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RESEARCH ARTICLE

Serious and Persistent Mental Illness Treatment and Support Services in Ohio: Perceptions from Consumers, Family Members, and Service Providers

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ABSTRACT

Background: Given the prevalence of unaddressed mental health conditions in the United States, and the unique challenges that mental health service providers face in their therapeutic work with people living with serious and persistent mental illness (SPMI), it is imperative to understand how and where current services are meeting or falling short according to consumers of SPMI services, their family members, and service providers.

Methods: Utilizing a mixed-methods approach, SPMI recovery-oriented practices were assessed throughout Ohio. Data were collected from 332 participants (consumers of SPMI services, their family members, and SPMI service providers) via focus groups and surveys from June through November 2020.

Results: Overall, consumers and family members were satisfied with current services but felt negative about the process of finding services. Family members discussed that the behavioral health system did not do a good job of explaining what services were available and how to access those services. While participants generally held a positive perception that the mental health treatment system embraced the core principles of recovery, they overwhelmingly reported that service expansion was needed, both in terms of additional services and a higher volume of existing services, and they discussed the need to combat stigma. Most participants reported that they had perceived negative attitudes toward persons living with SPMI. Two-thirds of service providers perceived negative attitudes in service delivery.

Conclusion: Findings illustrate aspects of SPMI treatment and support services as possible areas for improvements, such as heightening community outreach and education, employing navigators, expanding transportation and telehealth options, and expanding crisis services. To address stigma, there were many calls across participant types for increased community education on SPMI and what it means to live with SPMI, with an outreach focus on reframing and positive community messaging.

Keywords: SPMI; Recovery-oriented practices; Stigma; Mental health; Mixed-methods

INTRODUCTION

Properly managed mental health is an integral component of overall health and well-being, yet unaddressed mental health conditions are prevalent. Among adults in the United States in 2020, 21.0%, or 52.9 million people, experienced any mental illness, while 5.6%, or 14.2 million people, experienced serious mental illness in the past year.[1] Among the 14.2 million adults living with serious mental illness, 35.5% did not receive inpatient or outpatient mental health services or take prescription medication for a mental health issue in the past year, and 49.7% perceived an unmet need for mental health services.[1]

Given the prevalence of mental health conditions in the United States, the need for treatment is great. Mental health service providers face unique challenges in their therapeutic work with people living with serious and persistent mental illness (SPMI), including clients' persistent, and sometimes sudden, recurrence of symptoms, loss of developmental achievements, and regressive behavior, as well as stigma from the community.[2] Therefore, it is imperative to understand how and where current services are meeting or falling short for individuals living with SPMI.

While there has been previous research focusing on perceptions of SPMI treatment and support services among individuals participating in those services, their family, and their treatment providers, to our knowledge this is the first research to assess SPMI services from all 3 groups in a single study. And, although states have published case studies reviewing the development/implementation of new mental health service/treatment models,[3,4] a statewide assessment of SPMI treatment and support services was nonexistent at the time of this present study.

Through the utilization of a mixed-methods research approach, the present study was designed to assess knowledge and availability of SPMI recovery-oriented practices throughout Ohio. The specific objectives were: assess knowledge of persons living with SPMI and their family members as to the availability of community treatment and support services, as well as knowledge of how to access needed services; assess community professional perceptions of treatment and support service needs, as well as their program/agency/organization's ability to provide appropriate services to persons living with SPMI; identify barriers and gaps in SPMI services; and assess current community messaging related to SPMI in examination of stigma of persons living with SPMI. The results from this study may inform policy to develop and improve accessibility to SPMI treatment and support services.

METHODS

From June through November 2020, a total of 6 regional epidemiologists (REPIs) collected survey data and conducted focus groups. A REPI was assigned to each of Ohio's 6 state psychiatric hospital catchment areas. The state operates a psychiatric hospital in each of its geographical regions: Northeast, Northwest, Central, Southeast, and Southwest. The Northeast region, due to its dense population, has 2 state psychiatric hospitals, and thus, consists of 2 catchment areas. The REPIs were professionals with at least a master's degree in social science.

The study's principal investigator (PI) trained REPIs on the implementation of study protocols as well as provided REPIs with ongoing monitoring and technical assistance. Prior to focus group/interview (FGI) start, REPIs obtained participant informed consent, administered a brief survey of participant background, and administered assessments of SPMI recovery-oriented practices in participant communities. The REPIs conducted FGIs following scripted protocols and audio recorded all FGI proceedings with participant knowledge and informed consent. Study participation was voluntary. Focus groups were no larger than 11 participants and were 1 to 2 hours in duration. An applicable institutional review board approved this study.

Participants

Participants for this research needed to have lived experience, ie, persons who had lived experience in having SPMI (ie, bipolar disorder, borderline personality disorder, major depressive disorder, schizoaffective disorder, schizophrenia), persons who had lived experience in having a family member/loved one with SPMI, and persons who had lived experience in providing treatment/support services to persons living with SPMI (eg, case managers, counselors, law enforcement officers, psychiatrists, and social workers). The REPIs were required to interview, per catchment area, a minimum of 15 persons living with SPMI, a minimum of 15 family members/loved ones of persons living with SPMI, and a minimum of 30 community professionals who provided SPMI services. Since the study's objectives included assessing treatment/support needs of persons living with SPMI and their family members, both consumers of services, 15 respondents of each were targeted. Thus, 30 consumers of services and 30 community professionals who deliver services were targeted for recruitment per catchment area. The study's overall target sample size was 360 participants.

Our sample size was determined based on the time allotted and resources available for the study. Note, since persons living with SPMI were recruited from treatment/support programs, they are referred to as 'consumers' in this study (ie, consumers of SPMI treatment/support services). In addition to biological relations, the term 'family member' includes loved ones of persons living with SPMI (ie, non-biologically related significant other, eg, spouse or romantic/domestic partner, relation by adoption/marriage, close friend). Also, participating family members may or may not have been connected to a participating consumer; they may have referenced a loved one not enrolled in this study.

Our sampling plan was based on strategies for mixed purposeful sampling. Purposeful sampling is selecting information-rich cases for in-depth study with sample size and specific cases dependent on the study's purpose.[5] The purpose of this research initiative was to conduct a statewide assessment of SPMI treatment and support services. Our sampling combined the strategies of maximum variation sampling and convenience sampling. Maximum variation sampling picks a wide range in variation among persons of interest. Our sample size was determined based on time allotted and resources available for the study.

Consumers were recruited to participate in the study through treatment/support programs. The REPIs and the study coordinator contacted community agencies by phone or email within each of the 6 psychiatric hospital catchment areas to invite study participation of agency staff, treatment clients, and family members of persons living with SPMI who participated in agency family programming. Other community professionals who provided treatment/support services to persons living with SPMI were also contacted by phone or email and solicited for study participation within each hospital catchment area. The REPIs also contacted local chapters of NAMI (National Alliance on Mental Illness) Ohio to assist with advertisement of the study and recruitment of consumers and family members. Due to difficulty in obtaining parental consent for minor participants, only individuals aged 18 years or over were invited to participate in this study.

All study data were primary data, and most data were collected via focus groups. Note, focus groups were used to allow for a larger number of study participants within the study timeframe. Most data were collected via focus groups. Interviews were conducted when only one participant showed for a scheduled focus group, or in the case of service providers, when mutual time among a group of service providers could not be found for a focus group.

Instrumentation

Participants completed a brief demographic survey prior to FGI start. The researchers wrote these pencil and paper surveys to capture the following participant information: sex, ethnicity, race, age, level of education, as well as additional characteristics by participant type. Participants also completed the Recovery Self-Assessment Revised (RSA-R) questionnaire prior to FGI start. The RSA-R is a self-reflective, self-administered pencil and paper questionnaire designed to identify strengths and target areas for improvement in the provision of recovery-oriented care.[6] There are 4 versions of RSA-R: Person in Recovery (administered to consumers), Family Member/Significant Other (administered to family members), Provider (administered to treatment/service providers), and Administrator (not administered due to too few administrator participants). Each RSA-R version is comprised of 32 to 40 items designed to gauge the degree to which programs implement recovery-oriented practices. Participants are presented with a list of statements and instructed to indicate how accurately each statement describes the activities, values, policies, and practices of the provider.

Each version of the RSA-R is comprised of 6 domains: client choice, consumer involvement, diversity of treatment option, individually tailored services, inviting space, and life goals. In addition, the Family Member/Significant Other version includes a seventh domain, family involvement. The RSA-R scoring consists of an overall score and a score for each domain. Each item is scored from 1 to 5, with 5 indicating the most positive perception that a program/agency/organization engages in recovery-oriented practices. For a more detailed description of RSA-R domains and scoring, refer to O'Connell et al.[7]

In FGIs, all participants were asked open-ended questions to assess community messaging related to SPMI in examination of perceived stigma of persons living with SPMI. Consumers and family members were asked a series of open-ended and Likert-scale questions to assess their knowledge of available SPMI treatment/support services, as well as questions to assess their knowledge of how to access needed services. Providers were asked a series of open-ended and Likert-scale questions to assess their perceptions of community treatment/support service needs, as well as their program/agency/organization's ability to provide appropriate services to address the needs of persons living with SPMI. For focus group questions (scripted protocols), see Appendix.

Data Analysis

All analyses of quantitative data were conducted using the Statistical Package for the Social Sciences (SPSS) (SPSS Inc., Chicago, IL) and were descriptive and inferential in nature, consisting of counts, frequencies, and comparisons of means (one-way ANOVA). An alpha level of 0.05 was used for inferential testing. Qualitative data analysis was informed by grounded theory, with response categories generated to reflect the viewpoints of participants. Through an iterative, nonlinear process of discovery, response categories are identified and defined.[8] The REPIs independently analyzed FGI transcripts, coded for participant responses, identified recurrent responses, and aggregated response categories across FGIs to write a data summary report for each assigned catchment area. The study's PI and coordinator independently analyzed FGI transcripts and data summary reports for each catchment area, then aggregated thematic categories across catchment areas to compile a summary report of major findings. They reviewed and discussed any discrepancy in thematic coding until consensus.

RESULTS

A total of 332 participants enrolled in FGIs, 92.2% of the study's target enrollment goal (332/360). The number of individual interviews and focus groups stratified by participant type are shown in Table 1. For results of the participant background surveys, see demographic tables in Appendix.

Status of Treatment and Support Services

When surveyed on the types of SPMI treatment/support services provided/utilized during the past 12 months, participants noted many (Table 2). Across participant types, medications, counseling (individual/group therapy), case management, and peer support services were most often mentioned. When asked to identify the treatment and support services currently available in their

Table 1. Number of Interviews, Focus Groups, and Participants by Participant Type

Participant type	Number of individual interviews	Number of focus groups	Number of focus group participants	Focus group participant mean	Total number of participants
Consumer	20	15	56	3.7	76
Family	21	13	51	3.9	72
Providers	65	34	119	3.5	184
Total	106	62	226	3.6	332

communities for persons living with SPMI, participants named an array of services that varied by community type, agreeing that counties with urban centers had the most services, while service availability in less-populated counties was considerably lower. In some rural areas, there was limited knowledge of community offerings for managing SPMI. One consumer in a rural area reported, "I know there are a lot of things that aren't widely available."

Most participants (81.2%; N = 234) agreed that current treatment/support services met the needs of persons living with SPMI. Figure 1 provides the proportional breakdown of affirmative responses by participant type. Most consumers reported that they had received the kind of services they thought they needed, however, many discussed that in the past this had not always been the case. Comments included: "Eventually [I received needed services], but it took a long time; Has it been as responsive or as fast or as insightful as it could have been? No. I ultimately got what I needed, but sometimes I really had to fight for it." Greater than half of responding family members indicated that they thought their loved one had received the type of services needed, although family members also noted that this had not consistently been the case.

Most providers agreed that the services their agency/program delivered met the expressed needs of their clients living with SPMI. However, nearly all providers also felt that their agency had room to improve, or that they did the best they could with the resources they had. Treatment providers acknowledged barriers often outside their control that inhibited service delivery, such as disagreements with guardians or payees, number of available resources, and availability of doctors. They responded: "We do what we can … but there are [service] gaps because of workforce shortage; Intensive case management can only be offered to so many people."

When asked to describe the level of satisfaction with the services/care they/their loved one received, consumers reported overall high satisfaction, while family members expressed differing levels of satisfaction, with half of family members reporting general dissatisfaction with the services/care their loved one received. Family members assigning low satisfaction scores stated personal

Table 2. Types of Treatment/Support Services Offered/Utilized During Past 12 Months by Respondent Type[a]

Types of Treatment/Support Services Offered/Utilized	Providers (N = 183)	Family (N = 64)	Consumers (N = 72)
Assessment services	99 (54.1%)	X[b] (X.X%)	X (X.X%)
Case management	109 (59.6%)	28 (43.8%)	38 (52.8%)
Financial services	37 (20.2%)	17 (26.6%)	12 (16.7%)
Housing/supervised living/group homes	81 (44.3%)	3 (4.7%)	15 (20.8%)
Individual/group therapy (public/private)	96 (52.5%)	43 (67.2%)	55 (76.4%)
Inpatient substance use disorder (SUD) treatment	30 (16.4%)	4 (6.3%)	1 (1.4%)
Medications (psychiatry and medication assisted treatment [MAT])	85 (46.4%)	54 (84.4%)	68 (94.4%)
Outpatient SUD treatment, including intensive outpatient program (IOP)	64 (35.0%)	2 (3.1%)	7 (9.7%)
Partial psychiatric hospitalization	20 (10.9%)	5 (7.8%)	5 (6.9%)
Peer support services	84 (45.9%)	15 (23.4%)	39 (54.2%)
Psychiatric hospitalization	16 (8.7%)	15 (23.4%)	9 (12.5%)
Referrals to serious and persistent mental illness (SPMI) services/supports	117 (63.9%)	X (X.X%)	X (X.X%)
Services for dual diagnosis	83 (45.4%)	4 (6.3%)	5 (6.9%)
Other specified service(s)/support(s)[c]	49[d] (26.8%)	6[e] (9.4%)	8[f] (11.1%)
Advocacy and mental health education/training	7		
Clubhouse psych rehab/day treatment program	2		1
Crisis hotlines	2		
Crisis services, including mobile	7		
Employment/vocational services	7		
Family support services	2	1	
Funding source (ADAMHS—Alcohol, Drug Addiction and Mental Health Services board and Medicaid)	4		
Primary care (medical)	4	2	
Support/12-step/recovery groups	3		3
Supported employment	4		
Transportation, including medical cab service, bus pass	4		
Youth services, including school-based counseling	2		

[a] Responses are not rank ordered.
[b] X denotes response option not provided for respondent type.
[c] Other specified service/support with only 1 response across respondent types are not listed in the table.
[d] The following 6 other services/supports were each provided by 1 professional: assertive community treatment (ACT teams), crisis intervention training (CIT) for police, food assistance (pantry), reentry services, SBIRT (screening, brief intervention and referral to treatment) and street outreach. The total number of other responses are greater than 49 as providers were able to specify more than 1 other service/support.
[e] The following 3 other services/supports were each provided by 1 family member: assistance with activities of daily living (ADLs), guardianship, and unspecified other service/support.
[f] The following 4 other services/supports were each provided by 1 consumer: art therapy, telehealth, NAMI—National Alliance on Mental Illness/ADAMHS board sponsored programs, and unspecified other service/support.

Figure 1. Proportion of Respondents Who Agreed Current Services Meet Needs of Persons Living with Serious and Persistent Mental Illness (SPMI)

difficulties in accessing care, inconsistent quality of care, and lack of some services as precluding them from rating satisfaction as high. Some dissatisfied family members acknowledged that their loved one's course of illness made it harder for services to work with them but thought the system should be more equipped to deal with this scenario, as it is common. Consumers referenced the services they were currently receiving and indicated high satisfaction with the level of these services. Several consumers noted that their satisfaction had increased over time, or that previous services had been lacking in comparison.

A large proportion of consumers (44.6%; N = 56) and most family members (82.1%; N = 56) reported that they had had unmet service needs. When asked to indicate the level of need for additional treatment/support services in their community for persons living with SPMI, participants overwhelmingly reported that additional services were needed a great deal. There was consensus that service expansion was critical to meet unmet needs, both in terms of additional services and a higher volume of existing services.

Service Accessibility

When asked to rate how easily persons living with SPMI accessed treatment/support services, participants of all types most often reported moderate ease. However, almost universally, participants reported that there was insufficient community knowledge of the availability of behavioral health and recovery support services. Treatment providers generally thought that care was available but that people needing help did not always know how to access it. Treatment providers reported, "Part of the problem is a lot of people don't know how to access services, but once they figure out how to access it, then I think services are fairly readily available; The public doesn't always understand the system…. Our responsibility is to help them understand."

Family members also discussed that the behavioral health system did not do a good job of explaining what services were available and how to access those services. One family member shared, "The system is very crisis-oriented. When somebody is in crisis or hospitalized, they're going to get treatment. But they have to be in crisis. It's much more difficult for somebody to find treatment before they're in crisis." Consumers expressed dissatisfaction with the process of accessing treatment; often cited were difficulties in knowing what to do, long wait times for appointments, and a struggle to find providers who accepted their insurance. They noted that accessing services and moving through systems was made easier by referrals, usually from a doctor to a behavioral health system that worked well together.

Thoughts on Improving Service Accessibility

In addition to workforce development and increasing service capacity at all levels of care, participants offered many ideas as to what could be done to make accessing SPMI treatment/support services easier. Table 3 shows a list of participant recommendations for improving service accessibility. These recommendations were responses aggregated across participant types and they did not vary by participant type. The most frequently discussed ideas are detailed below.

Table 3. Participant Recommendations for Improving Service Accessibility[a]

Workforce development (recruit/retain staff)
Increase service capacity
Heighten community outreach/education
Employ navigators
Provide immediate care (ie, treatment on demand)
Expand crisis services
Make follow-up care after crisis standard
Expand transportation/telehealth options
Open insurance options
Increase access to injectable long-acting medications

[a]Data collected from focus group/interviews (FGIs).

Heighten community outreach and education. Most participants generally thought that while care was available, people needing help did not always know about treatment/support options or how to access them. To increase general awareness of behavioral health services, participants prescribed heightened community outreach. One treatment provider stated, "How do people know what they don't know?" Providers discussed behavioral health outreach and engagement on the streets, in homeless camps, and around communities as highly important, including outreach to other systems (ie, hospital and criminal justice systems). Law enforcement advocated for 'in-reach' into jails, connecting people to needed services upon jail release. Family members called for more education: both about mental illness and about how to navigate treatment services. Consumers thought that better advertising of services, especially no-cost services, was needed throughout their communities. For instance, not all participants reported awareness of a 24-hour crisis hotline, although most discussed the utility of around-the-clock crisis and informational services.

Employ navigators. There was consensus that there was a need for providers (ie, case managers) and peers that could act as navigators. Treatment providers noted success with having peer supporters help others navigate the behavioral health system. In fact, providers mentioned peer support most often as a necessary component to linking consumers to services. There was a shared belief that a network of relationships with people with similar experiences was crucial to long-term treatment/recovery. A provider remarked, "I think what we have done with client navigation is amazing ... having someone able to walk through the whole process with the client, from the beginning to the end…." Family members felt the most successful path was when they had gotten connected with one service or provider that then helped them navigate the system at large. Family members reported, "When he left [hospital commitment], he was able to get help and resources. If we hadn't had him committed, we would not have known what kind of resources there were; We didn't get hooked up with [a wraparound service provider] for 3 to 4 years, and once we did, everything got easier." Consumers concurred that case management and peer support were extremely valuable in connecting to needed services.

Expand crisis services. Providers discussed that crisis services not only address an immediate crisis, but they were also instrumental in linking persons with SPMI to ongoing treatment and support services. Moreover, providers noted a need for care that would prevent people from decompensating to a crisis level. Some treatment providers saw this as more wraparound support in the community, a 24-hour crisis center, or a level of care between hospitalization and people living on their own. Providers also advocated for crisis stabilization units, stabilizing a person in crisis to conduct a needs assessment and make appropriate linkages to services.

Perceived Stigma of Persons Living with SPMI

When asked if there is any prejudice against persons living with SPMI when receiving services, 6 out of 10 participants reported that they had perceived negative attitudes (59.9%; N = 274). Figure 2 illustrates the proportion of each participant type that agreed prejudice existed.

Providers, consumers, and family members reported hearing consistent negative messaging about SPMI. All groups recognized that negative messaging reinforced stigma and prejudice against persons living with SPMI, further creating feelings of shame, and discouraging people from openly discussing mental health and seeking services. A support services provider stated that many family members and consumers would rather not discuss SPMI diagnosis, remarking their preference often is to, "keep it quiet because they're ashamed." Family members discussed still working to overcome their feelings of shame regarding their loved one's SPMI diagnosis. One family member explained, "The first thing people do is drop their voice [when talking about SPMI]. After getting involved with [family supports], I no longer drop my voice." Several consumers reported dealing with feelings of shame around their SPMI primarily triggered by the reactions they received from others. A consumer shared, "I've been hurt by discrimination pretty badly, so I am always worried by what other people are thinking." Table 4 displays the most offered preferred messages across participant types.

Table 4. Participants Preferred Community Messaging Related to Serious and Persistent Mental Illness (SPMI)[a]

SPMI is a chronic illness and should be viewed as other chronic illnesses.
SPMI is an "unseen wound" but the need for care is real.
SPMI can be managed.
Recovery is a long-term process, but it is possible.
People living with SPMI function in and contribute to society.
SPMI does not define a person.
There is help available.
There is hope in recovery.
It is okay to talk about mental health/SPMI.

[a] Data collected from focus group/interviews (FGIs).

RSA-R Results

The RSA-R scores paralleled the level of satisfaction expressed by participants above. When compared with consumers and providers, family members' mean overall RSA-R scores, as well as each domain score, were the lowest, indicating that family members were not only the least satisfied with services, but they also held the least positive perception of recovery-oriented practices. Generally, professional mean scores were slightly higher than consumer scores, but both scores indicated a positive perception of the treatment system and its providers and agreement that the

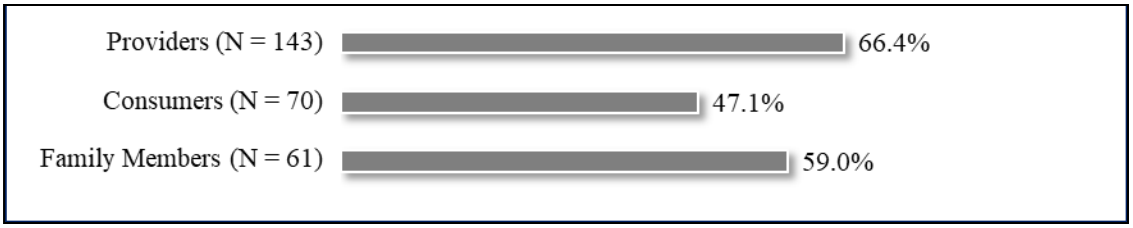


Figure 2. Proportion of Respondents Who Perceived Prejudice Against Persons Living with Serious and Persistent Mental Illness (SPMI) When Receiving Services

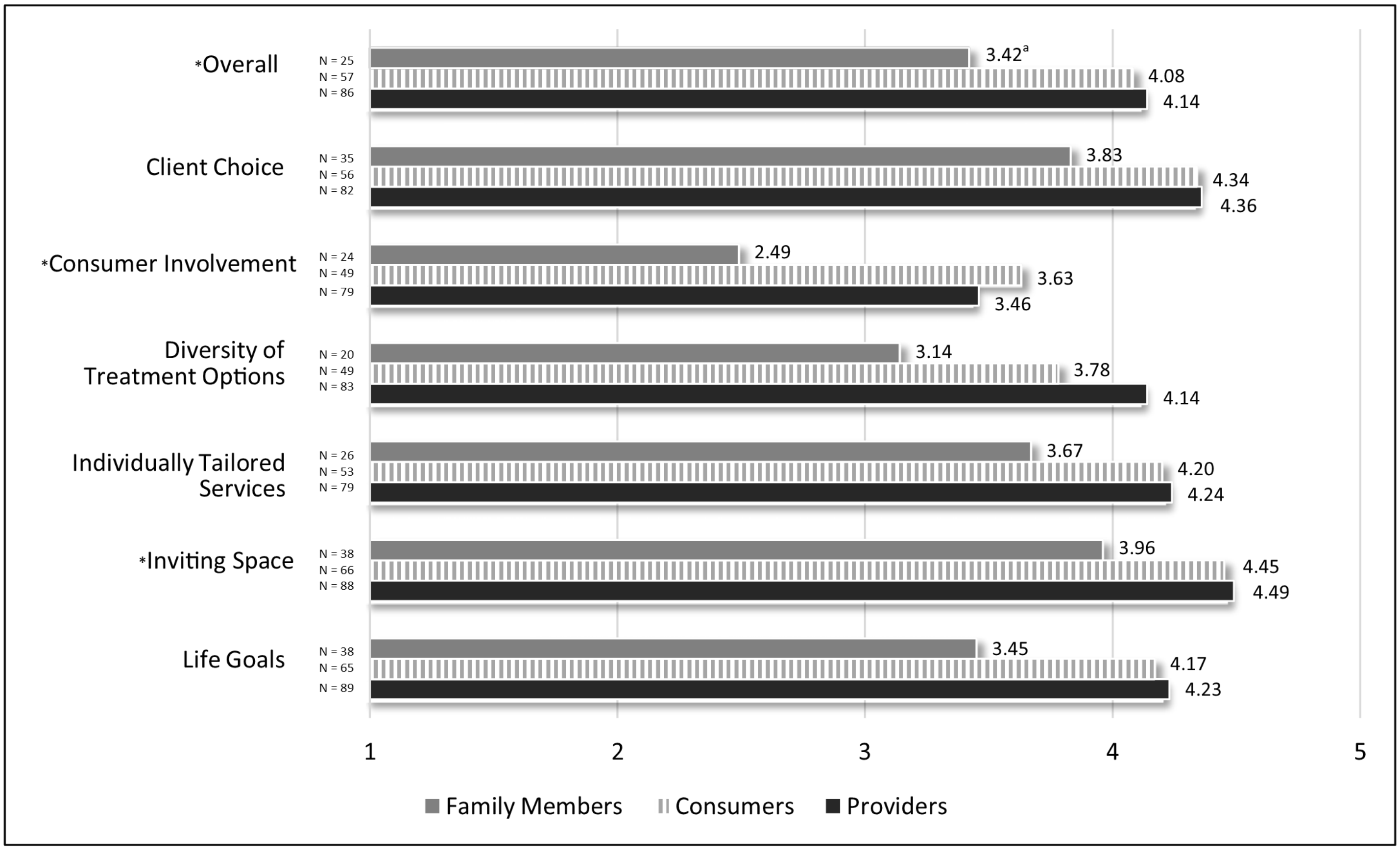
treatment system embraced the core principles of recovery. Figure 3 shows a comparison of RSA-R mean scores across participant types.

To determine if there were statistically significant mean differences between participant types for RSA-R overall score and for each domain score, a series of one-way ANOVAs was performed. Statistically significant mean differences were found between participant types and RSA-R overall scores: ($F(2,165) = 8.878$, $p < 0.001$). In addition, statistically significant mean differences were found between participant types and 'Consumer Involvement' mean scores: ($F(2,149) = 9.840$, $p < 0.001$; and participant types and 'Inviting Space' mean scores: ($F(2,189) = 5.805$, $p = 0.004$). Post hoc comparisons using LSD (least significant difference) tests revealed significantly lower mean RSA-R overall scores for family members (M = 3.42, SD = 0.94) than for consumers (M = 4.08, SD = 0.85) and providers (M = 4.14, SD = 0.64); significantly lower mean scores on 'Consumer Involvement' for family members (M = 2.49, SD = 1.17) than for consumers (M = 3.63, SD = 1.12) and providers (M = 3.46, SD = 1.02); and significantly lower mean scores on 'Inviting Space' for family members (M = 3.96, SD = 0.96) than for consumers (M = 4.45, SD = 0.85) and providers (M = 4.49, SD = 0.76).

DISCUSSION

This study was unique in conducting a statewide assessment of SPMI treatment and support services. While previous research has focused on perceptions of SPMI services among individuals participating in those services,[9,10] their family,[11] and their treatment providers,[11] our study presents perceptions of SPMI services from all 3 groups in a single study. In addition, our study contributes to the research of stigma affecting persons living with SPMI with its focus on reframing and positive community messaging.

Study results found that consumers and family members had considerable knowledge of available SPMI services; however, almost universally, participants reported that there was insufficient community knowledge. Family members discussed that the behavioral health system did not do a good job of explaining what services were available and how to access those services. Most consumers expressed that the process of finding, applying for, and accessing services could be overwhelming for a person living with SPMI. They often cited difficulties in knowing where to start and what to do. Participants of all types advocated for a way to assist people living with SPMI to navigate the behavioral health system. Most providers thought that current services addressed the needs of persons living with SPMI, but there was consensus that there was



*Significant difference at $p \leq 0.05$.
[a]Overall mean score for family members does not include the additional 'Family Involvement' domain.

Figure 3. Mean Recovery Self-Assessment Revised (RSA-R) Scores

always room for improvement and additional services. A large proportion of consumers and most family members reported that they had unmet service needs.

In terms of stigma, most participants reported that they perceived negative attitudes toward persons living with SPMI. Two-thirds of providers discussed negative attitudes toward persons living with SPMI in service delivery. Providers noted exemptions in current housing and employment services that disqualified persons living with SPMI. Treatment providers said staff were not always appropriately trained on SPMI diagnoses, often leading to stigmatizing attitudes. Treatment providers also pointed out that staff burnout and compassion fatigue could lead to negative attitudes. Consumers reported instances of not being believed/heard by providers, their concerns being dismissed, and being judged unfairly due to their SPMI. Most family members reported that they have perceived negative attitudes toward their loved one when receiving treatment. Providers, family members, and consumers all recognized that the stigma and prejudice against persons living with SPMI elicited feelings of shame and discouraged people from openly discussing mental health and seeking services.

In this study, participants described the importance of accessible and effective recovery-oriented SPMI services. However, people with SPMI are more likely to experience barriers accessing services and receive lower quality care.[12,13] Social determinants of health were sometimes noted as contributing factors, including lack of information and access challenges (especially in rural areas), health payor barriers, limited resources, workforce shortages, and stigma. Individuals with SPMI are also at higher risk for other health concerns,[14] so access to recovery-oriented care is essential not only for mental well-being but overall health. Therefore, a public health approach is needed to support individuals living with SPMI.

PUBLIC HEALTH IMPLICATIONS

The RSA-R results are useful when identifying strengths and target areas for improvement.[15] To strengthen recovery-oriented care, programs should consider communicating more clearly with family members and loved ones about how consumers are involved in their treatment plans as well as in program and organization-level decisions. Previous research has shown that, of the 6 subscale domains, programs that score high on 'Consumer Involvement' consistently score higher on overall recovery orientation.[15] Family members scored this domain the lowest. Increasing communication would likely increase the perception of consumer involvement, as well as increase family involvement. The 'Diversity of Treatment Options' domain had the largest difference in scores between consumers and providers. In addition to increasing awareness of current treatment options offered, programs may want to consider offering additional treatment options and/or other resources/activities in which consumers are interested.

To improve access to SPMI treatment and support services, programs should consider heightening community outreach and education, employing navigators, expanding transportation and telehealth options, and expanding crisis services. In-person community outreach can be an effective way to connect with people with SPMI, particularly in rural areas.[16] Research has shown that navigators can help consumers overcome barriers to access care, improve adherence to care, reduce hospital readmissions, and increase consumer satisfaction through effective referrals to services, care coordination, medication access assistance, and supportive listening.[17,18]

To address stigma in the general public, there were many calls for increased community education on SPMI and empathy for what it means to live with SPMI. Providers noted that a lack of understanding about mental illness has led to many misconceptions and prejudices. Participants highlighted that SPMI should be seen in the same light as physical illnesses and that those living with SPMI should not be defined by their diagnosis. This would improve understanding and decrease the stigma around seeking help and normalize open discussion of mental health. It is also important to communicate messages of hope, such as "recovery is possible." Participants emphasized that not only should there be no shame in living with and seeking treatment for SPMI, but also mental health services are for everyone. Participant messaging recommendations could be incorporated into various anti-stigma strategies. Contact-based initiatives facilitating contact between people living with and without mental illness are most effective at reducing stigma; communication campaigns can reduce stigma if goals are well-defined and target audiences are reached consistently over time.[19]

Limitations

This study has limitations. Our sampling plan might have created selection bias due to the exclusive recruitment of persons living with SPMI from treatment programs. The experiences of persons receiving treatment might have differed from persons living with SPMI who were not in treatment or from those who had never accessed treatment. To minimize this bias, consumer data were corroborated with data collected from family members of persons living with SPMI, many of whom shared experiences of loved ones not in treatment or of loved ones who had never accessed treatment. Also, although study epidemiologists were assigned to each of Ohio's psychiatric hospital catchment areas to create a geographic representative sample, findings of this study may not have fully captured the experiences, feelings, and beliefs of the state's diverse populations since our sample was predominately White, female, and older. Diverse populations might have different pathways and preferences for mental health services.

Conclusion

The assessment objectives of this research study were met. Key findings indicated that, overall, consumers and family members were satisfied with current services but felt negative about the process of finding services. They generally held a positive perception that the mental health treatment system embraced the core principles of recovery. Participants overwhelmingly reported that service expansion was needed, both in terms of additional services and a higher volume of existing services, and they discussed the need to combat stigma. The data generated through this study may inform community strategies to reduce stigma and enhance treatment and support services for persons living with SPMI and for their families.

CONFLICTS OF INTEREST

The authors report there are no competing interests to declare.

AUTHOR CONTRIBUTION

R. Thomas Sherba designed the study, wrote protocols, coordinated data collection, conducted data analysis, summarized findings, and wrote manuscript. Julia Ashwood conducted data analysis, summarized findings, and wrote manuscript. Sarah Kriebel and Hannah MacDowell summarized findings and wrote manuscript.

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APPENDIX—Scripted Protocols of Focus Group Questions, Demographics Tables

Consumer Focus Group Questions

1. What treatment services are currently available in your community for persons living with a mental health disorder?
2. How well do you think current treatment services address the needs of persons living with a mental health disorder on a scale from ‘1’ to ‘7,’ where ‘1’ is ‘not well at all’ and ‘7’ is ‘extremely well’? Please explain.
3. What is the ease in which people access mental health treatment services on a scale from ‘1’ to ‘7’, where ‘1’ is ‘very difficult/felt I could not access treatment’ and ‘7’ is ‘very easy/felt I had no trouble accessing treatment at all’? Please explain.
4. How would you describe the need for additional treatment services in your community for persons living with a mental health disorder on a scale from ‘1’ to ‘7’, where ‘1’ is ‘not needed at all’ and ‘7’ is ‘needed a great deal’? Please explain.
5. Are there support services available to assist persons living with a mental health disorder (educational, vocational, housing, etc)? *If yes, please describe.*

Consumer Experiences in Accessing/Utilizing Services

6. Think about how you currently connect with treatment/support services and *please describe* the way in which you access services.
   - *How did you find your current treatment provider?*
   - *How were you linked with support services?*
   - *What, if any, were the barriers you encountered when trying to access services?*
   - *What might be different that would make it easier or more helpful to you?*
7. Please describe what your life in recovery consists of, keeping in mind the following: employment/work, school, housing, family/friend relationships, volunteering, parenting, fitness, hobbies, etc.
8. What mental health treatment services are you currently receiving? W*hat support services are you currently receiving?* Please explain *the benefit of these services to your recovery.*
9. Of the treatment/support services you receive now, which are most valuable in helping you meet your recovery goals? Please explain.
10. Have you received the kind of services you needed? Please explain.
11. Were the services you received the right approach for helping you? *If yes, why? If no, why not?* Please explain.
12. If a friend or loved one were in need of similar help, would you recommend the same services? *If yes, why? If no, why not?* Please explain.
13. Was there any type of service that you felt you needed from the program/agency/organization but had not received? *If yes, what?* Please explain.
14. Please describe your level of satisfaction with the services/care you have received on a scale from ‘1’ to ‘7’, where ‘1’ is ‘completely dissatisfied’ and ‘7’ is ‘extremely satisfied.’ Please explain.
15. How much input do you have in setting the goals and priorities on your treatment plan?
16. Whom do you call or contact first (or most often) if you have a question or concern about your treatment/recovery?
17. Whom do you call or contact if you have a mental health crisis?

Coordination of Care

18. In your opinion, how well do treatment/support programs/agencies/organizations in your community work together, on a scale from ‘1’ to ‘7’, where ‘1’ is ‘they don’t seem to work together at all’ and ‘7’ is ‘they work together completely’? Please explain.
19. How smoothly do medical services (eg, family doctor), addiction treatment services (eg, medication assisted treatment (MAT) prescriber) and mental health services (eg, your current mental health counselor or case manager) work together on a scale from ‘1’ to ‘7’, where ‘1’ is ‘they don’t seem to work together at all’ and ‘7’ is ‘they work together completely’? Please explain.
20. In your opinion, why do some people drop out of mental health treatment?
21. What roles have your family members played in your treatment and recovery?
22. In addition to the family roles you’ve described, what other roles in general do family members play in the treatment and recovery of persons living with mental health disorders?

Cultural Considerations

23. Do you feel that there is any prejudice against you or negative attitude about you when receiving treatment? *If so,* please explain *why you feel this way? What do you think can be done about it?*
24. Are service providers sensitive to accommodating your ethnic background? *If so, how?* Please explain.
25. Do service providers respect your beliefs about your mental health? *If no,* please explain.

Perceived Stigma

26. What is the most consistent message you hear about mental health disorders and persons living with mental health disorders?
27. What messaging about mental health disorders would you want people in your community to hear? *If you were to reframe the messages, what would they say?*

Closing Question

28. What other thoughts or ideas would you like to share?

Family Member Focus Group Questions

1. What treatment services are currently available in your community for persons living with a serious and persistent mental illness (SPMI)? Please describe.
2. How well do you think current treatment services address the needs of persons living with SPMI on a scale from ‘1’ to ‘7,’ where ‘1’ is ‘not well at all’ and ‘7’ is ‘extremely well’? Please explain.
3. What is the ease in which persons living with SPMI access treatment services on a scale from ‘1’ to ‘7’, where ‘1’ is ‘very difficult/felt my loved one could not access treatment’ and ‘7’ is ‘very easy/felt my loved one had no trouble accessing treatment at all’? Please explain.

4. How would you describe the need for additional treatment services in your community for persons living with SPMI on a scale from ‘1’ to ‘7’, where ‘1’ is ‘not needed at all’ and ‘7’ is ‘needed a great deal’? Please explain.
5. Are there support services available to assist persons living with SPMI (educational, vocational, housing, etc)? *If yes, please describe.*

Family Member Experiences in Accessing/Utilizing Services

6. Think about how your loved one (living with SPMI) currently connects with treatment/support services and please describe the way in which they access services.
   - *How did they find their current treatment provider?*
   - *How were they linked with support services?*
   - *What, if any, were the barriers they encountered when trying to access services?*
   - *What might be different that would make it easier or more helpful to them and others living with SPMI to access/utilize treatment/support services?*
7. Have you ever had to act on behalf of your loved one living with SPMI to get them help/services during a mental health crisis? *If yes, whom did you call or contact?* Please discuss your experience.
8. In lieu of services, or while awaiting services, what are things families do to help their loved one living with SPMI cope/manage psychiatric symptoms? Please describe.
9. What treatment/support services is your loved one (living with SPMI) currently receiving? Please describe.
10. Of the services your loved one (living with SPMI) receives now, which are most valuable in helping them meet their recovery goals? Please explain.
11. If no current receipt of services: How is your loved one managing their SPMI? Please explain.
12. Did your loved one (living with SPMI) receive the kind of services they needed? Please explain.
13. Were the services your loved one (living with SPMI) received the right approach for helping them? *If yes, why? If no, why not?* Please explain.
14. If a friend or another loved one living with SPMI were in need of similar help, would you recommend the same services? *If yes, why?* If no, *why not?* Please explain.
15. Was there any type of service that you felt your loved one (living with SPMI) needed but had not received? If yes, *what?* Please explain.
16. Please describe your level of satisfaction with the services/care your loved one (living with SPMI) received on a scale from ‘1’ to ‘7’, where ‘1’ is ‘completely dissatisfied’ and ‘7’ is ‘extremely satisfied.’ Please explain.

Coordination of Care

17. In your opinion, how well do treatment programs/agencies/organizations in your community work together in meeting the needs of persons living with SPMI, on a scale from ‘1’ to ‘7’, where ‘1’ is ‘they don’t seem to work together at all’ and ‘7’ is ‘they work together completely’? Please explain.
18. How smoothly do medical services (eg, family doctor), addiction treatment services (eg, MAT prescriber) and mental health services (eg, mental health counselor or case manager) work together to provide the best services to persons living with SPMI on a scale from ‘1’ to ‘7’, where ‘1’ is ‘they don’t seem to work together at all’ and ‘7’ is ‘they work together completely’? Please explain.
19. In your opinion, why do some persons living with SPMI drop out of treatment?
20. What role do you play in the treatment and recovery of your loved one (living with SPMI)?
21. In addition to the family role you’ve described, what other roles in general do family members play in the treatment and recovery of persons living with SPMI?

Family Member Supports

22. Where do you get support to help you cope with having/living with a loved one with SPMI? Please describe.
23. Are there services/supports specific to loved ones of persons living with SPMI in your community*? If yes, what are they and are you accessing them?* Please describe your experiences with accessing services/supports. *If you are not accessing available services/supports, why not?* Please explain.
24. What services/supports would be helpful to family members if available? Please describe.
25. Do you participate in a family support group for loved ones of persons living with SPMI? If yes, *what? How often does this group meet? Is it beneficial to you?* Please describe your experiences with family support groups.

Cultural Considerations

26. Do you feel that there is any prejudice against your loved one (living with SPMI) or negative attitude about them when receiving treatment? *If so, please explain why you feel this way? What do you think can be done about it?*
27. Are service providers sensitive to accommodating the ethnic background of your loved one (living with SPMI)? If so, *how?* Please explain.

Perceived Stigma

28. What is the most consistent message you hear about SPMI and persons living with SPMI?
29. What messaging about SPMI would you want people in your community to hear? *If you were to reframe the messages, what would they say?*

Closing Questions

30. Have you participated in any trainings/classes/conferences related to SPMI and persons living with SPMI? If yes, *what, when and where?* Please describe.
31. What other thoughts or ideas would you like to share?

Community Professional Focus Group Questions

1. What treatment services are currently available in your community for persons living with serious and persistent mental illness (SPMI)?

2. How well do you think current treatment services address the needs of persons living with SPMI on a scale from ‘1’ to ‘7,’ where ‘1’ is ‘not well at all’ and ‘7’ is ‘extremely well’? Please explain.
3. What is the ease in which persons living with SPMI access mental health treatment services on a scale from ‘1’ to ‘7’, where ‘1’ is ‘very difficult/felt they could not access treatment’ and ‘7’ is ‘very easy/felt they had no trouble accessing treatment at all’? Please explain.
4. How would you describe the need for additional treatment services in your community for persons living with SPMI on a scale from ‘1’ to ‘7’, where ‘1’ is ‘not needed at all’ and ‘7’ is ‘needed a great deal’? Please explain.
5. Are there support services available to assist persons living with SPMI (educational, vocational, housing, etc)? If yes, please describe.
6. In your opinion, what can be done to make accessing treatment/support services easier for persons living with SPMI?

Your Community’s Mental Health Treatment System

7. In your opinion, how well do treatment programs/agencies/organizations in your community work together to provide the best services to persons living with SPMI on a scale from ‘1’ to ‘7’, where ‘1’ is ‘they don’t seem to work together at all’ and ‘7’ is ‘they work together completely’? Please explain.
8. How well do you think these stakeholders communicate with each other about the needs of persons living with SPMI on a scale from ‘1’ to ‘7,’ where ‘1’ is ‘not well at all’ and ‘7’ is ‘extremely well’? Please explain.
9. How efficient do you think persons living with SPMI move into, through and out of the various community help systems, on a scale from ‘1’ to ‘7’, where ‘1’ ‘completely inefficiently’ and ‘7’ is ‘completely efficiently’? Please explain.
10. What are the gaps that you perceive in your community mental health treatment system? *In your opinion, what could be done to fill these gaps?*
11. In terms of recovery supports, what supports do persons living with SPMI need? In your opinion, *which recovery supports are the most beneficial to long-term recovery?* Please describe/explain.

Coordination of Care

12. Has your program/agency/organization been successful in linking persons living with SPMI to needed treatment/other community services? Please explain, *describing success(es) and to what/whom do you attribute success(es)?*
13. Have you referred persons living with SPMI to needed treatment/support services in the past? *If yes, why and where? If no, why not?* Please explain.
14. What criteria are used to determine appropriate referrals?
15. How satisfied are you with the way the staff of different programs/agencies/organizations work together to ensure that persons living with SPMI get the help they need on a scale of ‘1’ (completely dissatisfied) and ‘7’ (completely satisfied)? Please explain.
16. How smoothly do medical services (eg, family doctor), addiction treatment services (eg, MAT prescriber) and mental health services (eg, mental health counselor or case manager) work together to provide the best services to persons living with SPMI on a scale from ‘1’ to ‘7’, where ‘1’ is ‘they don’t seem to work together at all’ and ‘7’ is ‘they work together completely’? Please explain.
17. What roles do loved ones (family members) play in the treatment and recovery of persons living with SPMI? Please explain.

Ask questions 18-21 of treatment/support professionals only.
Skip to Cultural Considerations questions for all other community professionals (Q. 22).
Ask questions 22-29 of ALL community professionals.

18. How much input do persons living with SPMI have in setting the goals and priorities on their treatment plan?
19. Do the services your program/agency/organization deliver meet the expressed needs of your clients living with SPMI? *If no, why not?* Please explain.
20. In your opinion, are the services offered by your program/agency/organization for persons living with SPMI of good quality? Please explain.
21. If your program/agency/organization were to close, where would your clients living with SPMI go to receive treatment/support services?

Cultural Considerations

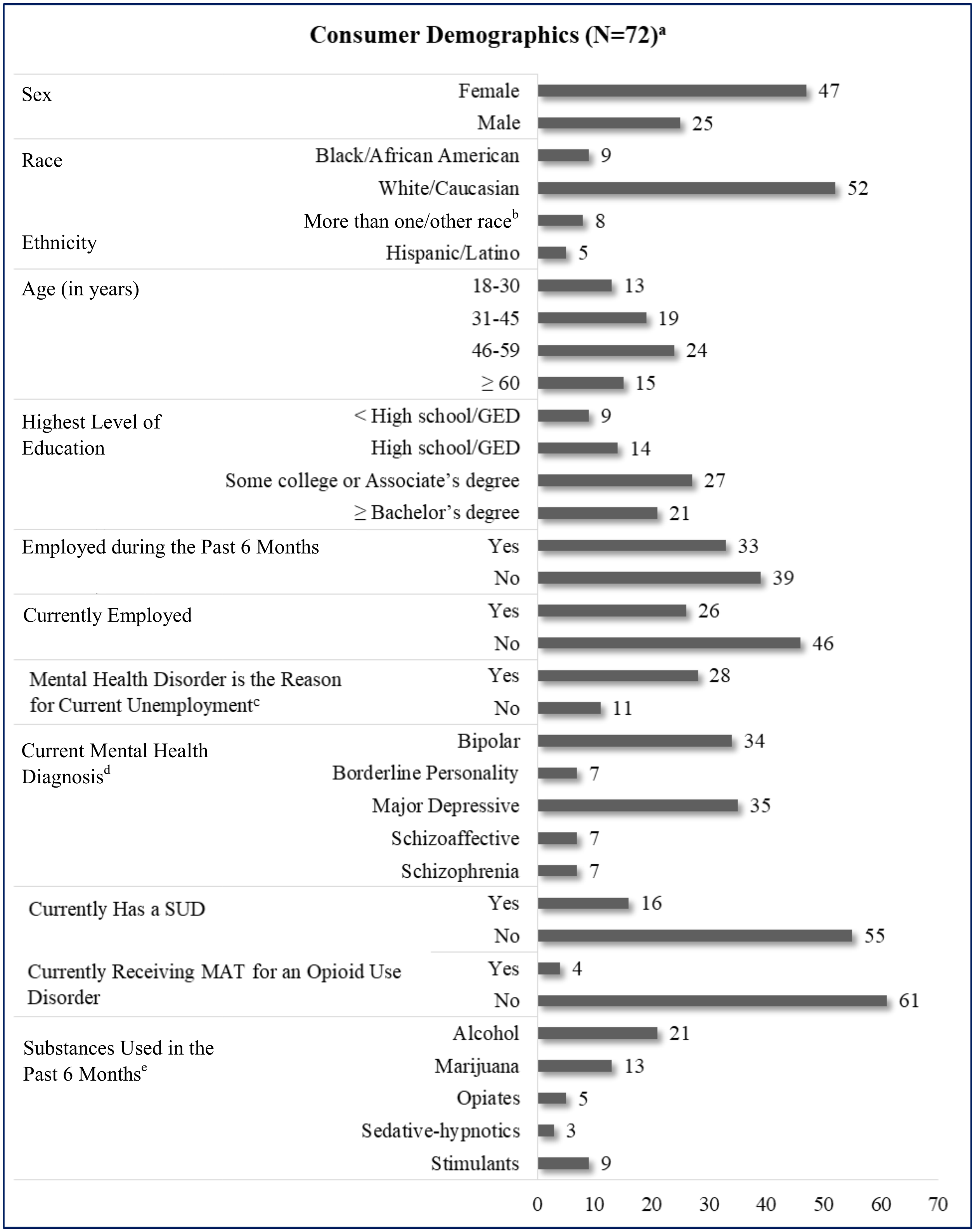
22. Do you feel that there is any prejudice against persons living with SPMI or negative attitude about them when receiving treatment? *If so, please explain why you feel this way? What do you think can be done about it?*
23. Are service providers sensitive to accommodating the ethnic background of persons living with SPMI? *If so, how?* Please explain.
24. Do service providers respect the personal beliefs of persons living with SPMI regarding their mental health? *If yes, how so? If not, why not?* Please explain.

Perceived Stigma

25. What is the most consistent message you hear about SPMI and persons living with SPMI?
26. What messaging about SPMI would you want people in your community to hear? *If you were to reframe the messages, what would they say?*

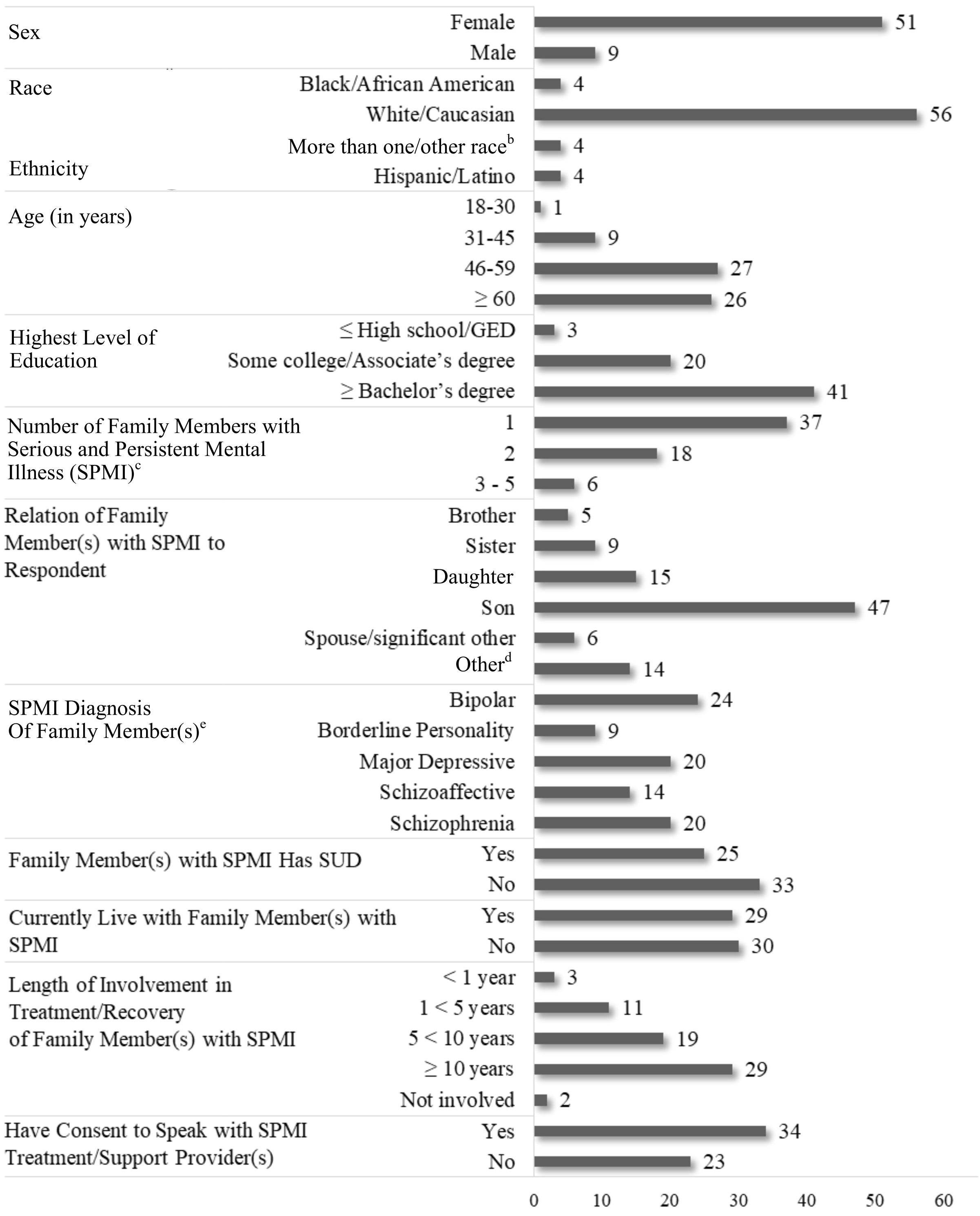
Closing Questions

27. In your opinion, why do some persons living with SPMI drop out of treatment?
28. Have you participated in any trainings/classes/conferences related to SPMI and treating/providing services to persons living with SPMI? *If yes, what, when and where? If not, why not?* Please describe/explain.
29. What other thoughts or ideas would you like to share?



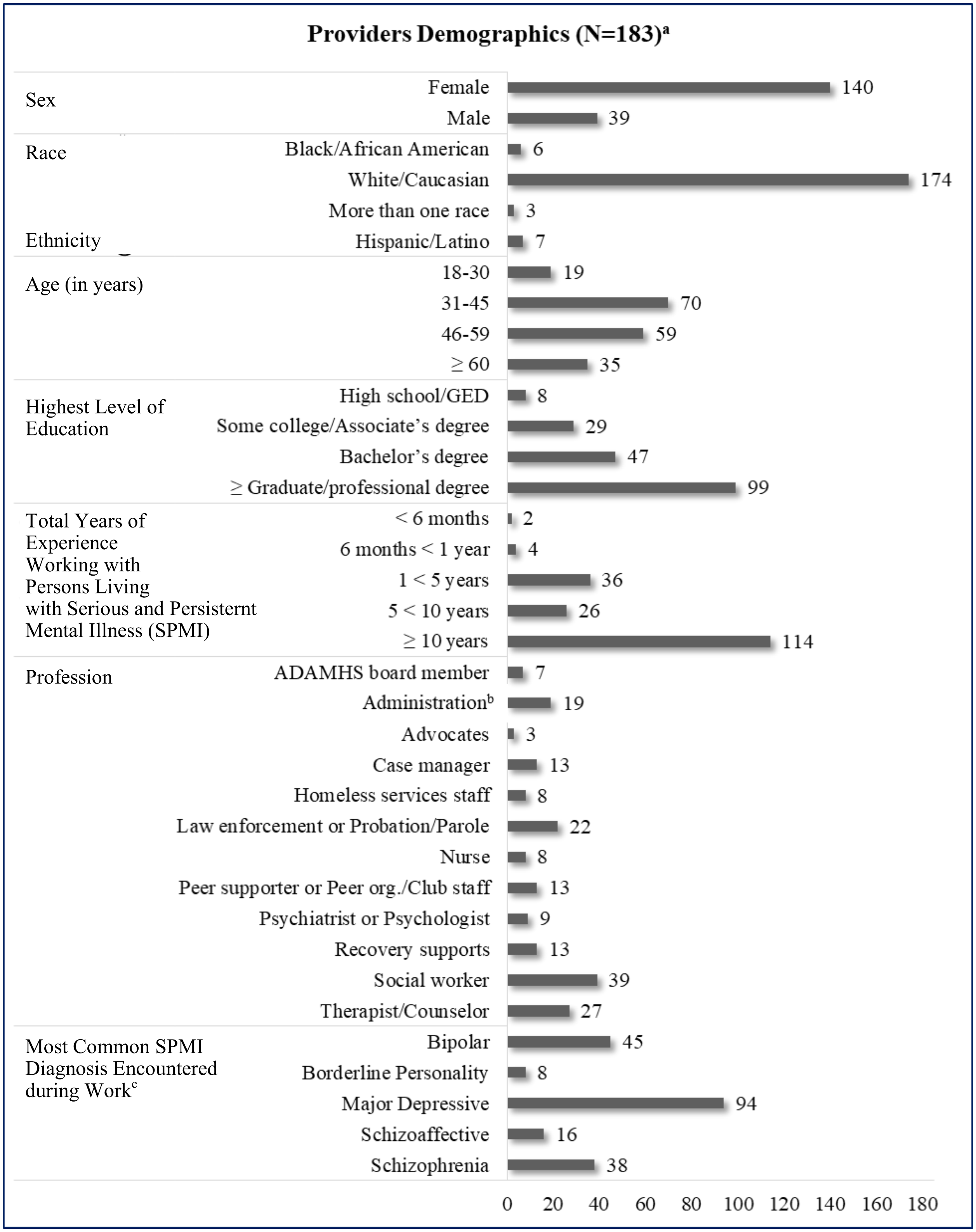
Consumer Demographics (N=72)[a]

[a] Due to missing or excluded invalid responses, variable totals may not equal 72.
[b] "Another race" includes a respondent who did not specify their racial identity.
[c] Question was only asked to respondents who indicated that they were not currently employed.
[d] Respondents were allowed to choose more than 1 diagnosis. Diagnoses are not mutually exclusive.
[e] Respondents were allowed to choose more than 1 substance. Substances are not mutually exclusive.



Family Member Demographics (N=64)[a]

[a] Due to missing or excluded invalid responses, variable totals may not equal 64.
[b] "Another race" includes American Indian or Alaska Native.
[c] Respondents were allowed to list more than 1 family member. Family members are not mutually exclusive.
[d] "Other" includes niece, mother, cousin, grandson, nephew, and aunt.
[e] Respondents were allowed to state up to 4 diagnoses. Diagnoses are not mutually exclusive.


Providers Demographics (N=183)[a]

[a] Due to missing or excluded invalid responses, variable totals may not equal 183.
[b] "Administration" includes executive directors, chief executive officers, and chief clinical officers, as well as program managers, facility mangers, and respondents in Human Resources and operational roles.
[c] Some respondents selected more than 1 diagnosis. Diagnoses are not mutually exclusive.