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## Preferences for Family Involvement Among Veterans in Treatment for Schizophrenia

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### Abstract

**Objective:** Examine preferences for family involvement in psychiatric care in a large, representative sample of Veterans in treatment for schizophrenia.

**Method:** Veterans with schizophrenia or schizoaffective disorder (n=801) completed an assessment which included questions about demographic and clinical characteristics, status of family support, and preference for family involvement in their psychiatric care. Open-ended items were independently coded by two raters and categorized; Cohen's kappa was calculated for each category.

**Results:** Among the 801 participants, 496 (61.9%) indicated that they had a family member who provided them with regular support; 304 (37.9%) had no family member who provided support; and 1 did not respond. Among the 304 without support, 272 (89.4%) had a living family member. Of the 496 participants who had a supportive family member, 135 (27.2%) wanted their family member involved in their care. Of the 272 participants who did not have a supportive family member, but with living family, 57 (21.0%) wanted their family involved. Barriers to involvement included concerns about privacy and burden. Preferred method of involvement included contact with the patient's psychiatrist and education about the illness.

**Conclusions and Implications for Practice:** Preferences indicated by this large representative sample of individuals in care for schizophrenia indicate that a majority have supportive family and a substantial minority want family involved in their psychiatric care. Clinicians can address concerns about privacy and burden and deliver preferred services by phone or mail, overcoming anticipated barriers. Desire for family support groups was limited but present.

### Keywords

Schizophrenia; Family Interventions; Psychosis; Patient Preferences; Veterans

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### Impact:

Preferences for care practices can be expressed by individuals with schizophrenia. In specialty mental health, the traditional approach of physicians and other providers deciding what is best for individuals with serious mental illness, including schizophrenia, is evolving to incorporate more input from those individuals about their treatment preferences, including family involvement in that care. Efforts to ask and meet these preferences are likely to improve satisfaction with care, utilization of family services, and may impact relapse of symptoms. Preferences should drive services implemented and offered.

Schizophrenia causes significant behavioral and functional impairments, and comprises a large proportion of individuals at mental health clinics (Whiteford et al., 2013). In fiscal year 2015, more than 82,000 Veterans with schizophrenia were treated within the Veterans Health Administration (VHA) and 12.6% of this population had at least one hospital stay in that year for a psychiatric relapse (Bowersox, Visnic, & McCarthy, 2016). Relapses can be costly to the healthcare system and devastating to the individual and society. In VHA in fiscal year 2015, the mean hospitalization cost, for psychiatric and non-psychiatric reasons, was \$36,170 per Veteran with schizophrenia (Bowersox, Visnic, & McCarthy, 2016). In addition to the trauma and cost of a psychiatric hospitalization, significant recurrence of psychiatric symptoms of schizophrenia can lead to job loss, relationship deterioration or loss, homelessness, suicide, victimization, violence, or incarceration.

It is widely recognized that Family Psychoeducation (FPE), lasting at least 9 months, significantly reduces relapse and rehospitalization rates, with effect sizes comparable to psychopharmacologic trials for schizophrenia.(McFarlane et al., 1995; Randolph et al., 1994; TARRIER et al., 1988) As a result, FPE is recommended in treatment guidelines for schizophrenia (Dixon et al., 2010). Over the years, though, it has been shown repeatedly that delivery and uptake of such an intensive family intervention is sporadic and poor due to predictable barriers at the system-level (e.g., need for evening hours, staffing shortages), provider-level (need for specialized training, protected time), and individual-level (e.g., travel and time commitment) (Cohen, Glynn, Hamilton, & Young, 2009; Dausch et al., 2012). In an attempt to entice more family involvement in the care of individuals with schizophrenia, VHA, in partnership with research and clinical experts in family interventions, developed a family treatment framework where individuals could be offered less intensive family services or the more intensive FPE (Cohen et al., 2009; Dausch et al., 2012). Lasting anywhere from one to five sessions, these less intensive interventions have been found to impact the individual by strengthening their commitment to their treatment plan and prescribed medications (Boyer, McAlpine, Pottick, & Olfson, 2000; Olfson et al., 1999). But, there remains the question of what preferences individuals have for family involvement in their psychiatric care, whether it be FPE, shorter therapeutic family services, or something else entirely.

There is growing evidence that individuals with a serious mental illness such as depression (Dwight-Johnson, Lagomasino, Aisenberg, & Hay, 2004) and schizophrenia (Beusterien et al., 2017; Bridges, Kinter, Schmeding, Rudolph, & Muhlbacher, 2011; Kinter, Schmeding, Rudolph, dosReis, & Bridges, 2009) can identify their treatment preferences, but routine inquiry in usual care practices is rare. There have been a handful of research reports in the last decade identifying individual preferences for family involvement in psychiatric treatment. A sample of 179 Veterans with major or minor depression, being seen in primary care, were asked if they wanted their romantic partner involved in their treatment by providing medication reminders, accompanying them to an appointment, or speaking with their treatment provider. Over half of the sample (64%) reported their partner was already involved in one of these ways; and nearly all Veterans who did not already have the involvement of their partner wanted it (Hershenberg, Mavandadi, Klaus, Oslin, & Sayers, 2014). In another study, a convenience sample of 110 Veterans with post-traumatic stress disorder (PTSD) who were engaged in outpatient treatment for the disorder were given a needs assessment for family involvement in their care. Almost everyone reported having family and 79% expressed interest in greater family involvement in their care. Services of greatest interest were education for the family on PTSD (85%) and other mental health issues (76%) and attending a family or couples therapy group (72%) (Batten et al., 2010). In another study, a sample of 69 Veterans with serious mental illness, including 52 with schizophrenia or schizoaffective disorder, were asked about their desire for family involvement in their psychiatric care. This sample was gathered from inpatient, partial hospitalization, and outpatient clinics, and over half the sample (64%) wanted family involvement, but a significant subsample was concerned their families were too busy (35%) or had no interest (29%). There was also concern about family conflict (33%) getting in the way. There was a preference for their family to receive information on their progress (81%)

and education about their psychiatric illness (77%). Preference for engagement in a family support group was lower (48%), but still a large subsample (Murray-Swank et al., 2007). Lastly, a sample of 232 Veterans with serious mental illness, including 100 with schizophrenia or schizoaffective disorder, who were engaged in outpatient treatment, were asked about family treatment preferences as part of a study aimed to engage families in care. There was some concern by Veterans that involvement would lead to a loss of privacy (41%) or be burdensome to the family member (40%), but there was little concern it would lead to increased tension (16%). Despite these concerns, the vast majority of this sizable sample (78%) wanted family involvement; many (62%) wanted their family to receive written education; or for their family to attend a general or educational support group (56%) (Cohen et al., 2013b).

The current report builds on the small literature on preferences for family involvement in psychiatric care by examining these preferences in a large, representative sample of Veterans in outpatient treatment for schizophrenia. Specifically, the report aims to elucidate what percent of individuals with schizophrenia have supportive family, any barriers to family involvement anticipated by these individuals, and their preferences for methods of involvement. This work examined data from a multisite, clinic-level controlled trial called EQUIP (Enhancing Quality and Utilization in Psychosis). Prior to the current report, the preferences of Veterans for family involvement in treatment had been examined only in small non-representative samples.

## METHOD

### Study Design

Data from EQUIP comprise this cross-sectional analysis. EQUIP was a clinic-level controlled trial conducted in four Veterans Integrated Service Networks (VISNs). Leadership in each VISN named a pair of specialty mental health clinics that were matched on academic affiliation [known to affect organizational engagement in quality improvement] (Weeks, Yano, & Rubenstein, 2002; Yano, 2000) and number of individuals with schizophrenia; and one was assigned to implementation and one to control (usual care), for a total of 4 implementation and 4 control sites across 4 states. EQUIP evaluated the effectiveness and implementation of evidence-based care for schizophrenia at mental health clinics in the VHA.

### Participants

Individuals were eligible to participate if: 1) they were at least 18 years old, 2) had a diagnosis of schizophrenia or schizoaffective disorder, and 3) had at least two VA mental health clinic visits during a 6-month period. During a 12-month enrollment period, the population of potentially eligible individuals who met these criteria was identified. The list of eligible Veterans was constructed using a partial Health Insurance Portability and Accountability Act (HIPAA) waiver which allowed review of medical records. This list was used to conduct an established visit-based sampling protocol (Young, Sullivan, Burnam, & Brook, 1998). Specifically, to ensure that the sample was representative of the overall clinic population, each individual with a treatment visit during the enrollment period who was on

the eligibility list had a random determination regarding whether they were approached for study participation. To ensure that visit frequency did not affect the probability of being selected, individuals were only screened at their first visit during the enrollment period. The probability of inclusion in the sample to be approached was determined based on the overall eligible population, desired sample size, and expected rate of non-participation. 1964 individuals were eligible to be approached, 801 enrolled (41%) and 633 (32%) refused participation. The remaining 530 were not approached because the sample size satisfying the power calculation had been met.

The 801 individuals enrolled completed written informed consent prior to the baseline assessment. Of the 801 participants, 734 were male and 67 were female. Participants reported a mean age of 54.29 (SD = 9.20) and were primarily of non-Hispanic ethnicity (86%). Race consisted of 44% White, 44% African-American/Black, 8% multi-racial, and 3% “other” (including American Indian, Alaska Native, Asian, Native Hawaiian or other Pacific Islander).

The baseline assessment used for the current report was completed before any intervention occurred; therefore, implementation and control site data were examined together for this report. Further study procedures, not relevant to the current report, can be found elsewhere (Armstrong, Cohen, Helleman, Reist, & Young, 2014; Brown, Cohen, Chinman, Kessler, & Young, 2008; Cohen, Chinman, Hamilton, Whelan, & Young, 2013a; Cohen et al., 2013b; Hamilton et al., 2013; Pedersen, Huang, Cohen, & Young, 2018; Young et al., in press). The study was approved by the Institutional Review Boards of all participating sites.

## Measures

The 60-minute assessment included, in part, interview questions eliciting demographic and clinical characteristics, status of family support, and preferences for family involvement in care. The assessment was conducted in-person in an interview format by research assistants with considerable previous experience with the population with schizophrenia. Research assistants were trained to a high level of reliability on all assessment measures, and quality assurance checks were completed during the study (Ventura, Green, Shaner, & Liberman, 1993).

**Demographic characteristics.**—Demographic characteristics obtained included participant age, gender, race, marital status, number of children, level of education, and employment status.

**Clinical characteristics.**—Psychiatric diagnosis of schizophrenia or schizoaffective disorder gathered through the HIPAA waiver was confirmed at baseline using an abbreviated version of the Structured Clinical Interview for DSM-IV (SCID; First, Spitzer, Gibbon, & Williams, 1995). Additionally, symptoms were assessed using nine items from the clinician-rated Brief Psychiatric Rating Scale (BPRS; Ventura et al., 1993). Items were included to assess positive and negative symptoms and disorganized thinking. Subscale scores for positive symptoms were obtained by taking the mean of the four items that measured grandiosity, suspiciousness, hallucinations, and unusual thought content ( $\alpha = .75$ ). Subscale scores for negative symptoms were based on the mean of another four items

representing blunted affect, motor retardation, emotional withdrawal, and uncooperativeness ( $\alpha = .80$ ). The third subscale represented disorganized thinking which is based on one item. All items were rated from 1 (not present) to 7 (extremely severe) based on the clinical interview during the assessment. Higher subscale scores indicate greater symptom severity.

**Family involvement.**—Family involvement questions and their branching are presented in the Figure. All response choices for these questions are presented in the Tables. Each question had an “other” response choice and responses to “other” were further categorized as part of the statistical analyses for this report.

### Statistical Analyses

Analyses were primarily descriptive, including means, standard deviations, and percentages. We conducted independent samples t-tests and chi-square tests to examine differences on demographics and psychiatric symptoms between those in the sample who reported having a family member who provided them support on a regular basis and those who had living family, but whom the participant reported did not provide them with support on a regular basis. Given that there were a substantial number of open-ended “other” responses to the family involvement items, open-ended responses were coded into two categories. Two raters independently coded the open-ended responses into categories for each of the six questions with other open-ended responses. We reached at least “substantial agreement” on inter-rater agreement values during this first round of coding (all Cohen’s kappa > 0.61), (Landis & Koch, 1977) then resolved through discussion items where disagreement occurred. Regarding the question, “Would you like your family member to be involved or more involved in your psychiatric treatment?,” we coded 31 responses with a kappa of 0.87. Kappa values were 1.00 for “What has kept your family member from being involved?” and “How would you like your family member to be involved with your care?,” where we coded 7 and 2 items, respectively. We coded 119 open-ended responses and obtained an initial kappa of 0.82 on the question, “Would you like your (family member who helped the most) to be involved or more involved in your psychiatric treatment?” We reached an initial kappa rating of 0.62 on the 45 items we coded from the item, “What has kept your (family member who helped the most) from being involved?” Lastly, we reached a kappa of 1.00 for the 6 open-ended responses on “How would you like your (family member who helped the most) to be involved with your care?”

## RESULTS

### Existence of Family Member Support

Among the 801 participants, 496 (61.9%) indicated that they had a family member who provided them with support on a regular basis (see Figure). These family members were primarily a brother or sister (37.9%), parent (31.5%), spouse/significant other (16.9%), or child (7.9%). Other family members included a cousin (2.0%), an aunt or uncle (1.2%), a niece or nephew (1.0%), an in-law (0.6%), or other family member (grandmother, granddaughter, unspecified “family;” 0.6%). One participant indicated he considered his conservator his “daughter.” Over one third ( $n=304$ ; 37.9%) of the 801 participants had no family member who provided them with support on a regular basis. Among these 304, 272



(89.4%) indicated they had a living family member, but no family member gave them support. The other 32 participants reported they did not have a living family member and one participant did not respond.

Table 1 shows the demographic and clinical characteristics of those with a family member who supports them on a regular basis and those with living family members but no family member who supports them on a regular basis (N=768). Those who reported having a family member who provides regular support were younger and more likely to be married than those without a supportive family member. In addition, those with a supportive family member were rated significantly less severe on positive and negative symptoms and disorganized thinking per the BPRS.

### **Reasons for Not Wanting More Family Involvement**

Of the 496 participants who indicated they had a family member who supports them regularly, 355 (71.6%) reported they did not want their family member more involved in their psychiatric treatment. Two hundred and fifteen of the 272 (79.0%) participants who did not have a supportive family member, but living family, reported they did not want their family involved in their psychiatric treatment. Reasons are shown in Table 2. The most endorsed reason by both participants with and without a supportive family member was related to concerns about privacy, which was endorsed by about 39% and 44% of those with and without supportive family members, respectively. About one-quarter in both groups endorsed that their family was too burdened or busy to be more involved. About 15% of those with a supportive family member endorsed that their family was already involved enough in their care, while about 22% of those without a supportive family member endorsed having bad relations with their family as a reason for not wanting to involve them more.

### **Barriers to More Family Involvement**

Of the 496 participants who indicated they had a family member who supports them regularly, 135 (27.2%) reported they wanted their family member more involved in their psychiatric treatment. Fifty-seven of the 272 (21.0%) participants who did not have a supportive family member, but living family, reported they wanted their family involved in their psychiatric treatment. Participants who endorsed they would like more family involvement identified several barriers reported in Table 3. The three most endorsed barriers by both participants with and without a supportive family member were related to having little time to come to VA to talk with care providers (about 28% in both groups), transportation difficulties (about 16% and 21% of those with and without a supportive family member, respectively), and family member living too far away to help (about 14% and nearly 46% of those with and without a supportive family member, respectively). Approximately 19% of those without a supportive family member reported that their relationship with the family was not good. Across the sample about 1 in 10 acknowledged that that a barrier to involvement had been that their VA clinicians did not offer a chance for family members to be involved.



## Preferences for More Family Involvement

Participants who wanted more involvement (N=192) identified how they would like their family members more involved in care. As shown in Table 4, over one-half of those with and without a supportive family member indicated that they would like their family member to meet or talk on the phone occasionally with their psychiatrist. The other most frequently endorsed ways for family to be involved were for the family to learn how to help the individual get better, learn about the individual's illness, learn how they—the family member—could cope better with the individual's problems, learn more the individual's medications, meet or talk with the individual's case manager, or find support through connections with other families. A small minority wanted regular family counseling sessions.

## DISCUSSION

This is possibly only the third study to systematically assess the preferences, anticipated barriers, and desired methods for involvement of family in psychiatric care, from the perspective of individuals with schizophrenia. These results expand and improve on the existing literature by assessing a very large representative population with schizophrenia engaged in usual outpatient care across 8 VA medical centers, across 4 states.

In terms of supportive family, the vast majority of individuals reported having a family member who provides regular support. The minority who did not have a supportive family member were more likely to be unmarried and have more positive and negative symptoms and more disorganized thinking. The sample was predominately male in their mid-50s and those with supportive family named a sibling in that role. The high number of supportive family in an aging group is promising for a population usually characterized for its high caregiver burden.

In terms of involvement in their psychiatric care, the vast majority, about three-quarters of the total sample, did not desire involvement. Specifically, amongst those with supportive family, the majority did not see a reason to involve these family members further. This was due to concerns about privacy or further burdening the family member, but may also be due to satisfaction with current levels of involvement. Amongst those without supportive family, but with family living, the concerns were also about privacy and burden, but also the challenges of travel to the medical center and existing bad relationships.

There was a considerable minority, a quarter of the total sample, who did want more involvement of their family. The anticipated reasons why they had not already started or increased their involvement was due to limited time to come to the VA, transportation difficulties including living too far away, and existing bad relationships. Despite these anticipated barriers, individuals preferred their family involvement in a number of ways including the ability for family to talk to the individual's psychiatrist and case manager; education around the psychiatric illness, coping, medication, and getting better; and finding support through other families. These methods for involvement can be addressed through phone calls and mailed education, and likely do not require the need for travel, an anticipated barrier by study participants.

Concerns about privacy in the current study are in line with the one large previous study of preferences in individuals with schizophrenia (Cohen et al., 2013b). This concern speaks to the importance of a systematic discussion with the individual with schizophrenia regarding the limits that can be set to confidentiality, while still having a family member involved in their care. Limits can be set by the individual with schizophrenia and can vary by topic and the involved person. This discussion can take place annually, maybe with the nurse or case manager, and can be placed in the medical record and shared with the individual's team. Dixon and colleagues recruited a large sample of Veterans with serious mental illness, largely bipolar disorder, schizophrenia or schizoaffective disorder, who had little to no recent family contact with the treatment team (Dixon et al., 2014). The authors designed and tested a shared decision-making process to discuss family involvement in care. The recovery goals of the individual with serious mental illness set the framework and then the individual defined family involvement parameters around each recovery goal (e.g., I want my mother to be able to discuss my efforts towards independent living but not regarding my medication or return to work). This shared decision-making process led to a fourfold increase in family involvement in participants' care and would address some of the Veteran concerns identified in the current study (Dixon et al., 2014).

Concern about further burdening the family has rarely been highlighted in the literature but this is at least the third study where this concern was identified by individuals with serious mental illness. More typical is the identification of an established poor relationship between the individual with schizophrenia and his family, which was also mentioned by this sample and the one previous study of preferences of individuals with schizophrenia. Both concerns, which impede family involvement, could be addressed through family therapy or services. Both this study and the previous studies of preferences of those with serious mental illness indicate a desire for family to attend a support group. In this study, those identified family supports were siblings, most likely in their 50s and 60s given the average age of participants, who are likely juggling competing demands of aging parents, a sibling with a mental illness, growing children, and employment. Given this context coupled with the individual's preference to not burden the family, there is a need by the organization to be flexible in service delivery. The VHA has recognized this and supported the design, clinician training, and implementation of a framework to meet the preferences of individuals with serious mental illness and their families for involvement in family services (Cohen et al., 2008; Dausch et al., 2012). The VHA has since established a Memorandum of Understanding with the National Alliance on Mental Illness (NAMI) and has a Point of Contact at each VA Medical Center so that families can find supportive community meetings. Additionally, the VA has established dissemination of brief (1–5 sessions) family consultation as well as abbreviated family interventions that are available at medical centers. There have been efforts in VA to explore service delivery via telehealth for individuals with schizophrenia and their family members (Rotondi et al., 2005) and delivery online via a website (Glynn, Randolph, Garrick, & Lui, 2010; Rotondi et al., 2010). These early attempts have shown mixed results in terms of impact on psychiatric symptoms, but feasibility has been established.

Given that this study and one previous indicated a desire by individuals with a mental illness for their family member to speak with their psychiatrist, there should be a real effort to this

end. Although this might seem easy to implement, there are barriers from the system, provider, and family. The system provides limited time to return calls from family members. Providers lack knowledge of the patient's release and limits to confidentiality. Family members do not when and how to initiate contact and can be unaware of service availability. Any one of these areas could be an avenue for targeted quality improvement, which would address the preferences of individuals with a mental illness and potentially lead to further involvement of family in the care of their loved ones.

There was evidence in this study and both previous studies of preferences in this population, for families to receive education about the individual's psychiatric illness. This is easy to implement as there is a wealth of well-vetted material developed by groups such as SAMHSA and NAMI, that is easily downloaded and available to be distributed by the care team in person or by mail.

The strength of the study is the size of the sample of individuals with schizophrenia. The sample was recruited from multiple sites across 8 large VA medical centers, across 4 states, and therefore likely represents individuals seen in typical VA outpatient mental health clinics. However, it is unknown whether the clinical or family characteristics of the sample differ from a non-VA sample or those who refused to participate. The sample did not include those with other serious mental illnesses, such as bipolar disorder, psychotic depression, or PTSD, and therefore cannot be generalized to those groups who might have a different level of family support and different preferences for involvement. Typical of a representative VA sample, the vast majority was male and this limited our ability to speak to any gender differences. The study is also limited in that preferences were limited to biological family and it is possible that individuals with schizophrenia find support and would desire involvement by close non-relatives. Overall, this study presents definitive findings about the support and preferences for family involvement in a large representative sample of Veterans with schizophrenia. Coupled with the few existing reports, these preferences indicate that involvement is desired in a substantial minority and services desired could be easily implemented without much burden to the clinical team or family member.

## CONCLUSION

Eliciting patient preferences is a growing emphasis in patient-centered outcomes research (Bridges, Kinter, Kidane, Heinzen, & McCormick, 2008). In specialty mental health, the traditional approach of physicians and other providers deciding what is best for individuals with serious mental illness, including schizophrenia, is evolving to incorporate more input from individuals about their treatment preferences, including family involvement in that care. This study found that the majority of individuals in this large representative sample of Veterans with schizophrenia in treatment have supportive family and many have family already involved in their care. Others expressed a preference for no involvement of family. Participants expressed specific ways in which they would like their family involved and many of those options could be delivered by phone (consult with the care team), through the mail (education), or via telemedicine or in the community (supportive groups). Efforts to ask and meet these preferences along with flexible delivery options that do not require medical

center visits are likely to improve satisfaction and utilization of family services and may impact relapse of psychotic symptoms.

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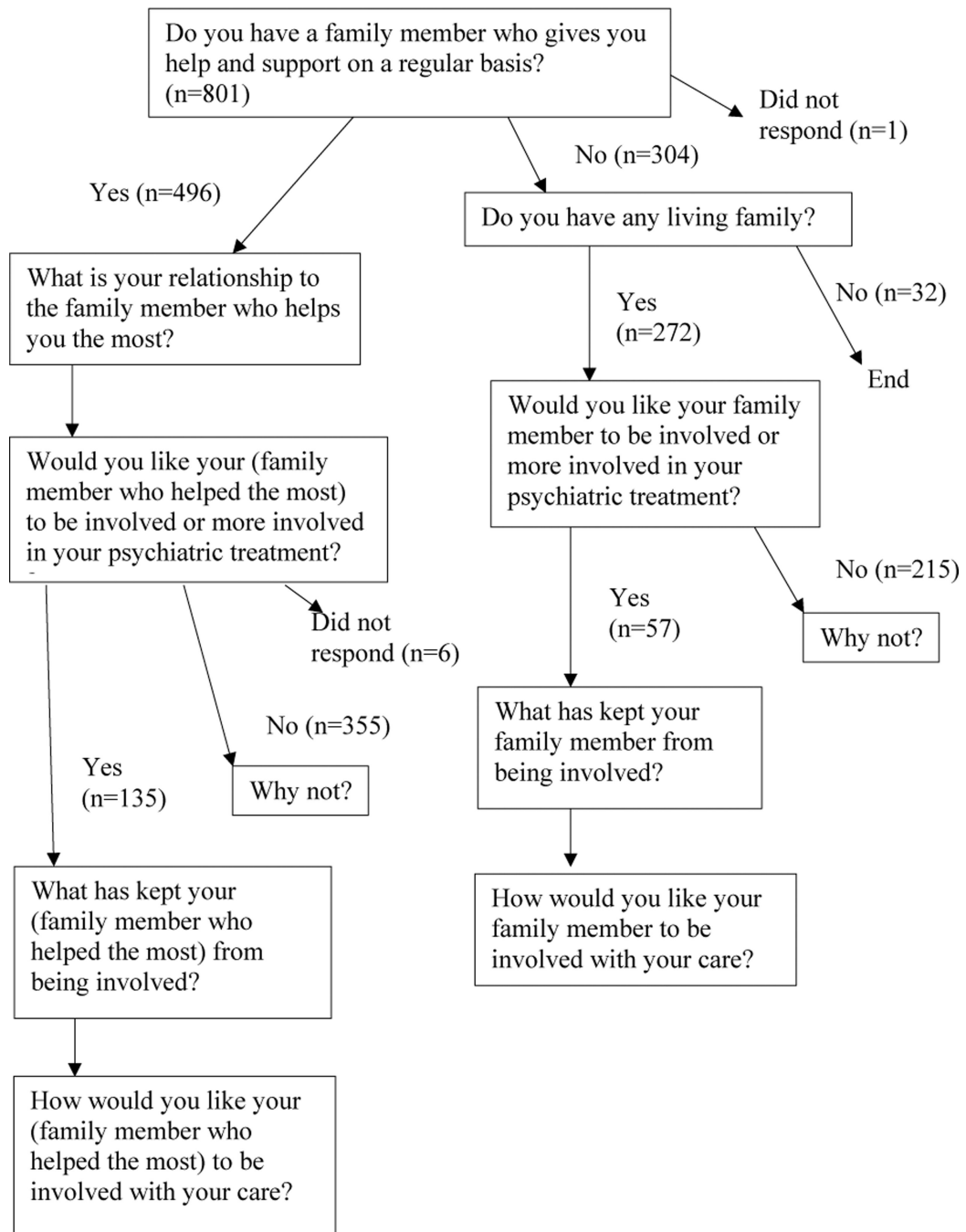
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**Figure.**  
Questions about family involvement



**Table 1**

Comparing Those With a Supportive Family Member to Those Without a Supportive Family Member but have Living Family

	Do you have a family member who gives you help and support on a regular basis?		<i>t</i> / <i>chi-square</i>	<i>df</i>	<i>p</i>
	Yes ( <i>N</i> = 496)	No, but has living family ( <i>N</i> = 272)			
	<i>M</i> ( <i>SD</i> )/Percentage	<i>M</i> ( <i>SD</i> )/Percentage			
<b>Demographics</b>					
Age	53.66 (9.46)	55.16 (9.06)	2.13	766	0.034
Male gender	90.7%	93.4%	1.59	1, 766	0.208
White race	45.3%	45.7%	0.11	1, 766	0.917
African-American/Black race	44.7%	47.6%	0.57	1, 766	0.450
Married	28.2%	17.7%	10.47	1, 766	0.001
Children	50.6%	53.5%	0.59	1, 766	0.442
Education <sup>a</sup>	59.5%	54.4%	1.81	1, 765	0.178
Worked in the past month for pay	16.1%	12.2%	2.18	1, 766	0.140
<b>Psychiatric Symptoms</b>					
Positive symptoms	2.33 (1.27)	2.60 (1.32)	2.69	748	0.007
Negative symptoms	1.70 (0.86)	1.83 (0.81)	2.06	747	0.039
Disorganized thinking	1.92 (1.23)	2.12 (1.30)	2.02	747	0.044

Note.

<sup>a</sup>Education represents the percent who endorsed at least some college. There were n=32 who did not have a supportive family member but had no living family and are not included in this table. There was n=1 who did not answer the question and is not included in this table. Differences in *df* are due to missing data.

**Table 2**

**Reasons for Not Wanting More Family Involvement from Those with Living Family**

	<b>Do you have a family member who gives you help and support on a regular basis?</b>	
	<b>Yes (N = 496)</b>	<b>No, but has living family (N = 272)</b>
	<b>No (N=355) 71.5%</b>	<b>No (N=215) 79.0%</b>
<b>Why not?</b>		
Protect my privacy	38.6%	43.7%
Family is already too burdened	25.1%	23.3%
They don't live around here	7.3%	17.2%
Bad relations with family	1.4%	22.3%
Family member is sick (mentally or physically) or frail	9.3%	8.8%
No contact with family	0.3%	9.8%
Other		
Already involved enough	14.9%	1.4%
Don't need/want their help	9.3%	6.0%
They don't understand	2.8%	2.8%
No time for them to come to VA	5.7%	--
Family doesn't want to be involved	--	0.9%
They might make things worse for me	0.8%	--
It might worry them if they were more involved	0.6%	--
They don't speak English	0.6%	--
Never asked them to be involved	0.6%	--
I don't know	0.8%	--
Unclear response	0.6%	0.5%

*Note.* Those in the “No, but have living family” category responded to items based on any family involvement. Those indicating they have family support on a regular basis were asked to consider “the family member who helps you most.” Blanks indicate that there were no open-ended “other” responses that fit that category. There was n=6 in the “Yes, I have a family member who provides support on a regular basis” who did not respond about further involvement. They are not included in Tables 2, 3, and 4.

**Table 3**

**Barriers Keeping Family from Being Involved Among Those Who Would Like More Family Involvement**

	<u>Yes (N = 496)</u>	<u>No, but has living family (N = 272)</u>
<b>Do you have a family member who gives you help and support on a regular basis?</b>		
	<u>Yes (N=135) 27.2%</u>	<u>Yes (N=57) 21.0%</u>
<b>Would you like your family member to be involved or more involved in your psychiatric treatment?</b>		
<b>What has kept your family member from being involved?</b>		
Family member lives too far away	14.1%	45.6%
No time to come to the VA	26.7%	28.1%
Transportation is difficult	15.6%	21.1%
Relationship with family member has not been good	3.0%	19.3%
My VA clinicians have not offered me chances for family members to be involved	13.3%	8.8%
They aren't interested	3.7%	8.8%
Need evening appointments	1.5%	1.8%
We've had bad experiences in the past at the VA when this family member was involved	0.7%	1.8%
We've had bad experiences in the past, but not at the VA, when this family member was involved	0.0%	0.0%
Other		
Already involved enough	7.4%	1.8%
Family already too burdened/busy	2.2%	5.3%
Patient never asked family member to be involved	5.9%	--
Not around here	--	1.8%
Family member is sick	1.5%	--
They think I can handle it on my own	1.5%	--
I don't know	--	1.8%
Unclear response	6.0%	--

*Note.* Blanks indicate that there were no open-ended "other" responses that fit that category. There was n=6 in the "Yes, I have a family member who provides support on a regular basis" who did not respond about further involvement. They are not included in Tables 2, 3, and 4.

**Table 4**

**Options for More Family Involvement Among Those Who Would Like More Family Involvement**

	<b>Do you have a family member who gives you help and support on a regular basis?</b>	
	<b>Yes (N = 496)</b>	<b>No, but has living family (N = 272)</b>
	<b>Would you like your family member to be involved or more involved in your psychiatric treatment?</b>	
	<b>Yes (N=135) 27.2%</b>	<b>Yes (N=57) 21.0%</b>
<b>How would you like your family member to be involved in your care?</b>		
Meet/talk on the phone occasionally with my psychiatrist	53.3%	52.6%
Learn how they can help me get better	34.1%	43.9%
Learn more about my illness	34.1%	42.1%
Learn how they can cope better with my problems	34.8%	40.4%
Learn more about my medications	26.7%	26.3%
Meet/talk on the phone occasionally with my case manager	23.0%	19.3%
Meet with other families of persons with problems like mine for support	11.1%	28.0%
Learn more about benefits	13.3%	24.6%
Regular family counseling sessions	13.3%	15.8%
Other	--	--
Visit more often	0.7%	1.8%
Learn about treatment options	--	1.8%
Be there for me when I need them	1.5%	--

*Note.* Blanks indicate that there were no open-ended "other" responses that fit that category. There was n=6 in the "Yes, I have a family member who provides support on a regular basis," who did not respond about further involvement. They are not included in Tables 2, 3, and 4.