

**Schizophrenics Anonymous Evaluation Final Report:
Member Engagement and Change**

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The purpose of this evaluation was to increase our understanding of how Schizophrenics Anonymous (SA) helps its members and how it expands to serve additional people. The evaluation had two components: a) an examination of member engagement and change and b) an exploration of SA's organizational expansion and leader development. This final report describes our findings concerning member engagement and change. The goal of this component of the evaluation was to develop an understanding of who attends SA and how SA helps its members. These questions were explored by surveying all interested SA members and leaders in Michigan (see Appendix A for a description of the survey methodology and a more detailed report of survey results) and by conducting intensive ethnographic interviews with a smaller sample of SA group members and leaders (see Appendix B for a description of the qualitative methodology and a more detailed report of the results). Using this data we were able to answer the following questions.

Question 1: Who attends SA?

SA serves a broad spectrum of individuals with schizophrenia, including those who live and work independently, those who live and work in supervised or sheltered settings, and those residing in psychiatric or forensic institutions. While SA participants vary considerably in terms of their current level of functioning, almost all have histories of multiple psychiatric hospitalizations. While having much in common with each other, SA leaders and members were significantly different from one another in terms of their sex, living situation, and level of education. SA leaders were more likely to be women, to live independently, and to have completed a higher level of education.

Member Characteristics: Sixty-four percent of the SA members surveyed were male. Their average age was 40 years old with a range from 19 to 68. The majority were white (66%) and never married (68%). Fifty-three percent had graduated from high school and an additional 22% had a college or graduate degree. Most were diagnosed with schizophrenia (78%) or schizo-affective disorder (10%). Almost all members (93%) had been hospitalized for psychiatric reasons, with a mean of 5 hospitalizations. The majority were either unemployed (69%) or in sheltered employment (11%) and were receiving disability benefits (76%). Thirty-five percent of the members lived independently in their own home or apartment.

Leader Characteristics: Sixty-six percent of the SA leaders surveyed were female. Their average age was 42 years old with a range from 21 to 66. The majority were white (78%) and never married (61%). Fifty percent had graduated from high school and an additional 44% had a college or graduate degree. Most were diagnosed with schizophrenia (63%) or schizo-affective disorder (23%). Almost all leaders (97%) had been hospitalized for psychiatric reasons, with a mean of 6 hospitalizations. The majority were either unemployed (60%) or in sheltered employment (3%) and were receiving disability benefits (64%). More than half of the leaders (67%) lived independently in their own home or apartment.

Comparison of Members and Leaders: Chi Square analysis indicated that SA leaders and members differed significantly from each other in terms of their sex, living situation, and level of education. While the majority of members were men (64%), leaders were more likely

to be women (56%). SA leaders were more likely to live independently (67%), while SA members (61%) were more likely to live with family members, in supervised housing, or institutional settings. Almost all SA leaders had finished high school (94%) and many had earned a college or graduate college degree (44%). In contrast, 25% of SA members had not completed high school and only 22% had a college or graduate degree (see Table 1).

Question 2: How long have SA members and leaders been involved in SA and how often do they attend SA meetings?

The SA members and leaders that we surveyed had been attending SA for varied amounts of times, ranging from 1 month to 12 years. The majority attended SA meetings at least once a week. It is important to keep in mind that attending SA meetings is only one aspect of SA involvement. Outside of SA meetings members may be involved in leadership activities, formal social activities and informal social contacts.

Involvement of Members in SA: The length of time of membership in SA for members ranged from 1 month to 12 years. Fifty-seven percent of SA members had been members for one year or less, 17% had been members for between 1-2 years, 13% had been members for 2-3 years, 13% had been members for more than 3 years. The majority of SA members attended SA meetings regularly, about once a week (55%) or more than once a week (13%). A smaller percentage of SA members attend two or three times a month (17%) or about once a month or less (15%).

Involvement of Leaders in SA: The length of time of membership in SA for leaders ranged from 1 month to over 12 years. Thirty-one percent of SA leaders had been a member of SA for one year or less, 19% had been members for between 1-2 years, 8% had been members for 2-3 years, 42% had been members for more than 3 years. The majority of SA leaders attended SA meetings regularly, about once a week (70%) or more than once a week (8%). A smaller percentage of SA leaders attend two to three times a month (17%) or about once a month or less (6%).

Question 3: Do SA participants identify with or feel they have a lot in common with one another (i.e., referent power)? How does this compare to how much they feel that they have in common with their therapists?

The survey explored whether or not SA participants feel they have a sense of identification (i.e., referent power) with other SA members and leaders. This sense of identification has been identified as a potential change mechanism in self-help groups. Our results indicate that many SA participants had a strong sense of identification with fellow SA participants. In addition, we found that SA members experienced a stronger sense of identification with fellow SA members and leaders than they did with their primary therapist.

Forty-six percent of the SA participants had a strong sense of identification (“a fair amount” or “a lot”) with SA members and 51% had a strong sense of identification with SA

leaders. In contrast, only 32% had a strong sense of identification with their therapist. A repeated measures ANOVA was performed to compare participants sense of identification with SA leaders, SA members, and their primary therapist. The analysis included one within-subjects factor (ratings of the three target groups-SA leaders, SA members, and Primary Therapists, one between-subjects factor (respondent's group role--member or leader), and one interaction term (rating target by group role). The mean ratings of referent power, listed in Table 2, indicated that the ratings of the three target groups were significantly different. Primary therapists received lower ratings than SA leaders and SA members. In addition, referent power ratings made by SA leaders were significantly higher than the ratings made by SA members.

Question 4: Does an individual's role in their SA group (member vs. leader) impact his or her feelings of identification with other participants?

SA leaders expressed stronger feelings of identification with other SA members and leaders than SA members did. In addition, SA leaders expressed a stronger feeling of identification with other SA leaders than they did with SA members. SA members did not make this distinction.

The F test for the Role by Target interaction effect was statistically significant (see Table 2), suggesting that the differences in the ratings of the three target groups was influenced by the respondents' role in their groups. SA leaders ascribed more referent power to other SA leaders than to SA members, while SA members ascribed an equivalent amount of referent power to SA leaders and members. In addition, while members and leaders rated professionals similarly, SA leaders reported more referent power than SA members with regard to other SA members and leaders. Significant differences between levels of referent power that members and leaders ascribed to fellow participants was confirmed with post-hoc t-tests (referent power ascribed to leaders: $t = 3.78$, $p < .05$; referent power ascribed to members: $t = 2.06$, $p < .05$).

Question 5: Do SA participants value the knowledge and expertise (i.e., expert power) of fellow participants? How does this compare to how they value the knowledge and expertise of their primary therapist?

The survey explored whether or not SA members and leaders value the expertise and knowledge of fellow SA participants. Experiential knowledge (i.e., knowledge gained from living with schizophrenia) has been identified as an important aspect of self help. The results indicated that the majority of SA participants feel that other SA members and leaders have valuable experiences and expertise to share. When compared to their therapists, SA participants viewed therapists and SA leaders as having more knowledge and expertise than fellow SA members. Importantly, respondents viewed professionals and SA members/leaders as most helpful with different types of problems. Professionals were viewed as best equipped to help with issues related to medication and symptom management, professionals and family/friends were viewed as the best equipped to help with interpersonal difficulties, and fellow SA participants were viewed as best able to help when they wanted to talk to someone who really understands what it's like to have schizophrenia. Participants were almost equally

divided among SA participants, professionals, and family/friends in terms of who they felt was best able to help them when they felt lonely.

Seventy-nine percent of SA participants valued the expertise and knowledge of other SA leaders (“a lot” or “a fair amount”) and 65% valued the expertise and knowledge of other SA members. A repeated measures ANOVA was performed to compare participants sense of expert power with SA leaders, SA members, and their primary therapist. The mean ratings of expert power, listed in Table 2, indicated that participants differed significantly in terms of their perceptions of the knowledge and expertise offered by SA members, SA leaders and their primary therapists. The SA participants ascribed the highest amounts of expert power to their primary therapist and to SA leaders, and the lowest amount to SA members.

In order to explore differences in the types of expertise ascribed to professionals and SA participants, respondents identified who had the knowledge and experience to best help them with different types of problems. In order to more accurately portray the helping role of SA and professional helpers, the respondents also had the opportunity to choose their natural network of family and friends as the best helping source for these problems. Chi-square analyses indicated that participants judgement of who was best equipped to provide help depended on the type of problem (see Table 3). SA participants were significantly more likely to view professionals as best able to help them with issues related to medication and symptom management, professionals and family/friends as the best equipped to help with interpersonal difficulties, and fellow SA participants as best able to help when they wanted to talk to someone who really understands what it's like to have schizophrenia. SA participants were almost equally divided among fellow SA participants, professionals, and family/friends in terms of who they felt was best able to help them when they felt lonely. Chi-square analyses comparing who leaders and members judged best able to help them with each type of problem indicated that leaders and members did not significantly differ in this regard. It is interesting to note, however, that for dealing with loneliness, the pattern of results was slightly different for leaders ($\chi^2(2) = 3.95, p = .14$). SA leaders were more likely to view fellow SA participants (46%), than family/friends (37%) or professionals (17%), as best equipped to help when they were feeling lonely.

Question 6: Does an individual’s role in their SA group (member vs. leader) impact their feelings of expert power?

SA leaders tended to perceive SA members, SA leaders, and primary therapists as having more knowledge and expertise than SA members thought they had.

There was a trend for SA leaders in our sample to rate all three target groups as higher in expert power ($p=.068$) than members did (see Table 2). The F test for the Role by Target interaction effect was low, suggesting that the differences in the ratings of the three target groups were not a function of the participants’ role in their SA groups.

Question 7: What predicts the perceived helpfulness of SA?

Participants were more likely to find SA helpful when they felt a sense of identification (i.e., referent power) with other SA members or believed that fellow members had valuable knowledge and expertise (i.e., expert power). Participants' belief that fellow participants had valuable knowledge and expertise was the strongest predictor of helpfulness. Length of membership in SA was also related to perceived helpfulness.

Participants' ratings of their groups' helpfulness were significantly correlated with the length of time they had been in SA ($r = .29, p < .05$). Ratings of their groups' helpfulness were also significantly correlated with their ratings of the expert power of SA leaders ($r = .53, p < .05$) and SA members ($r = .52, p < .05$). Finally, ratings of group helpfulness were significantly correlated with ratings of referent power of SA leaders ($r = .38, p < .05$) and SA members ($r = .37, p < .05$). In order to explore the independent predictive relationships of expert and referent power with group helpfulness, as well as their interactive predictive effect, two hierarchical multiple regression analyses were performed (one using the ratings made about SA leaders, one using the ratings made about SA members). Both analyses included the expert and referent power ratings in the first hierarchical step and a "referent power by expert power" interaction term in the second hierarchical step. In the first regression analysis with the ratings made about SA leaders, the standardized regression coefficients suggested that expert power was a better independent predictor of perceived helpfulness than referent power (see Table 4). The results of the second regression analysis, examining the predictive power of the expert power and referent power ratings made about SA members, paralleled the first analysis of ratings made about SA leaders. The stronger independent predictor was expert power compared to the referent power ratings (see Table 4).

Question 8: In what ways do SA members and leaders find SA helpful?

Survey participants report that SA was helpful to them with regard to many issues related to schizophrenia. The majority of members report that attending SA helped them to manage their symptoms, increase their knowledge about schizophrenia, combat feelings of loneliness, make friends, and improve their social life.

Seventy-three percent of SA participants reported that attending SA helped them ("a fair amount" or "a lot") in the management of the symptoms of their illness, 83% reported that SA helped them to learn more about schizophrenia, 72% reported that SA helped them to feel less alone, and 68% felt that SA helped them to make friends and improve their social life.

Analysis of the ethnographic interview data allowed us to explore in more depth exactly what SA members and leaders found the most helpful about their involvement in SA. Allowing participants to describe their experience in SA in their own words yielded a rich description of what involvement in SA means to its members. Participants reported that their involvement in SA: 1) helps them to learn about the illness and how to cope with it, 2) changes their feelings about themselves, 3) provides opportunities for participation in meaningful social roles, and 4) helps to combat feelings of loneliness and social isolation. (See Appendix B for a detailed

description of the qualitative methods and results).

Learning More About Schizophrenia and How to Cope With It

Learning about schizophrenia, through formal information disseminated at the meetings and through the sharing of experiences in the group, has given members of SA greater insight and understanding into their own illness and enhanced their ability to cope with it. Members value the sharing of information about schizophrenia; about resources, treatments, and medications; and about the experiences others have had coping with their illness. They feel that learning more about their illness helps them to accept it and to adopt a proactive role in managing their own illness. Some members also report that the information they receive in SA helps them to educate their families about their illness.

Learning about the illness. For SA members learning about symptoms, side effects of medications, different treatment and medication options, the availability of resources, and how others handle issues related to their illness is an important aspect of their experience in the group and helps them to cope more effectively with their illness.

I've learned a lot over the years. When I began I learned a lot. I was able to put the disease in perspective, where before that I was just a victim. So it [SA] did that. I guess I learn about different treatments constantly and I'm able to listen to different members' problems and I've learned a lot of information that I withdraw as needed, so I know I have tons, you know, recognizing different side effects and things like that, and that's from the experience [of other members].

Members are particularly helped by what they learn about medication:

That's a big factor that might get understated, too, is we keep track of the new meds that come out. We hear from our different group members. We know, I get enough stuff coming in the mail to me that I know what the upcoming meds are. And you hear experiences that other people say about meds. Zyprexa has really helped me. I heard about it, I knew about it coming, from the literature coming in. Then one of our

members was having a really good experience with it. I was able to do the same thing and take it.

Acceptance of Illness. Access to information about schizophrenia helps members to accept the fact that they have schizophrenia.

I've learned that I guess I do have some mental problems. I do have a mental illness. I was in denial because I felt like I could work as a normal person. I guess that's what I've learned the most. But I've also learned how to deal, how to cope with it. Which, that helps out a lot. I learned how to deal with it...I've learned to take my medicine and if I have any problems, to discuss it during group. And when we discuss our problems

during group, it helps out when it's open table because there's always someone who gives helpful advice in how to deal with it.

Playing Active Role in Managing Ones' Illness. Being educated about the illness also helps participants to take control of their lives and to play an active role in maintaining their health and managing their illness.

I learned how to handle my illness better, knowing when I get sick....And it's just like a diabetic. You gotta know about your illness in order to take care of it. And I don't think one can be, take responsibility for their illness or their life unless they're educated in the illness.

Educating Families. Information about schizophrenia made available through SA is used by SA members to educate family members or others who are close to them. Members report that the sharing of information about schizophrenia can help friends and family members to better understand their experiences and to cope more effectively with the manifestations of their illness.

The literature has been very good. I've made numerous copies of three or four different articles and I've given copies of this to my mom, my brother's family, and to my oldest sister's family and her husband. To my old housemate. I don't think he read any of it but... And to my minister, my, one of the elders at church and to my friend, [Paula]¹, who I used to live with, and her son. I gave a copy to her, copies. So I'm seeing it's a matter of education....

Changing Their Feelings About Themselves

Members report that their involvement in SA helps them to change how they feel about themselves. They described decreased feelings of shame; enhanced feelings of value, worth, and esteem; forgiveness and acceptance of oneself and others; development of more realistic expectations and new goals; and increased feelings of hopefulness.

Decreased Feelings of Shame. SA helps many members to address the shame that accompanies a diagnosis of schizophrenia and to consequently feel better about themselves.

Not to be ashamed of having a mental illness. I talk openly about it more than I used to.

Enhanced Feelings of Value, Worth, and Esteem. Participation in SA provides members with opportunities to engage in social interactions that reinforce positive feelings about themselves.

¹All participants' names have been replaced by pseudonyms.

I come away feeling like a good person. A person who is liked. I do... It just boosts my self esteem actually.

Forgiveness and Acceptance of Self and Others. The SA program, and specifically the six steps, helps members to forgive themselves and others for past wrongs and mistakes and to accept themselves for who they are.

The steps? Yeah, they help in every day life, yeah...My favorite one is forgiveness. That it really helps to relieve the burden if you can forgive yourself, especially yourself and others.

More Realistic Expectations and New Goals. Members also report that SA helps them to learn about what to expect from the illness over time and to redefine goals and expectations based on this information.

...I wanted to be a chief executive officer and now I'm just a dispatcher. I'm happy with that job. Glad to have a job. And glad to have benefits and steady employment and just lead a normal life, you know. And not try to be superwoman of the 80s that we were brought up to be, you know... I was really gung ho on being top boss.

Increased Feelings of Hopefulness. Participating in SA helps members feel more hopeful about their recovery and the possibilities for their life.

I'm learning how to dream and not look at my life... I'm learning how not to look at the terrible things that are happening right now. I'm learning how to dream and have hopes and aspirations... they've let me express myself by talking in the group and they let me hope and plan for the future.

Providing Opportunities for Participation in Meaningful Social Roles

SA provides members with the opportunity to participate in meaningful social roles, including leading meetings, helping others, working on literature and other educational materials for SA, public speaking to address the issue of stigma, etc. These opportunities provide members with a sense of meaning and purpose.

It's [SA] given me worthwhile things to do. I guess that's really a big factor. Big factor is giving me things, something worthwhile to do with my life at times when I was very down.

Helping to Combat Feelings of Loneliness and Social Isolation

There are many ways that SA helps to combat members' feelings of loneliness and social isolation. It helps members to realize that they are not alone with their illness; provides a sense of identification with others who really understand their experiences; provides a safe place to talk about their illness; and provides support, acceptance, friendship and fellowship.

Decreases Social Isolation "We are not alone". Participating in SA decreases members sense of being alone because they learn that there are many others who share similar experiences.

I think the thing that I most got out of it is the feeling of not being alone.

Identification with Other Members. SA members describe the value of being with others who they can identify with and who can really understand their experiences.

We could all relate, you know, and I think the big issue of being able to relate to one another is a big step. You know, having something in common. And let's face it, that's what most relationships are based on is something in common, you know?

[I] felt like a puppy that had been reunited with his litter.

Some compare their experience in SA to their experience with professionals.

Because I can relate to these people. They can relate to me and my psychiatrist and my therapist cannot... Just like if I had my arms and legs chopped off and I had to see a therapist about it, I would rather see a therapist that was in the same position that I was than someone who was not, because they wouldn't understand and that's how I feel. I want someone who understands.

A psychiatrist only knows what the textbook tells him. He doesn't know what the voices are telling you, cause he hasn't had any talk to him.

A Safe Place to Talk About Schizophrenia. SA provides a setting that encourages members to express their feelings and to be open and communicative with other members. For many SA members, this is the first time they have been able to talk openly and freely about their experiences and illness.

It's meant a lot to me as far as meeting people with the same illness that understand my illness. I can talk about my illness without worrying about chasing people away, you know, scaring people away. There's new faces all the time, new people to talk to.

For some members, this helps them to develop better social skills and to interact more comfortably with other people.

...it's made me come out from being by myself. I stayed in a room all the time by myself and I wasn't talking to people. So I think it has helped me to come out with my problems and be able to see other people and talk with them. Which before, I couldn't do.

Support, Friendship, and Fellowship. Participating in SA provides members with feelings of belonging, acceptance, support, friendship, and fellowship.

The camaraderie with people who have the same problems I have. Support. Belonging. Really feeling like you belong....That people really do care. That people really do care.

I have to say that this is one of the most wonderful things that ever came into my life. It definitely is a strong, huge 2 X 4 that holds up my life.

Acceptance, absolute acceptance. I have a problem with tardive dyskinesia but here, it doesn't matter...In the hospital, in group therapy, everybody tries to outdo everybody else. But here, you're accepted...To me, that's wonderful.

They are kind of a tether for my balloon. It's kinda like you see these hot air balloons all inflated and they've got their tethers down and it's kinda like all the balloons are schizophrenics and the crew is influenced by [a] schizophrenia inflated thing and they all tethered each other down until it's time to be released.

Role and Value of Shared Experience. The shared experiences that emanate from having schizophrenia are an important aspect of SA. Members value hearing each others stories and experiences. They value the sharing of experiential knowledge (i.e., knowledge gained from living with schizophrenia) and learn how to cope with their illness from the experiences of others.

It's support from the fact that you're hearing what other people are experiencing and you can compare it to your own situation and then decide if there's some aspect you

might improve yourself....It's helped me, I think, learn of other people's experiences.

Summary

Based on the survey data it is clear that SA serves a broad spectrum of individuals with schizophrenia, including those who live and work independently, those who live and work in supervised or sheltered settings, and those residing in mental health or forensic institutions. While SA members vary considerably in terms of their current level of functioning, almost all have histories of multiple hospitalizations.

SA plays a unique role in the lives of its participants. They view the helping roles of SA and professionals quite differently. SA participants tend to view professionals as the *best* equipped to help them with medication and symptom management. Fellow SA participants, on the other hand, are viewed as *best* equipped to help when they are feeling lonely or want to talk to someone who understands what it is like to have schizophrenia. This finding is consistent with SA's goal to provide support in conjunction with professional services.

SA participants report that they experience a sense of identification with SA members and leaders. They do not tend to feel the same level of identification with their primary therapist. The majority of SA participants also feel that other SA members and leaders have valuable expertise to share. Participants are more likely to find SA helpful when they feel a sense of identification (i.e., referent power) with other SA members or believe that fellow members have valuable knowledge and expertise (i.e., expert power).

Members report that SA is helpful to them regarding many issues related to schizophrenia. The majority of members report that attending SA has helped them to manage their symptoms, increase their knowledge about schizophrenia, combat feelings of loneliness, and make friends and improve their social life.

The qualitative findings echo these results. SA participants report that their involvement in SA helps them in a variety of ways. First, it helps them to learn about the illness and how to cope with it. Learning about schizophrenia, through formal information disseminated at the meetings and through the sharing of experiences in the group, has given SA participants greater insight and understanding into their own illness and enhanced their ability to cope with it. Participants value the sharing of information about schizophrenia; about resources, treatments, and medications; and about the experiences others have had coping with their illness. They feel that learning more about schizophrenia helps them to accept their illness and to adopt a proactive role in managing it. Some participants also report that the information they receive in SA helps them to educate their families about their illness.

Second, SA participants report that their involvement in SA helps them to change how they feel about themselves. They describe decreased feelings of shame; enhanced feelings of value, worth, and esteem; forgiveness and acceptance of themselves and others; development of

more realistic expectations and new goals; and increased feelings of hopefulness.

Third, SA provides opportunities for participation in meaningful social roles, including the role of helping others, working on literature and other educational materials for SA, and public speaking to address the issue of stigma. These opportunities provide members with a sense of meaning and purpose that may not be available to them in other life domains.

Fourth, involvement in SA helps to combat feelings of loneliness and social isolation. It helps members to realize that they are not alone with their illness, provides a sense of identification with others who really understand their experiences, provides a safe place to talk about their illness, and provides support, acceptance, friendship and fellowship. In addition, the shared experiences that emanate from having schizophrenia are an important aspect of SA. Participants value hearing each others stories and experiences. They value the sharing of experiential knowledge (i.e., knowledge gained from living with schizophrenia) and learn how to cope with their illness from the experiences of others.

Overall, these findings suggest that SA provides support, fellowship, and information to a range of people experiencing a schizophrenia-related illness. It helps participants to combat feelings of loneliness and isolation that often accompany a diagnosis of schizophrenia and provides a setting where members feel that their experiences are shared and understood by others. While most SA participants value the help they receive in professional settings, SA provides a unique type of help in dealing with schizophrenia that members do not receive from professionals or from other mental health organizations.

Table 1
 SA Leaders' and SA Members' Responses to Demographic Questions

Demographic Variable	Group Role		χ^2
	Members (<u>n</u> = 120)	Leaders (<u>n</u> = 36)	
Gender			
Men	77 (64%)	16 (44%)	4.47*
Women	43 (36%)	20 (56%)	
Ethnicity			
Nonhispanic White	80 (67%)	28 (78%)	2.08
African-American	34 (28%)	6 (17%)	
Hispanic/Latino	3 (3%)	1 (3%)	
Other	3 (3%)	1 (3%)	
Marital Status			
Never married	81 (68%)	22 (61%)	3.48
Currently married	10 (8%)	7 (19%)	
Separated, divorced, widowed	28 (24%)	7 (19%)	
Education Level			
Did not complete HS	30 (25%)	2 (6%)	10.43*
HS graduate or some college	63 (53%)	18 (50%)	
Associates, BA or Graduate degree	26 (22%)	16 (44%)	

table continues

Table 1 (continued)

Demographic Variable	Group Role		χ^2
	Members (<u>n</u> = 120)	Leaders (<u>n</u> = 37)	
Living Situation			
Lives independently	46 (38%)	24 (67%)	10.95*
Lives with family member	27 (22%)	5 (14%)	
Supported/supervised residence	32 (27%)	5 (14%)	
Hospital/forensic center	14 (12%)	1 (3%)	
Homeless/other	1 (1%)	1 (3%)	
Employment Status			
Unemployed	82 (69%)	21 (60%)	5.95
Sheltered employment	13 (11%)	1 (3%)	
Part-time or full-time employment	20 (17%)	11 (31%)	
Retired	3 (3%)	2 (6%)	
Receiving Disability Benefits?			
Yes	91 (76%)	23 (64%)	2.01
No	29 (24%)	13 (36%)	
Diagnosis			
Schizophrenia	87 (78%)	22 (63%)	4.36
Schizo-affective	11 (10%)	8 (23%)	
Depression or manic-depression	14 (12%)	5 (14%)	
Psychiatric Hospitalization			
Yes	112 (93%)	35 (97%)	1.03
No	8 (7%)	1 (3%)	

* $p < .05$

Table 2
Means and Standard Deviations of Expert and Referent Power Ascribed to SA Leaders, SA Members, and Primary Therapist by SA Leaders, and SA Members

Type and Target of Rating	Respondents' Group Role				F Tests		
	Leaders		Members		Group Role	Target of Rating	Role X Target Interaction
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>			
Expert Power Ratings of							
Primary Therapist	3.40	.77	3.24	.82	3.39 ^a	4.45*	.55
SA Leaders	3.43	.70	3.12	.82			
SA Members	3.24	.72	2.99	.80			
Referent Power Ratings of							
Primary Therapist	2.42	.91	2.33	.83	6.35*	22.10*	4.26*
SA Leaders	3.23	.68	2.68	.75			
SA Members	2.99	.72	2.69	.76			

* $p < .05$

^a $p = .068$

Table 3

The Number (and Percentage) of Respondents Indicating the Source of Help Who Has the Knowledge and Experience to Help for a Variety of Problems Related to Schizophrenia

Questions: Who Has the Knowledge and Experience to Best Help You with...	Source of Help			TOTAL	χ^2 (df = 2)
	MH Professional	SA Leaders and Members	Family Member or Friend		
...Concerns About Medication?	131 (85%)	10 (6%)	14 (9%)	155 (100%)	182.87*
...Difficulties Managing Symptoms?	101 (66%)	28 (18%)	25 (16%)	154 (100%)	72.17*
...Difficulties Getting Along with Others?	62 (40%)	36 (23%)	57 (37%)	155 (100%)	7.37*
...Feeling Lonely and Isolated?	45 (29%)	53 (34%)	56 (36%)	154 (100%)	1.26
...Needing to Talk About What it is Like to Have Schizophrenia?	45 (29%)	96 (62%)	13 (8%)	154 (100%)	68.27*

* $p < .05$

Table 4

Results of Multiple Regression Analyses Using Expert and Referent Power Ratings About SA Members and About SA Leaders to Predict Ratings of Helpfulness

Step and Rating Type	Target of Ratings	
	SA Leaders ($n = 152$)	SA Members ($n = 154$)
Step One:		
Referent Power Ratings	$\beta = .14$	$\beta = .13$
Expert Power Ratings	$\beta = .45^*$	$\beta = .46^*$
	$\Delta R^2 = .29^*$	$\Delta R^2 = .29^*$
Step Two:		
Referent x Expert Power Interaction Term	$\Delta R^2 = .06^*$	$\Delta R^2 = .05^*$
	Final $R^2 = .35^*$	Final $R^2 = .34^*$

* $p < .05$

Note: The standardized regression coefficients for predicting helpfulness ratings (β) were computed before entering the interaction term in two.

Appendix A

SURVEY METHODS

Procedure

This study was conducted in collaboration with SA and Mental Health Association of Michigan (MHAM). SA and MHAM invited the research team to conduct a program evaluation study. The survey study was the part of this collaboration. The data collection instruments and procedures were reviewed on several occasions by SA organizational leaders and revised according to their feedback.

Survey data was collected from SA participants at SA meetings and at SA's annual leadership conference. A participant was defined as anyone who had attended at least two SA meetings and considered themselves a member of SA. At the annual leadership conference, all those in attendance at a presentation about the study were invited to fill out a survey. Conference participants who did not attend the presentation were approached throughout the day and invited to participate.

In order to collect data at SA groups, a letter was sent to each SA leader in Michigan explaining the study and asking the leaders to call MHAM if they did not want a member of the research team to contact them. Since no leaders declined to be contacted, each SA leader was phoned and invited to participate. For each group that agreed to participate, member(s) of the research team arrived before or after the SA meeting and invited members to complete a survey. Research team members read the consent form aloud, answered questions, and assisted those in need of help completing the survey. Each respondents was paid \$3.

Sample

Survey data was collected from 19 of the 23 SA groups in Michigan. One group declined participation, one group was dropped from the sample due to traveling distance, and two groups were in hospital or forensic settings where we were unable to obtain permission from the institution to invite the group to participate.

Surveys were collected from 167 SA participants (131 SA members and 36 SA leaders) for an overall response rate of 95% (167/175) of those invited to participate in the study. This represents a response rate of 94% (135/143) of those present at the SA meetings where data collection took place and 100% (32/32) of those invited to participate at the conference. Eleven of the surveys were not included in the data analysis due to unreliable or incomplete data, yielding a final sample of 156 participants (120 SA members and 36 SA leaders).

Measures

Data was collected with a survey designed for this study. The items assessed demographics; referent and expert power of SA members, SA leaders, and professionals; helpfulness of SA; and what types of concerns SA was best able to help participants with.

Referent power. Referent power was measured separately for three target groups: SA leaders, SA members and the participant's primary therapist. For each target, referent power was measured using 3 items. Each item employed a 4-point scale (1=not at all, 2=a little bit, 3=a fair amount, 4=a lot). The items assessed identification with and desire to be like the target individual(s) (i.e., "I have experiences in common with other SA members", "I am a lot like other SA members", "I want to become more like other SA members"). For each target group, a mean item score (computed for each set of three items) was calculated. The alphas for the three scales were acceptable considering the small number of items (ratings of SA leaders: .69, ratings of SA members: .66, ratings of primary therapist: .70).

Expert power. Expert power was also measured separately for three target groups: SA leaders, SA members, and the participant's primary therapist. For each target, expert power was measured using 2 items. Each item employed a 4-point scale (1=not at all, 2=a little bit, 3=a fair amount, 4=a lot). The items assessed the extent to which the respondent valued the information and knowledge/expertise of the target individual(s) (i.e., "I value the expertise and knowledge of my primary therapist", "I value the technical information provided by my primary therapist"). Previous measures of expert power have explicitly tied expertise to specialized training. The items in our measure were constructed to measure expert power in a manner that did not tie expertise to professional training, but instead allowed for either a professional or experiential basis of knowledge and expertise. For each target group, a mean item score (computed for the two items) was calculated. Correlations between the two items for the three scales indicated acceptable internal consistency (ratings for SA leaders: .65, ratings for SA members: .45, ratings for SA primary therapist: .56).

Helpfulness of SA. A 5-item scale was used to assess the extent to which SA participants felt helped by their involvement in SA. Respondents used 4-point scales for each item (1=not at all, 2=a little bit, 3=a fair amount, 4=a lot). Four items assessed different issues related to living with schizophrenia (i.e., knowledge of schizophrenia, feelings of loneliness, friendship, symptoms management) and one item assessed the overall helpfulness of SA meetings. These items were selected in collaboration with SA members to reflect what they identified as SA's key features: information, fellowship, and a pathway to recovery which allows individuals to function at their own highest potential. SA explicitly refrains from focusing on changes in independence (e.g., employment, living independence) as criterion for successful growth. A mean item score (computed across the five items) was used to measure the overall helpfulness of SA. The alpha for this scale was .85.

Types of concerns best addressed in SA. Five items asked respondents to identify who (mental health professionals, SA leaders and members, or family/friends) had the knowledge or

experience to best help them with five different types of concerns (i.e., medication, symptom management, interpersonal difficulties, loneliness, wanting to talk to someone who really understands what it is like to have schizophrenia). These concerns were selected in collaboration with SA members to reflect issues that they felt were addressed in both mutual-help and professional relationships. Family/friends was included as a response option in order to not misrepresent the role played by mutual-help groups and professionals by forcing respondents to choose one of the two as best equipped to help them with the particular issue.

Appendix B

QUALITATIVE METHODS

Procedures for Recruiting Interview Participants

To establish contact with prospective groups and interviewees, a letter was sent to all SA group leaders in Michigan explaining the study and asking the leaders to call the MHAM if they did not want a member of the research team to contact them. At the time the interviews took place there were 26 active SA groups in Michigan. After eliminating 12 groups due to lack of current attendance (N=3), driving distance (N=1), lack of use of SA program and large size (N=1), location in an inpatient hospital or prison settings (N=5), or the group being on hiatus (N=2), a total of 14 groups were invited to participate in the study. Two of these groups declined to be contacted, for a group response rate of 86% (12/14).

The leaders of each of the 12 SA groups were phoned and informed about the overall purpose of the study. They were asked whether they felt their group would be interested in participating. They were then asked to get permission from the group members for one of the research team members to visit the group to discuss the study. A member of the research team visited each group, explained the study, and invited members to fill out a “Consent to Contact Form” if they were interested in participating. At the time the group was visited, a member of the research team asked the leader(s) to estimate the total number of current group members. Based on the aggregated estimates of the total number of current group members given by leaders at the time the interviews took place, 76% (69/91) of the SA members volunteered to participate in the study. Members were told during this visit that they would receive ten dollars to participate in the interview and that the interview could be conducted at a place of their choosing. The “Consent to Contact Form” provided information on how to get in touch with the individual, as well as information about their role and involvement with the SA organization.

Procedures for Selecting Participants

The interview participants were purposively selected on dimensions that the research team felt might influence the participant's experience of being a member of a SA group. First, participants were selected according to how long they had been involved in the SA group they were attending at the time data collection took place (1=involved with SA 2-6 months, 2=involved with SA for over 6 months up to 2 years; 3=involved with SA for over 2 years). Second, participants were selected according to the different roles that they occupy within their groups or within the larger SA organization (i.e., group member, group leader, organizational leader). Third, participants were selected according to their group membership, so that all twelve groups are represented as evenly as possible in the final sample.

All group and organizational leaders were interviewed, but because of the large number of possible participants who were members, one SA group member from each SA group was randomly selected from each of the 3 “length of participation” categories. This allowed for the

selection of only 3 members from each SA group, while maintaining the credibility of the sample and ensuring that each “length of participation” category was adequately represented in the final sample.

Ideally, this sampling procedure would have resulted in 3 members being sampled from each group. However, in some instances there were not members in all categories or only one or two members were attending a specific group during the time that the interviews took place. In these cases, up to 3 members were selected for participation regardless of length of involvement. In addition, all members from two groups that had just recently started at the time of the interviews were included in the interviews in order to follow them longitudinally as case studies of group development.

The final sample selected for participation consisted of all organizational leaders and all leaders of the 12 SA groups (N=19) and a random selection of members based on the criteria discussed above (N=30). Two leaders subsequently refused participation and one member was hospitalized before the interview could commence. The final completion rate for leaders was 89% (17/19) and the completion rate for members was 97% (29/30), for an overall completion rate of 94% (46/49).

Consent Procedures

In addition to completing the “Consent to Contact Form,” each participant signed one of three different consent forms, depending on their role within the organization. This formal consent form was signed by the participant prior to beginning the interview and after the participant had a chance to read it and the interviewer reviewed the important elements of anonymity, confidentiality, voluntary participation, and risks of participation. Before the interview commenced, the participant was reminded that at any time during the interview they could refuse to answer specific questions or to discontinue participation in the study.

Procedures for Conducting Interviews

The interviews were conducted with an emphasis on allowing individuals to tell their story within a semi-structured format in order to ensure that certain aspects of their experiences were covered that were important. The interview protocol consisted of four distinguishable sections: (a) the participant’s story about their involvement in Schizophrenics Anonymous; (b) the participant’s story of their mental illness; (c) questions concerning interpersonal relationships and social support; and (d) demographic information and mental health service utilization. Each section of the interview consisted of a number of questions with the most open-ended question starting the section, except in the case of section (d), which consisted of mostly closed ended demographic questions. Each question also had a list of pre-determined probes, which were used if the participant did not touch on certain aspects of their experience within their story. However, the interviewers were not restricted to the predetermined probes and were allowed to develop their own probes based on the content and flow of the particular interview. Interviewers pursued meaning by asking the participants for examples of what they

were describing or by asking additional questions to ensure that the interviewer and participant shared a common understanding of the phenomenon.

The interview began by asking the participant to tell the story of their involvement in SA. This question was followed by more specific questions about their involvement with SA, which were only asked if they were not brought up in the participant's story. The second section began by asking the participant to tell their story of their mental illness. Again, this question was followed by a series of more specific questions that were asked if they did not emerge from the participant's story. The third section consisted of both open-ended questions about social support and forced response questions asking about the participant's satisfaction with relationships and social support. The last section focused on eliciting demographic and mental health service utilization data. Most of the questions in this section entailed one or two word responses or provided multiple response options for the participant to choose from.

All the interviews were conducted in a setting of the participant's choice, which included: individuals' homes, restaurants, mental health agencies, or other community settings (e.g., library). Interviews were conducted by two graduate student both of whom had been involved with the larger evaluation study for at least one year at the time of the interviews. Interviewers took notes on the content of the interviews, as well as questions that arose during the interview. In addition, all interviews were audio taped. As participants addressed specific questions or probes they were checked off on the interview protocol to verify that they had been covered and would not need to be addressed again.

The interviews varied in length, with the shortest interview tape lasting 45 minutes and the longest interview tape lasting 6 hours. Often longer interviews were conducted in more than one session depending on the participant's preference. Two to three sessions were needed to complete an interview on many occasions. After each interview was completed the interview was transcribed verbatim. The transcription was then checked for accuracy by listening to the entire interview tape and comparing the transcribed text with the spoken words. During this process all identifying information was removed from the transcribed document to maintain the anonymity and confidentiality of the participants.

Sample Characteristics

The SA members who participated in the interviews were mostly white (85%) and the majority were female (57%). Their ages ranged from 22 to 74 years old with an average age of 42 years old. Some of the participants (24%) had at one or more children. Most participants (72%) identified themselves as belonging to an organized religion, with 48% identifying as Protestant and 22% identifying as Catholic. Thirty-nine percent had graduated from high school and an additional 30% had received either an Associates, Bachelors, or Graduate Degree.

The SA members who participated in this interview had varying degrees of independence and integration into the community. Most of the participants (61%) lived

in an independent apartment or house, either alone (39%), with family (22%), with a partner or spouse (15%), or with a roommate (20%). Thirty-five percent of the participants worked for pay.

Most of the participants (62%) had a diagnosis of schizophrenia, 17% had a diagnosis of schizo- affective disorder, 12% had a diagnosis of manic depression, and 10% had another diagnosis. Most of the SA participants (91%) had been hospitalized at least once in their lifetime, with an average of 8 and a range in number of hospitalizations from 1 to 50.

Analytic Procedures

The qualitative analysis for exploring member change and helpfulness of SA began by condensing the interview transcripts into a manageable and meaningful format. First, the interview transcripts were transcribed verbatim and checked for accuracy. Then, they were formatted and imported into NU*DIST, a computer software package for qualitative research, which helps to facilitate data management, data reduction, and thematic content analysis. After all of the interviews were imported into NU*DIST, a cross-case analysis was used to explore aspects of member change and helpfulness of SA. The purpose of this strategy is to identify and code themes of member change and helpfulness of SA that appear across cases (interviews) and are salient for the SA participants.

One graduate student, who was very familiar with the interviews, read each interview and specifically focused on the responses to questions pertaining to the helpfulness of SA. A constant comparative method was used to arrive at the themes and patterns. This involves "categorizing" or bringing together information units that look alike or feel alike in content until each unit of information has been examined and put with other units of information that are similar. A theme was retained when a significant number of units (e.g., more than six) of information were assigned to it.

A name was then assigned to each theme that captured the essence of the properties that defined the theme. All subsequent units of information were then excluded or included in the theme based on their fit with the properties. As the coding themes were developed, an iterative process was used to move back and forth between the interview transcripts and the coding categories. Each time a theme was revised or a new theme added, coding was started back at the first interview. This was done until the themes became discrete and consistent in meaning.

The themes and coded responses were then reviewed by one of the principle investigators. Any questions or disagreements were discussed and a final set of themes was determined. The coded responses were then reviewed for agreement and any disagreements were discussed and a final code determined.

QUALITATIVE RESULTS

Analysis of the ethnographic interview data allowed us to explore in more depth exactly what SA members and leaders found to be the most helpful about their involvement in SA. Allowing participants to describe their experience in SA in their own words yielded a rich description of what involvement in SA means to its members. Members reported that their involvement in SA: 1) helps them to learn about the illness and how to cope with it, 2) changes their feelings about themselves, 3) provides opportunities for participation in meaningful social roles, and 4) helps to combat feelings of loneliness and social isolation. Each of these is described below.

Learning More About Schizophrenia and How to Cope With It

Learning about schizophrenia, through formal information disseminated at the meetings and through the sharing of experiences in the group, has given members of SA greater insight and understanding into their own illness and the ability to cope with it more effectively. Members value the sharing of information about schizophrenia; about resources, treatments, and medications; and about the experiences others have had coping with their illness. They feel that learning more about their illness helps them to accept it and to adopt a proactive role in managing their own illness. Some members also report that the information they received in SA helps them to educate their families about their illness.

Learning about the illness. For SA members learning how to recognize symptoms, side effects of medications, different treatment and medication options, the availability of other resources, and how others handle similar issues and situations has been an important aspect of their experience in the group and has helped them to cope more effectively with their illness. For example, members stated:

Well, I think I've learned my disorder, all about my disorder.

I learned about different mental illness, different disorders. Learned about different medications, how to deal with the community mental health therapists or doctors because, you know, sometimes you can have problems. Then, you know, we [SA group members] would hash it all out. You know, you wouldn't feel alone. Like I would think is it just me that they're doing this to and they said no. Or how to go about it. Like [my group leader] would explain how to go about changes, because I had trouble, one time with this one doctor because I was having trouble with the medication and how to go about changing it....And Social Security and a lot of things. If you have to go on Social Security, what you had to do. You know, people with problems or what you can and can't do and things like that. A lot of it is just life's learning experience.

...just sharing with other people what kind of side effects they had and things like that. Just really helped me become more educated about schizophrenia.

I wouldn't have gotten that information from anywhere else, I don't think.... I remember, my father's studying to be a nurse right now. He just got a job on a psych ward in a hospital which is amazing. And his girlfriend is in school, too, and they were studying together and asking each other questions for psychology, and by God, I knew all the answers. And I was like how do I know all this stuff? You know, and it's from going to SA and they were asking, you know, questions about different medications and I recognized a lot of medications that they were saying.

What have I learned? A lot of things. I can't pinpoint any one thing. If I had to, it would probably be I have learned the difference from what goes on in my head and reality.

I've learned more about the illness. I've learned more about people. I've learned more about how to interact with people. I developed some social skills ... I've learned about new drugs that were coming out. I would go home and I would tell my mom about them and my mom would get a pamphlet from NAMI and they would have the same thing almost. And I would learn new medications to ask my doctor to go on. I learned more about tardive dyskinesia. People who had it would talk about it and how to try to prevent it. There really isn't a way to prevent it, I guess, but to stay away from certain medications.

I've learned a lot over the years. When I began I learned a lot. I was able to put the disease in perspective, where before that I was just a victim. So it [SA] did that. I guess I learn about different treatments constantly and I'm able to listen to different members' problems and I've learned a lot of information that I withdraw as needed, so I know I have tons, you know, recognizing different side effects and things like that, and that's from the experience [of other members].

Oh, yes. All sorts of stuff. Not just about the illness, but dealing with the illness and coping with it and learning about ways of getting in touch with people who have the illness, too. I've learned about how much help there is out there for people with schizophrenia because, you know, when I was first diagnosed, they didn't tell me any of that stuff. You know, it was like shoo, go find it yourself. And with SA, I get all that info...

I've learned a lot about the illness. In doing the literature and this has forced me to become aware of the illness. And then, you know, people don't appreciate, I don't know if it is appreciate, people don't realize that as much as you sit and listen to all the different people say, over a period of say three years, come to SA and you get a wide variety of different stories about the illness, about the experience with the meds.

Yeah, it might sound silly, but anyway, if someone had said, oh, I want you to meet my friend who has schizophrenia, I would get scared and say no. Now I would say, Oh, I would be more than happy to meet them, please bring them over. Let's have coffee together. Let's get together. You see? See the change there? I'm open minded now about

it whereas my mind was closed to that before...And I realize it could happen to anyone. As far as that goes, from a waitress to an executive secretary.

Members are particularly helped by what they learn about medication:

That's a big factor that might get understated, too, is we keep track of the new meds that come out. We hear from our different group members. We know, I get enough stuff coming in the mail to me that I know what the upcoming meds are. And you hear experiences that other people say about meds. Zyprexa has really helped me. I heard about it, I knew about it coming, from the literature coming in. Then one of our members was having a really good experience with it. I was able to do the same thing and take it.

A new drugs will come out. They told us about it, you know, before it actually went public.

Well, we usually find out about new medications when a new person will come in or somebody will come that hasn't been there for a while and say oh, they changed my medication, I'm on this now, and this I got, these are the side effects. You know, because usually they say, oh, this sucks, the side effects and everything. Not like they're trying to give out information. They're just kind of talking about it like that and it's not like any pressure there. It just kind of flows down and that's how we find the information.

I would say you learn things and then you learn of the people's medications and you learn what their experiences have been...

We can even discuss medicines.... And we can exchange ideas on medicine. I think it's fabulous...

It is important to note that a few members felt that there was not much information provided by SA or that the information provided in the group wasn't very helpful.

Information about schizophrenia is not extremely helpful but it is always good to learn about different things. It is interesting.

There isn't a lot [of information], I don't think. Medical information. I'd like to see more of that. Of course, we do get newsletters which have information about new medications and things. More about the illness, you know. What to expect down the road, that type of thing. As we grow older, what do medications do to us and how the illness progresses and things like that.

There isn't too much information. That's what I think I would like to have. I would like to have more information about manic depression. I have it myself, just like I told you about the book, told people. They seem to be in the dark .

Acceptance of Illness. Access to information about schizophrenia helps members to accept the fact that they have schizophrenia.

I've learned that I guess I do have some mental problems. I do have a mental illness. I was in denial because I felt like I could work as a normal person. I guess that's what I've learned the most. But I've also learned how to deal, how to cope with it. Which, that helps out a lot. I learned how to deal with it...I've learned to take my medicine and if I have any problems, to discuss it during group. And when we discuss our problems during group, it helps out when it's open table because there's always someone who gives helpful advice in how to deal with it.

It [participating in SA] has made me more aware of my illness and less schizophrenic.

[I've] learned about people with a mental illness. People are people. People are no different. People with schizophrenia are not scary or violent. Just some people have a mental illness. Everybody has some type of handicap or disability.

I helped me to accept my disability. I worked fifteen years it was hard, being just disabled.

The acceptance that the other members had. They accepted their, how should I put it? They accepted their...mental disability. Any way you put it, it sounds real serious, you know. But they accepted it and they talk about it.

That's what I thought when I came here in October. There's nothing wrong with me. And I felt like it was other people around me that had the problem. I found out that what I was going through, it was normal. There are other people with schizophrenia. That helped out a lot.

Playing Active Role in Managing Ones' Illness. Being educated about the illness also helps participants to take control of their lives and to play an active role in maintaining their health and managing their illness.

I've learned a lot over the years... I was able to put the disease in perspective, where before that I was just a victim.

I learned how to handle my illness better, knowing when I get sick....And it's just like a diabetic. You gotta know about your illness in order to take care of it. And I don't think

one can be, take responsibility for their illness or their life unless they're educated in the

illness.

I sometimes like consider SA like another parent for lack of a better term. You know, and they always want you to do what's good for yourself, like not take drugs, not drink, etc. And to do those things that are healthy for you.

If I didn't have SA to go to, it might be very likely that I would be in the hospital again. I'd be hospitalized. I need to work on my recovery from the illness and I do believe that you need incentive to do that. You need some kind of motivation and SA gives me that.

Educating Families. Information about schizophrenia made available through SA is used by SA members to educate family members or others who are close to them. Members report that the sharing of information about schizophrenia can help friends and family members to better understand their experiences and to cope more effectively with the manifestations of their illness.

Well, we've had tapes about other people, other professionals who have had schizophrenia. They tell about what it's like for them. And they also offer advice for people who are close to me. My wife can't go to the meetings because she works. I tell her about it, you know. This will be helpful to me. This will be helpful to you. She's a nurse and she understands schizophrenia. She's worked with mental patients. And sometimes she gets alarmed. I said hey, this is the way it is and it's okay. You know. It's nothing to be alarmed about. Just take an interest in what I'm saying and doing and things like that. Instead of showing alarm because alarm makes me feel bad.

The literature has been very good. I've made numerous copies of three or four different articles and I've given copies of this to my mom, my brother's family, and to my oldest sister's family and her husband. To my old housemate. I don't think he read any of it but... And to my minister, my, one of the elders at church and to my friend, [Paula], who I used to live with, and her son. I gave a copy to her, copies. So I'm seeing it's a matter of education....

Changing Their Feelings About Themselves

Members report that their involvement in SA helps them to change how they feel about themselves. They describe decreased feelings of shame; enhanced feelings of value, worth, and esteem; forgiveness and acceptance of themselves and others; development of more realistic expectations and new goals; and increased feelings of hopefulness.

Decreased Feelings of Shame. SA helps many members to address the shame that accompanies a diagnosis of schizophrenia and to consequently feel better about themselves.

So it's not so much a shameful thing like I can so easily think.

I have become so called "normal people", you know? I'm not ashamed of having people over at my house and you know, I can carry on a conversation if I have to.

...one of the first things she [a therapist] told me is that it's not your fault. You know, there's nothing you could have done and it wasn't the fault of your parents. I had heard that but you know, it kind of went in one ear and out the other. I kind of half believed her. And this group reinforced a lot of the things that she told me.

It helped me change, it helped me not be ashamed about having a mental illness. You know, I rarely talked about the first breakdown I had.

Not to be ashamed of having a mental illness. I talk openly about it more than I used to.

Enhanced Feelings of Value, Worth, and Esteem. Participation in SA provides members with opportunities to engage in social interactions that reinforce positive feelings about themselves.

And I'm still a worthwhile person even though I have a handicap, a mental illness.

[What would you say you've learned from being in SA?] Pride.

...the more I talk about it, the more I start liking myself...

...it helps me out with my self-esteem because [Penny] will say well, [Ira], you look pretty today. You know, and I try my best to keep myself well groomed and that.

When I come out of group, I feel, you know like I could take the whole world on. Because it makes me feel so good, you know?

It's [attending the meetings] like a bonding. It's very heart lifting. Which is good for the heart by the way. It just brings us closer together. Like I said, it's very uplifting. You know, you can be down and I can go to the meeting sad, and I'll come out happy. I swear there's a lot of people who come in sad and leave happy. After they leave, they say, oh let's have coffee and everybody cheers up. It's like a dark cloud hanging when you first come in and the cloud is gone. When the meeting is over the cloud's gone.

I come away feeling like a good person. A person who is liked. I do... It just boosts my self esteem actually.

Forgiveness and Acceptance of Self and Others. The SA program, and specifically the six steps, helps members to forgive themselves and others for past wrongs and mistakes and to accept themselves for who they are.

But as far as, knocking myself over not completing school... stuff like that, to forgive myself, that was the most important step for me.

The steps? Yeah, they help in every day life, yeah...My favorite one is forgiveness. That it really helps to relieve the burden if you can forgive yourself, especially yourself and others.

Being able to accept myself with a mental illness. It taught me that. But I guess in that respect, as far as like, you know, accepting other people, loving other people, loving myself with a mental illness, understanding it, it could be interpreted that way.

[SA is] a place to turn to now. They can agree with me and God might agree with me. If they can agree with everything I think and everything I say and the way I consider my life important or whatever, whatever it is, whatever my life is. Maybe if they can support me, God can support me. He's better than they are, I guess. I assume he's better.

...But I guess you could say SA helped me to be more open.

More Realistic Expectations and New Goals. Members also report that SA helps them to learning about what to expect from the illness over time and to redefine goals and expectations based on this information.

[What have I] learned from being in SA? The illness isn't totally catastrophic. You can get better. With support, with support. As an adjunct to your doctors, you know.

That there are varying degrees of illness and that we're not alone. And a set back doesn't mean that you're not successful and success has a lot of different meanings.

...I wanted to be a chief executive officer and now I'm just a dispatcher. I'm happy with that job. Glad to have a job. And glad to have benefits and steady employment and just lead a normal life, you know. And not try to be superwoman of the 80s that we were brought up to be, you know... I was really gung ho on being top boss.

Increased Feelings of Hopefulness. Participating in SA helps members feel more hopeful about their recovery and the possibilities for their life.

I'm learning how to dream and not look at my life... I'm learning how not to look at the terrible things that are happening right now. I'm learning how to dream and have hopes and aspirations... they've let me express myself by talking in the group and they let me hope and plan for the future.

When all the other, when all the other odds are against me, there's still hope in spirituality. There's a kind of a worthy hope. It is not that there is scientific evidence supporting it but there's a lot of faith involved and being in seclusion, I can remember being in seclusion, myself in seclusion in the hospital and all I had was prayer. All I had

was prayer. I'm not a holy person by any stretch of the imagination. But you gotta use spirituality.

And it just educated myself so I think it helped. Accepting the illness and know that it's not so devastating. That there's hope for recovery.

The illness isn't totally catastrophic. You can get better. With support, with support. As an adjunct to your doctors, you know.

I'm more focused on my present and future now. This gives me hope. Like I said, I don't doubt my medications. I want to enjoy everyday of my life and I look forward to the future, making goals for myself now... Not everybody can get better on meds but a lot of people, you wake up one day and everything goes right for you. Then you say, this will work out. Why shouldn't it work out for you?...I'm not scared of death. But I believe heaven is another dimension away and I don't think they're up in the clouds somewhere.

Providing Opportunities for Participation in Meaningful Social Roles

SA provides members with the opportunity to participate in meaningful social roles, including leading groups, helping others, working on literature and other educational materials for SA, public speaking to address the issue of stigma, etc. These opportunities provide members with a sense of meaning and purpose.

Well, when I started leading the groups, then I began feeling better about myself. I think God made me schizophrenic to help people.

It's [SA] given me worthwhile things to do. I guess that's really a big factor. Big factor is giving me things, something worthwhile to do with my life at times when I was very down.

So I think it was therapy for me and it also was very rewarding and meaningful for me. And leading the group was very meaningful... I got a lot of feedback from people, how it helped and I felt it was worthwhile. It made me feel needed. I felt like, that I was helping other people and I think that's what we're all here for. To reach out and help other people.

I love to be able to help somebody, too. The opportunity to help somebody is something we, probably most people, have every once in a while.

You know, I know somebody's hurting, I can say something to them. That's really important to me, that I can say something to them and maybe help them. I can give them a few words of suggestion and they can decide if they want to accept it or not. But just being able to say something, and to help them.

I think I helped a lot of people. I know I've helped a lot of people.

...it gives me something that can be useful to me now, I can be helpful.

I don't know. I just like getting, you know, getting to meet with people. That's what I like, you know. I can see if I can help people because I feel like I'm at a good part in the illness, where I've overcome a lot. You know, the voices and the hallucinations and maybe I can help somebody else out since I'm not having any symptoms right now. My mind's kind of clear.

...not only do I get help, but [Jane] has made it clear that she counts on my point of view at times in order to shore up the others, believe it or not. When I am clear I can do this...

Being able to be a good example to others. But they probably don't know about it, didn't get exposure and experience what I experienced. You know. I used to hear voices for more than 20 years, believe me. I was a very small child back in '72...

Helping to Combat Feelings of Loneliness and Social Isolation

There are many ways that SA helps to combat members feelings of loneliness and social isolation. It helps members to realize that they are not alone with their illness; provides a sense of identification with others who really understand their experiences; provides a safe place to talk about their illness; and provides support, acceptance, friendship and fellowship.

Decreases Social Isolation “We are not alone”. Participating in SA decreases members sense of being alone because they learn that there are many others who share similar experiences.

I think the thing that I most got out of it is the feeling of not being alone.

I like knowing that there are people like me.

That there are varying degrees of illness and that we're not alone.

I found out that what I was going through, it was normal. There are other people with schizophrenia. That helped out a lot.

The contacts with other people that have the same kind of illness.

You're not alone.

Just that [there are] people who have mental illness like me, the fact that I was not alone in my illness.

Well, the most thing that I like about it was the people have the same illness I have and I was able to understand more. That I was not alone. There was people out there hurting just like I'm hurting.

You learn about the brain and misfunction in the brain. You learn about the voices and different things that happens to us. Like the FBI after us, thinking people reading your mind and you find out that you're not the only one suffering from all those things.

Identification with Other Members. SA members describe the value of being with others who they can identify with and who can really understand their experiences.

It's just nice knowing other folks that, folks sitting here with similar... maybe it's misery loves company but even that's not necessarily wrong. So I guess, you know, emotionally there's a bond. There's a bond....Just realizing that there's people who are worse off than I am. I might be worse off than some others but there's people who are worse off than me so it helps me to have more perspective than just my own, than my own thoughts.

Because I can relate to these people. They can relate to me and my psychiatrist and my therapist cannot. You know, no matter how much I try to make them understand, they will never know what it's really like. Just like if I had my arms and legs chopped off and I had to see a therapist about it, I would rather see a therapist that was in the same position than I was than someone who was not because they wouldn't understand and that's how I feel, I want someone who understands.

I think just sharing with other schizophrenic people. Yeah, hearing what their lives have been like and the hell they've gone through. That, for me, is the biggest part of it. It draws me to it because I can share my own story with them and they understand. They know what it's like to hear voices that nobody else hears or they know what it's like to get paranoid and think the whole world's talking about you and be convinced of it and not be able to shake the feeling, even though people reassure you, it doesn't mean a thing. That's touched me the most. Just hearing people's stories. The hell they've gone through. That's the most important thing I've gotten from it.

We could all relate, you know, and I think the big issue of being able to relate to one another is a big step. You know, having something in common. And let's face it, that's what most relationships are based on is something in common, you know? That I get to meet people who are similar to me and who have some of the same problems and some of the same hopes and dreams that I have.

...normally, anything that you say, there's at least one other person who's been there.

...talking with people who have the same problems.

It's meant a lot to me as far as meeting people with the same illness that understand my illness. I can talk about my illness without worrying about chasing people away, you know, scaring people away.

I like best, I think, well, I guess I'll call it the sociability. The communication between people with a common background. Common... well, and also getting to know them more intimately. You know, I think it's been a maturing thing for me, a growth process."

We all have a need to socialize, whether it is in the church or the market place. Now, what SA does, is I can be free to come in with anything that is within me, I try to limit what is within me. Not always successful. But I can feel free to come in, in any state of mind that I would perhaps be in, and I wouldn't even need to worry about it because they are already sharing my experience with me. I am already sharing my experience with them. I can talk about private matters in my own life and they know right off the reel what I am saying and how accurate it is.

I think it may be because for such a long time, probably each of them like myself had enough people telling them, they're not seeing, they're not hearing, and they're not thinking what it is they think they're thinking and hearing and seeing. They're not gonna tell you that you don't know what you're talking about. Because actually each of us are the only ones who does know what we're talking about. Nobody else knows about it. Not even another schizophrenic.

[I] felt like a puppy that had been reunited with his litter.

A Safe Place to Talk About Schizophrenia. SA provides a setting that encourages members to express their feelings and to be open and communicative with other members. For many SA members, this is the first time they have been able to talk openly and freely about their experiences and illness.

Well, they've let me express myself by talking in the group...

The problem is they're just afraid to open up, just like I was when I first started coming.

I learned not to hold my feelings in.

The fact that I can talk freely.

Being able to relate to others. Being able to express myself.

The fact that everyone there is on the same level. The fact that I know everyone there well enough that I'd like to... when they come around to their turn or my turn, it relieves us to say what we have to say.

It's meant a lot to me as far as meeting people with the same illness that understand my illness. I can talk about my illness without worrying about chasing people away, you know, scaring people away. There's new faces all the time, new people to talk to.

He [an SA member] used to put his schizophrenia on the table on Sunday and go on with his life. You know, that's so profound to me. And I say that in a lot of my... it's a place to talk about it but still go on with your life.

Because I never talked about it before I started SA. I never talked to anybody about delusions or... except for maybe my doctor, you know, or the nurses in the hospital. But I didn't feel lonely anymore... I think it healed some of that pain. Because now I can speak about it without tearing up or whatever.

Just to be able to talk to people, get out.

For some members this helps them to develop better social skills and to interact more comfortably with other people.

Before, when I was without SA, I was a quiet, shy, wouldn't know I was there kind of guy. And after SA, I started to open up more and I started to talk more and I started to express my feelings, even if they, you know, they hurt someone else. I'm not saying I would hurt someone but I'm just saying I had to find out, does this hurt your feelings if I express this. I would say it. They would respond. That's what it turned into after, you know, so many visits to SA and EA

To be more tolerant. Patient of others. How to relate better, I guess to people in generally. To talk more. Express more. Not to be so afraid. Not to be so fearful.

...it's made me come out from being by myself. I stayed in a room all the time by myself and I wasn't talking to people. So I think it has helped me to come out with my problems and be able to see other people and talk with them. Which before, I couldn't do.

I think it's helped me be more caring and have more of an open mind about people and what they're going through, you know? More compassion. Because you never know what

people are going through until you really talk to them and that's what the people at Schizophrenics Anonymous do.

Support, Friendship, and Fellowship. Participating in SA provides members with feelings of belonging, acceptance, support, friendship, and fellowship.

The camaraderie with people who have the same problems I have. Support. Belonging. Really feeling like you belong.

Acceptance, absolute acceptance. I have a problem with tardive dyskinesia but here, it doesn't matter...In the hospital, in group therapy, everybody tries to outdo everybody else. But here, you're accepted, if you want to speak, you can speak if you want. Nobody's going to jump on your case, nobody's watching you critically. To me, that's wonderful.

Being accepted. I've already said that. The acceptance... I'm just new in it. Non-judgmental, you know. Just like they, I know they're humans, other people but it's just something that's from inside is the way I feel for other people. I'm older, I know, I'm probably the oldest one there. But it's just the compassion that they feel cause they know, like myself, that I feel it myself and I can see it in them, you know... The acceptance and the compassion. I'm relaxing. I'm not getting my anxiety and panic attacks. You know, and wanting to run out, can't sit still, stand still. I just feel like nobody's really ignoring me or like I feel inferior to anybody or that anybody's acting superior to me. I feel like I belong. I don't know. It sounds crazy but I thought I found my niche for now, for now. Maybe a year from now, I don't know. Might be doing your job.

I even told [Harry], because we fight quite a bit sometimes, and you know, he'll say well, do you want to talk about it? I said no, I'll just talk about it at my meeting. And so I do think about that. I think about looking forward... I always look forward to Wednesday. Wednesday at 5:30 is my favorite time because I can just relax and know that things will be OK. I don't know where that feeling comes from but I as soon as I get there and walk through the door, it's like whew, I made it through the week, you know?

Just the support in overcoming, overcoming the trials and tribulations of dealing with people.

I'd gotten friendship and support and companionship and a lot of love and a lot of help.

I like the personalities of people. I like to know them for what they are and who they are. I like to, and I think the people have quality, and character...they're always, they're always real kind to me. But some of them are downright dedicated individuals, you know...It just feels good to shake people's hands. When I come to the meeting, I always shake their hands and I always shake their hands when I leave, too. And other than that,

I guess we talk about things that are silly and we talk about things that are important and we sorta mix up between the silliness and the seriousness.

The support I get....Probably friendship, definitely friendship.

The most helpful has been to make new friends and share information about illnesses and the most help, helpful has been the support I've gotten from other leaders and central SA.

I like the fellowship. I have friends that I've made.

The friendship, the friendship that I get out of it... I've never been a person to go out and make friends. I always had trouble making friends. But going here, it seems like I've had an easier time making friends....I mean, it helps each other. We support each other. And whatever advice we can give each other, it helps out a lot.

But I'm forced to socialize and get out and see people. And I think SA helped me the biggest with phone pals. You know, I have a lot of people. [Laura] called this morning, [Carmen] called this morning, [Roman] called last night, [Jane] called, [Justin] called. You know, phone peps.

I guess the friends that I've found...because normally, anything that you say, there's at least one other person who's been there.

The camaraderie with people who have the same problems I have. Support. Belonging. Really feeling like you belong....That people really do care. That people really do care.

The caring, the understanding.

The biggest thing that I got out of all of it ...was meeting [Frank] because I had been wanting to meet a boyfriend. So when I met him, it was like you know, I'm committed to SA because this is where I met him.... I've made lots of, well I don't want to say acquaintances because I'm closer than that to them. Friends for me are at the group and occasionally I'll have a friend over but to tell you the truth, a lot of people stress me out. So I'm happy to be more alone or just with [Frank].

One time, my therapist had given me a new medication and I took it before the group. Halfway through the group, I couldn't lift my head up. I was sweating and I was dizzy. Anyway, [Bruce] and [David] somehow got me upstairs and in my car and I zonked out. I finally had to call my husband to come and get me. They really cared about me and said, 'You can't drive. Come to my house.'

I like best, I think, well, I guess I'll call it the sociability. The communication between people with a common background. Common... well, and also getting to know them more intimately. You know, I think it's been a maturing thing for me, a growth process.

Yeah, we get a lot of friendship.

The support and fellowship.

Yeah, right along, like with that. The support, like listening and talking, you mean? And getting like feedback and feedback but also what people will share with you. You know, they're, how they handled maybe the same problem or they'll, not just hang in there but

give it time or you know, or you're a good person. They'll build you, we build one another up, you know. That kind of support.

What has been the most helpful to me? The people clapped, rewarded me, what I said. What other members had to say. ...Helped me get stronger, function through other things, to move on. I told you I learned in cooking. I kept my job for almost two years now and [Anna] says all right. You're working. We're so proud of you. A big clap, that's encouraging, that makes me want to go further. You get positive feedback from others and yourself. And even if I don't get my reinforcement from others, I just go ahead like positively because whatever I do, I do for me.

I have to say that this is one of the most wonderful things that ever came into my life. It definitely is a strong, huge 2 X 4 that holds up my life.

They are kind of a tether for my balloon. It's kinda like you see these hot air balloons all inflated and they've got their tethers down and it's kinda like all the balloons are schizophrenics and the crew is influenced by [a] schizophrenia inflated thing and they all tethered each other down until it's time to be released.

Role and Value of Shared Experience. The shared experiences that emanate from having schizophrenia are an important aspect of SA. Members value hearing each others stories and experiences. They value the sharing of experiential knowledge (i.e., knowledge gained from living with schizophrenia) and learn how to cope with their illness from the experiences of others.

Listening to people's talk and their problems....Listening to other people has been helpful...listen[ing] to the tape [of the founder of SA talking about her experiences].

You know, people with problems or what you can and can't do and things like that. A lot of it is just life's learning experience.

That's it. I'd say a tape with Joanne Verbanic, the leader of the group, country wide leader. I feel like she's a celebrity that I just met. I only heard her on tape, you know, and she seems to tell the same story I have to tell.

Well, they share that they can hear voices and stuff. You know, they can't read or they think that the television is talking to them or that they might be possessed by the devil or

something. The biggest one that I think is that they think there's nothing wrong with them. That the other people around them, that they're the one with the problem and that there's nothing wrong with them. That's what I thought when I came here in October. There's nothing wrong with me. And I felt like it was other people around me that had the problem. I found out that what I was going through, it was normal. There are other people with schizophrenia. That helped out a lot....They've been coming here longer than me. And then there's new people that come here all the time that I give them some support and help them out a lot because I know what they're going through.

Like I've learned a lot from [Tom]. He tells the group what his illness is and I know sometimes his illness is getting to him.

It's support from the fact that you're hearing what other people are experiencing and you can compare it to your own situation and then decide if there's some aspect you might improve yourself....It's helped me, I think, learn of other people's experiences.

One woman was telling me how she, it had started, had got to her, you know. I remember that. It did the same with me. And she told me she would go to work and have to leave because that's the same thing that happened to me.

And getting like feedback, but also what people will share with you. You know, how they handled maybe the same problem or they'll, not just hang in there, but give it time or you know, or you're a good person.

[I learned] to always take my medication until my doctor wants to reduce or take me off it. By doing that, I'll stay out of the hospital...Cause [Susan] has tried a lot of times to get off the medication on her own and she ended up back in the hospital a lot of times.

Experiences of the people...such as the lady saying of her abusive stepmother and stepfather. I would say when people bring up incidences of their life it can be enriching to yourself because you can learn from their experience.