That I’ll get real symptomatic and not get better.
How Consumers Cope with their Problems

We asked consumers to share with us how they have coped with their problems. Many said that they turned to prayer and reflection. Others spoke of turning to their friends and family. And yet others kept busy or wrote their thoughts down on paper. Here are some of their thoughts on coping:

*I try being truthful about my problems—realizing and admitting that you may have a problem.*

*I write down my problems or symptoms, and what can I do to cope. Then I look at my writings when I’m not rational.*

*Reading self-help books and attending recovery training groups.*

*Talking to somebody about daily routines, and my ups and downs.*

*Just accepting. Surrendering that some things cannot change.*

*Keep busy around home, doing chores around home.*

General Advice

We asked consumers what advice they would give to others who are just beginning to cope with mental illness. Here are some of their suggestions:

*With counseling, medication, and sobriety, my life has improved dramatically. I now have some modicum of independence thanks to the mental health professionals I have encountered.*

*As a long-term psychiatric patient I can’t say this enough. If your doctor provides medication, please do not stop taking the medication.*

*My advice to anybody with schizophrenia is to try not to be too stressed by other problems. Try not to focus too much on problems because it will make the schizophrenia worse.*
In their journey with mental illness, consumers reported having many positive and negative experiences. We would like to share some of these moments:

**On the Downside…**

*There are too many inexperienced mental health care providers… The people are good, but limited in what they are available to do.*

*I have a unique perspective about the mental health system while being in prison. The service is terrible. Just requesting to see a doctor takes more than a week. Sometimes longer.*

*I wish that the psychiatrist would take more time to listen to past problems to get better understanding on what’s going on now. You can’t dwell on the past but it should be mentioned.*

*People with mental health problems are often treated as criminals.*

*Switching caseworkers all the time is frustrating. I’ve had five caseworks in five years.*

*I would like to share that after 17 years in a community support program, it was determined that I no longer need their help.*

**On the Upside…**

*I have always had a few close friendships and those people have stood by me and cared about me through everything. Without the support of my family and friends and the fellowship I would be either dead or institutionalized by now.*

*The community support system has been very helpful to me in making friends. The quality of the social workers has drastically improved in the past 8-10 years.*

*Healing relationships with my family was the best choice I’ve made. Choosing to work on those relationships was the basis for my recovery.*

*I used to be suicidal. Now I’m just happy to be alive.*

*I’ve had some difficulty working in the past, but my present job is rewarding and I consider it a privilege to be working.*

*My experience with the mental health system has gone from very bad 30 years ago to extremely well in the past 10 years.*

*I was recently appointed as a member of the county’s human service board. This is a tremendous step for a mental health consumer to be recognized and accepted to such a responsible position.*
What’s Next?

We have learned a great deal from consumers. We believe that our findings about the health and quality of life of persons with schizophrenia provide valuable information concerning the unique needs of persons with schizophrenia as they age. This is a critical time for the mental health system because of impending budget cuts that will affect the range and intensity of services provided to persons with a serious mental illness. During this time, it is vital that we collect information from persons with schizophrenia and their families in order to have the data to document the mental health services needs of consumers and their family members. We are fortunate because the National Institute of Mental Health has provided us with funding to interview each family and consumer a third time. We very much hope that consumers 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.