

# Preferences for Family Involvement in Care Among Consumers With Serious Mental Illness

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**Objective:** Despite robust evidence of efficacy, family services for individuals diagnosed as having serious mental illness are of limited availability and drastically underutilized. This underutilization may be due to a mismatch between consumer and family preferences and the services offered. This study is the first systematic report on preferences expressed by consumers with serious mental illness for family involvement. **Methods:** The study enrolled 232 mental health consumers with serious mental illness who had contact with family but did not have any family regularly involved in their mental health care. Consumers were recruited from outpatient mental health clinics at three large medical centers in two Veterans Integrated Service Networks. Interviews elicited demographic characteristics, treatment preferences regarding family involvement, and perceived benefits and barriers to involvement. Chart diagnoses and measures of symptom severity, family functioning, and contact were collected. **Results:** Seventy-eight percent (171 of 219) of the consumers wanted family members to be involved in their care, and many desired involvement through several methods. Consumers were concerned with the impact of involvement on both themselves and their family member. The consumer's degree of perceived benefit of family involvement significantly predicted the degree of desire for family involvement after analyses controlled for service need (family conflict, family-related quality of life, and symptom severity), enabling factors (family contact and family capacity), demographic variables (age, gender, race, living with family, and marital status), and barriers perceived by the consumer. **Conclusions:** The extent of overall support for family involvement in care coupled with the heterogeneity of preferred modes and concerns and anticipated benefits underscore the imperative to offer diverse family services and to elicit consumers' preferences regarding whether and how to involve their families. (*Psychiatric Services* 64:257–263, 2013; doi: 10.1176/appi.ps.201200176)

Matching treatment to consumer preferences improves use of and adherence to appropriate treatments, consumer satisfaction, and outcomes (1–4). However, consumer preferences are not consistently solicited, despite an emerging emphasis on consumer-centered care, which requires proactive, informed consumers (5–7). The complexity of treatment choices and the need for consumers to fully understand and weigh each treatment's attributes and outcomes create challenges for involving consumers in treatment decision making.

Consumers with mental illness are especially likely to have unmet needs and preferences; health care organizations typically neither solicit treatment preferences nor evaluate whether the services provided are a high priority for consumers (8,9). Shared decision making is a method of eliciting consumer treatment preferences, providing education about treatment options and related outcomes, allowing consumers to deliberate about the possible attributes and consequences of these options, and then supporting the consumer's informed treatment choices. Shared decision making is critical to achieving true consumer-centered care and can improve uptake of effective treatment options, consumer outcomes, and satisfaction.

Shared decision making has great potential to increase utilization of family services for individuals with serious

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mental illness. Robust evidence indicates that when family members are involved in the care of such individuals through evidence-based family psychoeducation lasting nine months or longer, relapse rates are cut in half, and treatment adherence, clinical symptoms, and consumer functioning improve (10–15). Family interventions that are less intensive than family psychoeducation, such as family-led family education, also are effective in increasing knowledge, enhancing empowerment, and decreasing subjective burden among family members (16,17). Unfortunately, despite these demonstrated benefits, inclusion in guidelines, and many efforts to implement these practices, utilization continues to be unacceptably low (18). A mismatch between consumer and family preferences and the services offered may explain this gap (19,20).

Efficient and standardized approaches are needed to help individuals with diagnoses of serious mental illness identify and express their preferences for family involvement (21,22). The recovery-oriented decisions for relative's support (REORDER) intervention is an innovative, manualized protocol designed for this population and uses a shared decision-making process to facilitate a consumer's consideration of family involvement in care. REORDER has two phases, each offering up to three 50-minute sessions over approximately three months and led by a trained mental health professional. In phase 1, the consumer meets with REORDER clinicians to discuss preferences for family involvement, focusing on the consumer's mental health recovery goals, and exploring how the family could join with the consumer to meet those goals. Consumers receive information about the evidence regarding family involvement and decide whether and how family members will become involved. If desired by consumers and their families, phase 2 provides family support, education, and strategies to participate in promoting consumers' recovery goals.

This study examined baseline data from a recently completed multisite randomized controlled trial of the REORDER intervention. These data include consumer preferences and

expectations for family involvement in care, and the correlates and predictors of these preferences. We used the Andersen behavioral model to frame our focus on consumer preferences for family involvement (23,24), with specific focus on need for services, enabling factors, and psychosocial factors in predicting intention to use specific health care services.

## Methods

### *Sample selection*

Baseline data from the REORDER study contributed to this cross-sectional analysis. Individuals were recruited from outpatient mental health clinics at three large medical centers in two Veterans Integrated Service Networks. Eligible individuals were 18 to 75 years of age; had a chart diagnosis of schizophrenia, schizoaffective disorder, bipolar disorder, major depression with psychotic features, or psychotic disorder not otherwise specified; and had had at least two outpatient mental health visits and contact with a family member or caregiver in the past six months. Individuals were excluded if their families already had monthly or greater contact with the participant's clinician or had attended a family psychoeducational group in the past six months, suggesting existing engagement in care. Being homeless or having a history of a significant traumatic brain injury also precluded participation.

Participants were recruited through clinician referrals, review of clinic rosters, and flyers posted in participating clinics. A partial Health Insurance Portability and Accountability Act waiver was obtained to allow review of individuals' charts in order to determine eligibility prior to consent. The charts of potentially eligible consumers were reviewed to confirm that each met study criteria, and their clinicians verified their clinical stability. Eligible individuals were then approached at their clinic appointments to discuss the study.

At two of the three sites, eligible individuals who were not approached at their clinic appointment were sent a letter indicating that they may be eligible to participate. In these letters individuals were asked to contact study staff by using the phone number

provided or by returning a postcard giving study staff permission to contact them about the study. Only individuals who expressed interest in receiving more information were contacted by telephone. At the third site, no individuals were approached outside their clinic appointments. All individuals who expressed interest in study participation met in person with study staff, who reviewed study requirements and obtained written informed consent. Notably, individuals who agreed to participate in the study were not agreeing to receive family treatment; the consent process made that clear. Instead, they were merely consenting to discuss the possibility of receiving treatment during a conversation with the REORDER clinician.

### *Procedures*

A total of 436 individuals were approached for enrollment at their clinic appointment or by letter. Of those 436 individuals, 91 did not respond to letters or were awaiting patients' response regarding the study, five were withdrawn because they did not complete a baseline assessment, one additional person did not participate because of clinical instability, and 107 declined participation, leaving a total of 232 participants. Of the 232 individuals who consented to participate in the REORDER trial, each completed a 90-minute in-person interview by trained assessors between October 2007 and November 2010. The interviews occurred before randomization and the receipt of any family-based services. The study was approved by the institutional review boards (IRBs) at the University of Maryland School of Medicine and the Greater Los Angeles Veterans Affairs (VA) Healthcare Center.

### *Baseline assessment*

The baseline assessment included questions eliciting demographic and clinical characteristics, treatment preferences, and perceived benefits and barriers to family involvement. Demographic characteristics obtained included participant age, gender, race, marital status, and living arrangement (with or without family). Psychiatric diagnoses were obtained from the medical chart. Psychiatric symptom

severity was assessed with the Positive and Negative Syndrome Scale (PANSS) (25). The PANSS total score was used, with higher scores indicating greater symptoms.

In addition, we obtained measures of family functioning and contact, as described below.

#### *Additional measures*

**Family involvement.** The Family Involvement in Treatment (FIT) scale is a 21-item questionnaire we created from previous work. It queries respondents regarding their desire for different types of treatment involvement from their family members; it also queries respondents about benefits and concerns they would anticipate from such involvement. Respondents rate agreement with items on a 5-point Likert scale that ranges from 0, strongly disagree, to 4, strongly agree. With this scale, responses to individual items can be examined, and three FIT family involvement index scores were developed for this study: preferences, benefits, and barriers.

**Preferences.** Four statements from the FIT assess ways that respondents could involve their family in their care: "I want my family to receive written information or materials about my mental illness," "I want my family to attend a general or educational support group," "I want my family to attend my individual or group sessions that are a part of my treatment," and "I want my family to call my team if they are concerned or have a question." The preferences index was formed by adding up the number of involvement types endorsed as either agree or strongly agree, with higher scores representing greater desire for involvement and a preference for more ways for their family to be involved (range 0 to 4).

**Perceived benefits.** Two statements from the FIT assess ways that respondents perceive potential benefit from family involvement: "If my family were involved in my treatment, it would help me with my illness" and "If my family were involved in my treatment, it would help my family feel better and reduce their own stress." The benefit index was formed by adding up the number of benefit statements endorsed as either agree or

strongly agree, with higher scores representing a respondent's anticipation of more benefits to family involvement (range 0 to 2).

**Perceived barriers.** Five statements from the FIT assess respondents' concerns regarding family involvement: "If my family were involved in my treatment, I would lose privacy," "If my family were involved in my treatment, we would fight more," "If my family were involved in my treatment, they would have less time for other important family responsibilities," "If my family were involved in my treatment, I worry they may try to control my money," and "If my family were involved in my treatment, they could hassle me about my alcohol/substance use." The barrier index was formed by adding up the barrier statements endorsed as either agree or strongly agree, with higher scores representing a respondent's anticipation of more barriers to family involvement (range 0 to 5).

**Family conflict.** Severity of family conflict was assessed with the family composite score of the Addiction Severity Index (ASI) (26). The ASI family composite score is calculated with a family conflict ratio, the respondent's report of the level of distress from this conflict, and the importance of getting immediate treatment. The conflict ratio represents recent conflict across all family relationships, based on the number of family members (close and extended) with whom the respondent has had conflict during the past 30 days. Distress from family conflict is the extent to which the respondent is troubled by family problems in the past 30 days. The importance of treatment is the extent to which the respondent feels he or she needs immediate treatment or counseling because of family problems. The family composite scores range from 0 to 1, with higher scores representing endorsement of more family problems in the past 30 days.

**Family-related quality of life.** Family-related subjective quality of life and satisfaction with family relationships were measured with three items from the Lehman Quality of Life Interview (LQLI) (27,28): "How do you feel about your family in general?" "How do you feel about

the way you and your family act toward each other?" and "How do you feel about the way things are in general between you and your family?" Responses range from 1, terrible, to 7, delighted. The average score across these three questions was used, with higher scores indicating more satisfaction.

**Family contact.** The LQLI was used to calculate family contact on the basis of two items, how often the respondent talks to a family member by phone or gets together with a family member (28,29). Responses are 1, not at all; 2, less than monthly; 3, monthly; 4, weekly; and 5, daily. The average score of these two questions was used, with higher scores indicating more family contact.

**Family capacity.** General family functioning was measured with the problem-solving (five questions) and general functioning (12 questions) subscales of the McMaster Family Assessment Device (30). Response choices range from 1, strongly agree, to 4, strongly disagree. Higher scores represent poorer family functioning.

#### *Statistical analyses*

We first examined response frequencies of preferences, barriers, and facilitators to family involvement. In order to explore the predictors of intention to use family services, as measured by the preferences index and guided by the Andersen behavioral model, we performed a hierarchical linear regression analysis. Need for services—measured by family conflict, family-related quality of life, and the PANSS total score—was included in the first step of the model. The next step added enabling factors, measured by family contact and family capacity. The final step added demographic variables and the psychosocial factors, represented by the benefits index and the barriers index. The changes in  $R^2$  from model 1 to model 2 and from model 2 to model 3 were calculated. All analyses were conducted with SAS, version 9.2 (31).

#### **Results**

##### *Sample*

Table 1 shows participants' characteristics. The average participant was 52 years old, male, African American,

**Table 1**

Baseline characteristics of 232 mental health consumers

Characteristic	N	%
Demographic		
Age (M±SD)	51.6±9.1	
Male	195	84
Race		
Caucasian	83	36
African American	135	59
Other	12	5
Marital status		
Presently married	46	20
Widowed	6	3
Divorced or separated	102	44
Single or never married	78	34
Has children	153	66
Living arrangements		
Unsupervised	174	75
Transient	2	1
Supervised	56	24
Education and employment		
Completed some college	137	59
Education completed (M±SD years)	13.4±2.1	
Consumer holds a paying job	39	17
Family contact		
Lives with family	103	45
Talks to family member on telephone at least weekly	169	73
Gets together with family member at least weekly	113	49
Clinical		
Psychiatric diagnosis (chart)		
Bipolar disorder	104	45
Psychotic depression	17	7
Psychotic disorder	10	4
Schizophrenia or schizoaffective disorder	100	43
Symptom severity (Positive and Negative Syndrome Scale)		
Positive subscale (M±SD) <sup>a</sup>	13.3±5.1	
Negative subscale (M±SD) <sup>a</sup>	12.9±4.7	
General (M±SD) <sup>b</sup>	28.1±6.7	

<sup>a</sup> Possible scores range from 7 to 49, with higher scores indicating greater severity of symptoms.<sup>b</sup> Possible scores range from 16 to 112, with higher scores indicating greater severity of psychopathology.

and not currently married. Most participants had a child. The vast majority had a diagnosis of bipolar disorder or of schizophrenia or schizoaffective disorder.

### Family involvement in care

*Preferences for family involvement in care.* Table 2 shows consumer preferences for family involvement ("I want my family to. . ."). Notably, all items were endorsed by a majority of consumers, but preferences for each item also revealed considerable variation. Table 3 shows the pattern of consumer endorsements to the four involvement methods. The majority (N=171, 78%) of consumers wanted their family in-

involved in their care, and many (N=124, 57%) endorsed a desire for three of four or all four methods of involvement offered. A minority (N=48, 22%) wanted no involvement.

*Expectations for family involvement in care.* Table 2 also shows expected benefits of and barriers to family involvement ("If my family were involved. . ."). A majority of consumers expected family involvement to produce benefits both for themselves and their families. A considerable minority of consumers also anticipated barriers to family involvement, expressing concerns about a loss of privacy for themselves and worry that their family would have less time for other responsibilities.

*Predictors of consumer preference for family involvement.* Table 4 shows predictors of consumers' preference for family involvement. In model 3 the benefits index significantly ( $p<.01$ ) predicted the preferences index after the model controlled for need for family services (family conflict, family-related quality of life, and symptom severity), enabling factors (family contact and family capacity), demographic variables (age, gender, race, living with family, and marital status), and the barriers index. This model explained 32% of the variance in the preferences index, which was significantly more variance explained than the models without demographic characteristics and benefits and barriers ( $F=7.92$ ,  $df=7$  and  $149$ ,  $p<.001$ ). None of the measures of need, enabling factors, psychosocial factors, or the barriers index were significant individual predictors of the preferences index.

### Discussion

This is possibly the first study to assess the preferences and anticipated benefits and barriers of family involvement in care of a large group of individuals with serious mental illness who were receiving mental health services. Involvement, as defined in this report, was not limited to the nine-month-long evidence-based practice of family psychoeducation. Instead, we inquired about desire for family involvement in care that was much broader and included services representing a range of intensities and time commitments. These options for involvement were selected to be representative of the range of options available in typical community care. In considering these options, consumers' interest was strong but varied. Most consumers wanted at least one type of involvement; about one in five favored no family involvement. Those who wanted involvement expressed interest in several methods, indicating a desire for meaningful family involvement, including the family's receipt of written information, attendance at a support group, attendance at treatment sessions, and access to the consumer's provider by phone.

Consumers clearly considered the benefits and barriers to family involvement with respect to themselves



**Table 2**

Consumer preferences and expectations regarding family involvement in care

Item	N	Strongly disagree		Disagree		Neither agree nor disagree		Agree		Strongly agree	
		N	%	N	%	N	%	N	%	N	%
“I want my family to . . .”											
Receive written information about my mental illness	228	8	4	30	13	49	22	85	37 <sup>a</sup>	56	25
Attend a general or educational support group	221	7	3	40	18	51	23	80	36 <sup>a</sup>	43	20
Attend individual or group sessions	222	10	5	45	20	53	24	85	38 <sup>a</sup>	29	13
Call my team if they are concerned or have a question	228	7	3	19	8	40	18	114	50 <sup>a</sup>	48	21
“If my family were involved in my treatment . . .”											
It would help me with my illness	221	13	6	31	14	37	17	105	48 <sup>a</sup>	35	16
It would help my family feel better and reduce their own stress	219	11	5	25	11	30	14	115	53 <sup>a</sup>	38	17
I would lose privacy	229	16	7	90	39 <sup>a</sup>	29	13	73	32	21	9
We would fight more	216	30	14	118	55 <sup>a</sup>	33	15	26	12	9	4
They would have less time for family responsibilities	215	18	8	86	40 <sup>a</sup>	24	11	78	36	9	4
I worry they may try to control my money	226	34	15	120	53 <sup>a</sup>	20	9	36	16	16	7
They could hassle me about my alcohol/substance use	228	46	20	63	28 <sup>a</sup>	49	22	55	24	15	7

<sup>a</sup> Endorsed by the highest percentage for that question

and their family members. Most consumers felt that involvement would assist them with their illness and help their family feel better and less stressed. The concern that consumers have for their families—their desire to minimize the impact of their mental illness on family members—is rarely noted but is important for providers to understand (32). Consumers also expressed concerns about the negative effects of involvement, including a loss of personal privacy and decreased time for the involved family member to attend to other responsibilities. A shared decision-making process facilitates addressing such concerns. Overall, the variation in consumers' responses underscores the importance of eliciting and understanding each consumer's perspective.

The degree to which a consumer expected benefits from family involvement in care predicted the degree of desired family involvement, whereas anticipating barriers did not. The recovery literature has shown that hope is one of the best predictors of recovery (33). Anticipation of benefits may reflect the hope that improvement is possible, and families can be a support or conduit to that path of improvement. Consumers also may believe that barriers can be overcome.

Clinicians could bolster the consumer's beliefs that family involvement has benefits, including helping the consumer with his or her illness and being supportive to the consumer's family and reducing family stress.

Because most of the consumers expressed a desire for a range of family involvement methods and because of the historically limited reach of family

psychoeducation, we recommend that a variety of family involvement options be offered for the consumer's consideration and that facilities engage consumers in a shared decision-making process, such as REORDER. Such a personalized program has the ability to produce better-informed decisions based on thoughtful consideration of needs and preferences that can lead

**Table 3**Pattern of consumer preferences for family involvement in care<sup>a</sup>

Preferences endorsed	N	%	Preference endorsed			
			Receive written information	Attend support group	Attend treatment sessions	Call team
0	48	22				
1	3	1	X			
1	1	1		X		
1	14	6				X
2	3	1	X	X		
2	15	7	X			X
2	2	1		X	X	
2	5	2		X		X
2	4	2			X	X
3	6	3	X	X	X	
3	17	8	X	X		X
3	13	6	X		X	X
3	12	6		X	X	X
4	76	35	X	X	X	X

<sup>a</sup> N=219. X indicates response of either agree or strongly agree.

**Table 4**Models predicting the consumer's preferences for family involvement<sup>a</sup>

Variable	Model 1 <sup>b</sup>				Model 2 <sup>c</sup>				Model 3 <sup>d</sup>			
	B	SE of B	t <sup>e</sup>	p	B	SE of B	t <sup>e</sup>	p	B	SE of B	t <sup>e</sup>	p
Intercept	.44	.66	.67	.50	-.69	1.12	-.06	.54	-.56	1.31	-.43	.67
Family conflict	1.12	.64	1.74	.08	1.04	.66	1.56	.12	.58	.63	.92	.36
Family-related quality of life	.13	.08	1.59	.11	.14	.10	1.40	.16	.01	.09	.15	.88
Symptom severity	.02	.01	2.34	.02	.02	.01	2.40	.02	.01	.01	1.94	.05
Family contact					.17	.11	1.62	.11	.03	.11	.28	.78
Family capacity					.18	.27	.67	.50	.12	.25	.47	.64
Demographic characteristic												
Age									.01	.01	1.26	.21
Male									-.11	.27	-.39	.70
Caucasian									-.17	.21	-.79	.43
Lives with family									-.11	.22	-.52	.60
Currently married									.12	.27	.46	.64
Benefits index									.90	.13	6.90	<.01
Barriers index									-.10	.08	-1.16	.25

<sup>a</sup> F test for change in R<sup>2</sup>: model 2 versus model 1: F=1.58, df=2 and 193, p=.21; model 3 versus model 2: F=7.92, df=7 and 149, p<.001<sup>b</sup> Overall model statistics: F=3.34, df=3 and 197, p=.02; R<sup>2</sup>=.05<sup>c</sup> Overall model statistics: F=2.63, df=5 and 193, p=.03; R<sup>2</sup>=.06<sup>d</sup> Overall model statistics: F=5.78, df=12 and 149, p<.01; R<sup>2</sup>=.32<sup>e</sup> df=1

to enhanced utilization of family services.

The strength of the study is the size of the sample of consumers who had diagnoses of serious mental illness. However, it is unknown whether the clinical and family characteristics of this sample differed from consumers who refused to participate. However, the sample was recruited from multiple sites across three large VA medical centers and likely represents consumers seen in typical VA outpatient mental health clinics. This population included individuals with serious mental illness who had family contact, no consistent family involvement in care, and a willingness to discuss family involvement.

## Conclusions

This is the first study to systematically collect data on family involvement preferences from consumers with serious mental illness; it has important implications regarding both the value of soliciting consumer preferences and engaging families in care. Many consumers are open to involving their families in their care when consumers are offered a range of involvement possibilities. By encouraging consumers to consider the benefits of a range of choices regarding family involvement, mental health providers could leverage consumers' interest and, through them,

engage their families in care. This may increase the likelihood of utilization of family services by targeting consumers who want family involvement and by matching services to the preferred method, ultimately closing a critical gap in care for this population.

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The authors report no competing interests.

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## First-Person Accounts Invited for Column

Patients, family members, and mental health professionals are invited to submit first-person accounts of experiences with mental illness and treatment for the Personal Accounts column in *Psychiatric Services*. Maximum length is 1,600 words.

Material to be considered for publication should be sent to the column editor, Jeffrey L. Geller, M.D., M.P.H., at the Department of Psychiatry, University of Massachusetts Medical School, 55 Lake Ave. North, Worcester, MA 01655 (e-mail: jeffrey.geller@umassmed.edu). Authors may publish under a pseudonym if they wish.