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Impact of family engagement on client participation in coordinated specialty care for first episodes of psychosis

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Abstract

Background Coordinated specialty care (CSC) programs for first episodes of psychosis are increasingly offered in the United States. A component of CSC programs is active family engagement in treatment, though research on the impact of this engagement is limited. This study examined the characteristics of families engaged compared to families not engaged in treatment, and the impact of family engagement on client participation and medication adherence over the first 6 months of treatment.

Methods Using data from the Early Psychosis Intervention Network (EPINET) research hub in Minnesota (EPI-MINN), we compared two groups of individuals: clients who had a family member(s) engaged in their treatment vs. clients who did not. Family engagement was defined as any treatment services provided to a family member(s) by CSC clinical staff. The groups were compared on intake demographic variables, duration of untreated psychosis (DUP), hospitalizations, symptom severity, and functioning. A comparison of the total number of treatment visits during the first 6 months of treatment was tested using both nonparametric (Mann Whitney U) and parametric (ANCOVA) tests. Group comparisons on self ratings of "intent to attend visits," "intent to complete the program," and medication adherence were tested with ANCOVA and Chi-Square.

Results Family-engaged clients were younger, with less years of education, and more often White; clients without family engagement were more often Black. Family engagement was positively associated with increased total number of visits for all interventions with the exceptions of client peer support and case management visits. Family engagement increased clients' self-reported intent to attend visits, though not intention to complete the program, which was moderately to markedly high in both groups. No differences were noted with medication adherence, with high rates of adherence across the entire study sample.

Conclusions Overall, results of the study support the benefits of family engagement in CSC on client participation, though future research is needed to understand why Black families are less engaged and what treatment adaptations are needed to reduce these racial differences. The results also support the value of CSC programs for medication adherence, a critical factor in symptom reduction and mental health recovery.

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Keywords First-episode psychosis, Family engagement, Treatment adherence, Medication adherence

Background

First episodes of psychosis typically occur in early adulthood, interrupting psychosocial development. Family members are often the first to notice signs and symptoms of psychosis in a loved one [1–3]. Moreover, family members, often parents, provide “a comprehensive range of practical, emotional, and financial support for their [child] including initiating and sustaining engagement between them and local mental health services” [4]. Research shows that having family members involved in psychosis treatment is associated with decreased relapses in psychosis [5], reduced psychotic symptoms [6, 7], and even decreases in unintentional death among individuals experiencing psychosis [8]. Moreover, research shows that providing education and support to family [9, 10] is strongly associated with fewer relapses and hospitalizations, as well as improved service engagement, medication adherence, functional outcomes, and recovery [11].

Pursuant to this evidence base, CSC programs specifically prioritize early intervention for psychosis utilizing a multidisciplinary team approach [12] which includes family education and support as well as psychiatric medication management, individual cognitive behavioral therapy, and education and employment support. Team collaboration between providers, the client, and the client’s family offers a unique and beneficial treatment experience for all involved, and this collaboration has been shown to increase individuals’ treatment engagement [12]. Jones et al. [13] surveyed 761 clients of a CSC and found that 94% of individuals wanted some family engagement in their treatment. Furthermore, in this study researchers found that individuals who did not have family engaged in their treatment were more likely to discharge within a year of starting the treatment program. Likewise, Oluwoye et al. [14] found that including families in CSC treatment was associated with overall individual engagement in the treatment program. Despite these robust and consistent findings, much less is known about the effect of family engagement on the specific types of treatment sessions that clients attend or whether it shows any association with medication adherence, an important aspect of illness management and recovery.

We sought to investigate these unanswered questions through our Early Psychosis Intervention Network Study (EPINET) data. EPINET is a national network of CSC programs co-creating a learning healthcare system for early psychosis. EPINET links early psychosis clinics through standard clinical measures, uniform data collection methods, data sharing agreements, and integration of client-level data across service users and clinics. Clients and their families, clinicians, healthcare

administrators, and scientific experts partner within EPINET to conduct large-scale, practice-based research with an aim to improve early psychosis care and outcomes. Clinics involved in EPINET are grouped into specific “hubs” with unique research questions and interventions. The current study was conducted at our hub in Minnesota (EPI-MINN), which consists of five separate clinic sites. We sought to identify the demographic and clinical characteristics of clients whose families are actively engaged in their treatment versus those whose families are not engaged in their treatment, and to test three key questions: (1) If a client’s family is engaged in their treatment, does this impact the number and types of treatment visits a client attends relative to clients whose families are not involved in their treatment? (2) Does family engagement affect clients’ self-reported intent to attend treatment visits and complete the program? and (3) Does family engagement impact clients’ adherence to medications?

Methods

Setting and design

The overall aim of our EPI-MINN hub is to expand measurement-based psychiatric care (MBC) across 5 early psychosis CSC clinics in Minnesota serving approximately 200 individuals per year. Each program follows the NAVIGATE model’s curriculum, offering individual resiliency training (IRT), supported employment and education (SEE), family education, case management, and medication management to individuals ages 15–40 who have experienced a first episode of psychosis [12]. In addition, each site includes a psychometrist, who obtains the MBC measures, including the EPINET Core Assessment Battery (CAB), as standard of care, from clients at program enrollment and every 6 months thereafter until discharge or graduation.

In this study we compare clients whose families were engaged in their treatment versus not engaged in their treatment from 3 of the 5 CSC sites within the EPI-MINN hub for whom family treatment data were available. Family is broadly defined as any person(s) in the clients’ support system they’ve asked to participate in their care; most visits were attended by the same person(s) though could differ at times. Family engagement in treatment is defined as participating in any of the treatment services provided by CSC clinical staff: IRT, SEE, medication management, family education, family peer support and client peer support, and case management. We hypothesized that clients with family engagement would have a greater number of treatment visits across the full range of interventions offered relative to clients whose families

were not involved in their treatment. We also hypothesized that clients with engaged families would have higher self-report ratings on “intent to attend treatment visits” and “intent to complete the program,” as well as greater adherence to medications.

Client characteristics

The CSC program criteria includes individuals ages 15 to 40 with a diagnosed psychotic disorder; two of the programs require an onset within the past two years and three accept clients with onset within the past five years. A total of 172 clients were included in the analysis

comparing the number of attended treatment visits. A subset of 91 clients in this sample completed self-report measures on intent to attend treatment and complete the program, and on medication adherence. Demographic and clinical characteristics of the two groups are listed in Table 1.

Measures

Engagement in treatment services was measured as: (1) the number of visits from intake to 6 months in IRT, SEE, medication management, family education, family peer support, client peer support, and case management, (2)

Table 1 Demographic and clinical characteristics of individuals whose families are engaged in their treatment (FamEng) versus not engaged (NoFamEng)

	FamEng (N=98) Mean (SD)	NoFamEng (N=74) Mean (SD)	Test Statistic (p)
Age (years) ^a	20.26 (4.68)	23.49 (5.14)	-4.30 (<0.001)
Education (years) ^a	11.96 (2.19)	12.95 (1.96)	-3.06 (0.003)
Gender ^b			1.47 (0.48)
Male N (%)	60 (61.2%)	45 (60.8%)	
Female N (%)	36 (36.8%)	25 (33.8%)	
Non-Binary or Other N (%)	2 (2.0%)	4 (5.4%)	
Racial background n (%) ^b			11.81 (0.07)
Black/African American N (%)	11 (11.2%)	22 (29.7%)	
White N (%)	64 (65.3%)	37 (50%)	
Asian N (%)	7 (7.1%)	4 (5.4%)	
American Indian/Alaskan Native N (%)	3 (3.1%)	0 (0.0%)	
More than 1 race N (%)	10 (10.3%)	8 (10.8%)	
Prefer not to say N (%)	1 (1.0%)	1 (1.4%)	
Unsure/don't know N (%)	2 (2.0%)	2 (2.7%)	
Diagnosis ^b			8.86 (0.12)
Schizophrenia N (%)	10 (10.2%)	9 (12.2%)	
Schizoaffective N (%)	17 (17.3%)	14 (18.8%)	
Schizophreniform N (%)	8 (8.2%)	3 (4.1%)	
Psychosis NOS N (%)	61 (62.3%)	41 (55.4%)	
Major Depression w/ Psychotic Features N (%)	1 (1.0%)	0 (0.0%)	
Bipolar Disorder w/ Psychotic Features N (%)	1 (1.0%)	7 (9.5%)	
Duration of Untreated Psychosis (months) ^c	Median = 6 (Range = 0-203)	Median = 10.50 (Range = 1-183)	2.12 (0.15)
Hospitalized in the last 6 months ^b			0.04 (0.85)
Yes N (%)	56 (60.9%)	41 (59.4%)	
No N (%)	36 (39.1%)	28 (40.6%)	
[FamEng total N = 92; NoFamEng total N = 69] ^d			
Colorado Symptom Index mean item ^a score	1.97 (0.89)	1.76 (1.05)	1.03 (0.31)
[FamEng total N = 50; NoFamEng total N = 40] ^d			
MIRECC GAF Occupational Functioning Total ^a	52.11 (26.60)	53.00 (28.47)	-0.14 (0.89)
[FamEng total N = 63; NoFamEng total N = 27] ^d			
MIRECC GAF Social Functioning Total ^a	63.52 (19.63)	65.37 (18.39)	-0.42 (0.68)
[FamEng total N = 63; NoFamEng total N = 27] ^d			
MIRECC GAF Symptomatic Functioning ^a	48.87 (17.50)	48.07 (18.70)	0.19 (0.85)
[FamEng total N = 63; NoFamEng total N = 27] ^d			

^aIndependent Samples T-test; ^bChi-Square; ^cMann Whitney U

^dData were available on a subset of participants

the Intent to Attend scale [15], which asks clients to rate two questions on a scale of 0 (not at all) to 9 (extremely) on how likely they will attend the next appointment and how likely they will complete the program. Medication adherence was assessed with the Brief Adherence Rating Scale [16] which includes two client self-report questions on the percentage of days when the client did not take their medication, and the percentage of days when the client did not take the full prescribed dosage, and a clinician rating on the proportion of doses that the clinician believed were taken by the client in the past month (0-100%). Symptoms were assessed using the Modified Colorado Symptom Index [17]. Clients rated 14 items on a scale of 0 (not at all) to 4 (at least everyday). Clinicians provided ratings of functioning on a scale of 1 (dangerous) to 100 (fully-functional) using the Mental Illness Research Education and Clinical Center version of the Global Assessment of Functioning (MIRECC GAF) [18].

Procedures

Upon enrollment in one of our CSC programs, clients were approached by a psychometrist to complete self-report and interview-based measures as part of standard clinical practice. The only exception occurred when a clinician identified that the client was experiencing significant clinical instability. Completing the measures was voluntary, and clients were provided an explanation about MBC and how the MBC assessments were used in their treatment. CSC programs followed their usual clinical standard work, such as reminder calls, and no interventions specifically targeting visit attendance or medication adherence were utilized for the purpose of research.

Clients completed assessments in-person and/or remotely using the Mirah measurement-based care system (www.mirah.com), and a digitalized data acquisition platform developed in-house. The measures included are the EPINET Core Assessment Battery (CAB), program evaluation measures required by our EPI-MINN sponsors in the Minnesota Department of Human Services, and additional measures of symptoms, cognition and motivation. The full MBC battery took 1–2 h for clients to complete.

Clients were divided into two groups based on the answer from the following question that was completed by their clinician after 6 months of treatment: “Has any family member received any treatment services provided by the clinical staff (e.g., family therapy, individual sessions with the client, etc.)?” Families of 98 clients were engaged in their treatment (FamEng), and families of 74 clients were not engaged in their treatment (NoFamEng). We compared the two groups on demographic and clinical characteristics, number of treatment visits attended,

intent to attend visits and complete the program, and medication adherence.

Statistical analyses

Independent Samples T tests, Chi-Square, or Mann Whitney U tests (2-tailed) were used to compare the groups at intake in demographic variables, duration of untreated psychosis (DUP), hospitalizations, symptom severity, and functioning. A comparison of the number of treatment visits was tested using both nonparametric (Mann Whitney U) and parametric (ANCOVA) tests, given that the data on number of visits were skewed, and the groups differed in age and years of education. To compare the groups in adherence measures, Chi-Square and ANCOVA were conducted. Given our findings, post hoc Chi-Square tests were conducted to test for group differences in housing (e.g., living at home with biological or adoptive family versus other housing situations such as living alone or with roommates), and to test for differences in type of health insurance (e.g., commercial insurance vs. Medicaid). All analyses were performed using SPSS Statistics version 28 (IBM Corp).

Results

Demographic and clinical characteristics

There were significant group differences in age and years of education. The FamEng group were younger with fewer years of education relative to the NoFamEng group. The groups differed at trend level significance in race with more Black/African American clients in the NoFamEng group and more White clients in the FamEng group. The groups did not differ in gender, diagnosis, DUP, hospitalizations, or symptom severity and level of functioning at intake (Table 1). Not all clients completed each measure. In measures completed by a subset of clients, sample sizes are denoted in the first column of Table 1.

Given the group differences in age and education, post hoc analyses tested for group differences in housing, and were significant ($X^2(8, N=172)=23.81, p=.002$) with more clients in the FamEng group living with biological or adoptive family (81.6%) relative to the NoFamEng group (55.4%), and more clients in the NoFamEng group living alone or with roommates (independent) (28.4%) relative to clients in the FamEng group (11.2%).

Treatment visits

The groups differed significantly in the number of IRT, SEE, medication management, family education, and family peer support visits, with the FamEng group attending significantly more visits relative to the NoFamEng group from intake to 6 months of treatment (Table 2). A comparison of the mean of the distributions shows that the FamEng group has a larger mean rank in these 4 treatment visit types relative to the NoFamEng

Table 2 Type and number of treatment visits in individuals whose families are engaged in their treatment (FamEng) versus not engaged (NoFamEng) from intake to 6 months

Treatment Visits	FamEng (N=98) Median (range)	NoFamEng (N=74) Median (range)	Mann Whitney U (p)
Individual Resiliency Training (IRT)	14.50 (31)	11.00 (25)	-3.25 (0.001)
Supported Employment and Education (SEE)	6.00 (25)	1.50 (27)	-3.74 (<0.001)
Medication Management	5.00 (22)	3.00 (12)	-2.99 (0.003)
Family Education	10.00 (26)	0.00 (5)	-10.56 (<0.001)
Family Peer Support	0.00 (5)	0.00 (3)	-4.41 (<0.001)
Client Peer Support	0.00 (23)	0.00 (24)	-0.18 (0.86)
Case Management	0.00 (8)	0.00 (13)	1.35 (0.18)

group (Fig. 1). The groups did not differ in the number of client peer support or case management visits. While the data are skewed and violate the assumption of normality for ANCOVA, the results remained significant controlling for age and years of education: IRT $F(1,168)=10.37$, $p=.002$, SEE $F(1,168)=7.27$, $p=.008$, medication management $F(1,168)=9.98$, $p=.002$, family education $F(1,168)=121.80$, $p<.001$, family peer support $F(1,168)=9.89$, $p=.002$, and the difference between groups in case management visits reached statistical significance $F(1,168)=4.23$, $p=.04$, with the NoFamEng group attending more visits ($M=1.34$, $SD=2.88$) relative to the FamEng group ($M=0.53$, $SD=1.31$). Client peer support visits remained non-significant ($F(1,168)=0.09$, $p=.76$).

Given the group differences in case management visits, post hoc analyses tested if the groups differed in insurance type and were significant ($X^2(4, N=172)=13.79$, $p=.008$) with more FamEng clients using commercial insurance (72.4%) relative to NoFamEng clients (48.6%), and more NoFamEng clients using medicaid (41.9%) relative to FamEng clients (17.3%).

Self-ratings of "Intent to attend next appointment" and "Intent to complete the program"

Adherence measures were complete for 53 clients in the FamEng group and 38 clients in the NoFamEng group. Clients rated how likely they would attend the next appointment and how likely they would complete the program using the following scale: 0–1 not at all, 2–3 slightly, 4–5 moderately, 6–7 markedly, 8–9 extremely. The FamEng group rated that they were more likely to attend the next appointment relative to the NoFamEng group, although the mean group ratings for both groups were in the "markedly" range (Table 3). The results were significant controlling for age and years of education. The groups did not differ in their ratings of completing the program with both groups' ratings in the moderately to markedly range.

Medication adherence

Both groups showed excellent adherence to medications from self-report ratings and from clinician ratings. 96.2% of the FamEng group and 97.4% of the NoFamEng group reported few, if any, days during which they did not take not their antipsychotic medication (Table 3). 96.2% of the FamEng group and 89.5% of the NoFamEng group reported "never/almost never" taking less than the prescribed dosage. On a scale of 0–100%, clinician ratings of the proportion of doses taken by clients were 92.5% for the FamEng group and 91.8% for the NoFamEng group. All group differences were not significant.

Discussion

This study adds to the current literature regarding family engagement in treatment for early psychosis by deepening our knowledge of client factors that are related to family engagement, as well as, how family involvement in treatment services might be associated with clients' engagement in various kinds of CSC interventions. Specifically, we found that engaged families more often involved clients who were White, younger in age, with fewer years of education, commercially insured, and living with biological or adoptive families. Family engagement in treatment services was associated with increased visits with the exception of client peer support and case management, the latter of which was more frequently used by clients whose families did not engage. While family engagement was associated with increased rates of intention to attend the next appointment, no difference was found for intention to complete the program, nor were there differences between groups on medication adherence.

Prior research has shown greater family engagement with younger clients [19, 20]. Families may find it easier to engage in their loved one's treatment when they have a legal right to do so, such as with minor clients (age of consent for medical treatment in the State of Minnesota is 18 years). Younger clients may also find it more acceptable to include family in their treatment as compared to older clients for whom there exists a greater need for independence based on developmental stage. Living in

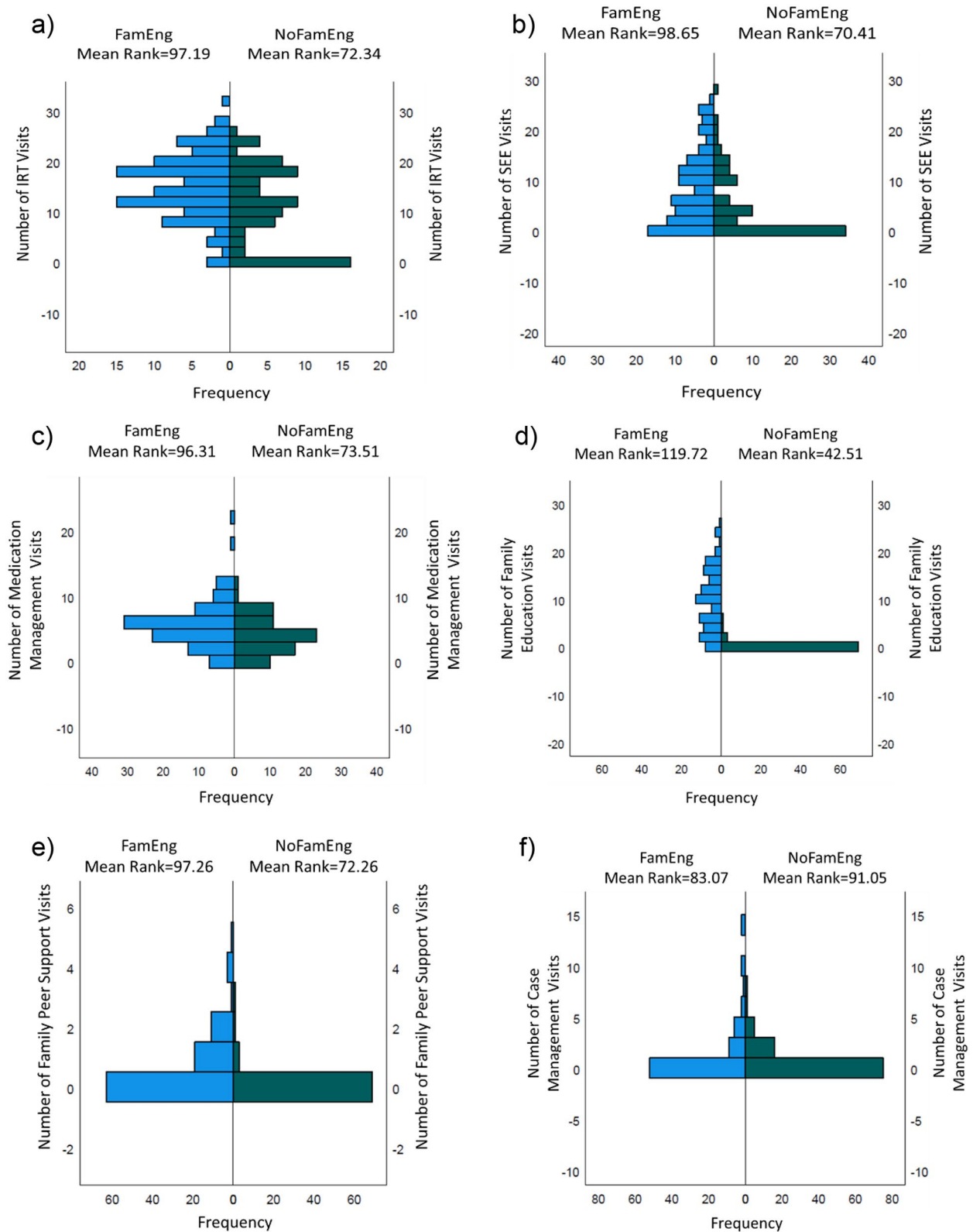


Fig. 1 FamEng and NoFamEng groups differ significantly in the number of **a)** IRT, **b)** SEE, **c)** Medication Management, **d)** Family Education, **e)** Family Peer Support, and **f)** Case Management visits

Table 3 Treatment adherence in individuals whose families are engaged in their treatment (FamEng) versus not engaged (NoFamEng)

Adherence Measures	FamEng	NoFamEng	ANCOVA or Chi-Square (<i>p</i>)
	(<i>N</i> = 53)	(<i>N</i> = 38)	
	Mean (SD)	Mean (SD)	
How likely is it that you will attend the next appointment?	7.09 (2.23)	6.13 (2.11)	4.42 (0.04)
How likely is it that you will complete the program?	6.15 (2.09)	5.74 (2.02)	0.86 (0.36)
^a Since your last visit with me, on how many days did you NOT TAKE your [name of antipsychotic]?	<i>N</i> = 51 (96.2%)	<i>N</i> = 37 (97.4%)	2.83 (0.24)
Few if any (less than 7 days)	<i>N</i> = 0 (0%)	<i>N</i> = 1 (2.6%)	
7–13 days	<i>N</i> = 0 (0%)	<i>N</i> = 0 (0%)	
14–20 days	<i>N</i> = 0 (0%)	<i>N</i> = 0 (0%)	
Most days (> 20 days)	<i>N</i> = 2 (3.8%)	<i>N</i> = 0 (0%)	
^a Since your last visit with me, how many days did you TAKE LESS THAN the prescribed number of pills of your [name of antipsychotic]?	<i>N</i> = 51 (96.2%)	<i>N</i> = 34 (89.5%)	4.38 (0.11)
Never/almost never (0–25% of the time)	<i>N</i> = 0 (0%)	<i>N</i> = 3 (7.9%)	
Sometimes (26–50% of the time)	<i>N</i> = 0 (0%)	<i>N</i> = 0 (0%)	
Usually (51–75% of the time)	<i>N</i> = 2 (3.8%)	<i>N</i> = 1 (2.6%)	
Always/almost always (76–100% of the time)			
Please enter the number that you believe best describes, out of the prescribed antipsychotic medication doses, the proportion of doses taken by the patient in the past month (0–100%).	92.5% (21.74)	91.8% (17.03)	< 0.001 (0.98)

^aChi-Square test

the same home may also increase family engagement via more opportunities for communication and knowledge of their loved one's treatment visit schedule; research on the impact of living apart from family on treatment engagement is mixed [21, 22]. Offering families tailored options to address unique circumstances and needs may improve engagement [23] regardless of living arrangements.

No differences were found between groups based on diagnosis, DUP, hospitalization in the preceding six months, or symptom severity and level of functioning at the time of intake. These results differ from other published research showing greater rates of family involvement when their loved one is having more psychiatric symptoms [24] and that longer DUP correlates with less family involvement and support [25]. It is not immediately clear why our results differ from prior studies and it is important to continue research to better understand the longitudinal relationship between clinical variables and family engagement.

Client utilization of case management services was significantly greater for those without family engagement in treatment services. Clients without family engagement may have a greater need for case management support, such as assistance with transportation to visits and applying for health insurance. Indeed, rates of Medicaid were significantly higher for clients without family engagement relative to those with family engagement, and rates of commercial insurance were significantly higher for those whose families were engaged, consistent with previous research [26]. Considering the insurance and housing results together, it is possible that clients for whom families are engaged are more likely to be on their parents' commercial health insurance or have less need for transportation support, and therefore less need to engage in case management services. Rates of family engagement

in CSC range widely [26–29] and most CSC models do not include case management as a standard intervention (e.g., NAVIGATE, OnTrackNY) but would likely benefit from including this service to facilitate access to critical resources. Further, minimal literature exists examining case management interventions in CSC and future research should explore the impact this service has on outcomes.

Demographic differences were noted with greater engagement of the families of White clients and less engagement of the families of Black/African American clients. United States census data from 2020 [30] indicated the overall population of Minnesota was 77.5% White and 7% Black. Despite the study having a greater representation of Black individuals (19.2%) as compared to both Minnesota and the counties in which the five CSC programs are located, rates of Black clients' family engagement were statistically lower than that of White clients' family engagement. Disparities in the treatment engagement of Black and White individuals in psychotherapy is well researched [31], including less engagement of Black families in NAVIGATE Family Psychoeducation [27]. Reduced engagement of the Black clients' families in this study may be associated with discomfort in working with predominantly White treatment team members, factors of systemic racism, lack of cultural sensitivity, and the absence of standardized cultural adaptations to the NAVIGATE treatment model. CSC Programs should increase cultural humility and modify treatment through cultural training, use of culturally appropriate assessments and educational materials, and adapt interventions, as well as employ treatment staff representative of the diverse client/family populations served. Some tools and recommendations to reduce racial disparities have

been developed and would be beneficial to implement in CSC programs [32, 33].

Family engagement in any CSC treatment service was associated with a larger number of total visit attendance in the first six months of treatment, as well as increases to specific visit types (Table 2). Clients may find it is easier to remain engaged in their care when their families have personal relationships with the treatment team and can more effectively reinforce the benefits of engagement. Clients may also have an easier time accessing their treatment when families are engaged, such as through instrumental support of families (e.g., transportation to appointments). The results suggest that family engagement improved the participation of their loved ones for most interventions, consistent with previous research [34]; family engagement is critical as research has shown that a lack of family involvement is strongly associated with client disengagement from CSC treatment [21, 24].

Family engagement was not associated with increased client peer support visits. There are several possible reasons for this finding. NAVIGATE, the model used by the CSC teams in this study, does not include client peer support as a standard intervention and not all of the teams have a client peer support specialist available to work with clients; access to the service may have been too limited to see any association. Another possibility is that families are less likely to engage in client peer support visits with their loved one, particularly when they have access to their own family peer support specialist. Families, on the other hand, are more likely to engage in medication management or SEE visits so that they may play a role in their loved one's pharmacological, academic, and vocational goals. Families may even be more likely to participate in IRT, such as during a joint session with the family education clinician. What these results highlight, however, is the need for better explanation and visibility of client peer support services so that engaged families can similarly encourage their loved ones to actively participate. Further, the writers are not aware of any publications examining the relationship between family involvement and client engagement in peer support, and additional research on this topic is indicated.

Self-ratings of the intent to attend their next treatment visit was significantly higher in the family engagement group; however, both groups rated their intent to complete the CSC program as moderate to markedly high (a longer-term intention), which is somewhat less than how they rated their intention to attend the next visit (a short-term intention). It appears clients, in general, had more confidence in their short-term intentions, but many individuals with first episodes of psychosis experience numerous losses (e.g., leaving a job, losing friends, dropping out of school [35]) and may find the future harder to predict leading to lower confidence in long-term intentions. The association between family engagement and higher client intentions to attend the

next visit may be related to several factors: living in the same home as family who know when visits are scheduled may increase motivation to attend, ease of traveling to visits with family who are also attending visits may enhance capacity and resources to attend, and families who know the treatment staff may be better able to offer encouragement that could increase decision to attend.

While one published study has found family involvement improves rates of medication adherence in CSC treatment [36], our results did not support the hypothesis that family engagement would increase rates of medication adherence, as both client- and prescriber-reported ratings for taking medications as prescribed were remarkably high, with about 90% or more in both groups reporting adherence for dosages and minimal missed days. This is in sharp contrast to published research, which shows a range from 24 to 40% of clients not taking medications as prescribed [37] and a CSC study showing only 41% full adherence to antipsychotic medications [36]. It is unclear from this study why our results differ so significantly from other published data and it is important to look at prescribing practices, such as use of long-acting injectable medications, and frequency of medication management visits to identify effective interventions for adherence, and attempt to replicate these findings in future research.

Study limitations

It is important to note several limitations to this study. The study samples were naturalistic and did not include random assignment into the family engagement and non-engagement groups. While the study is prospective in nature (i.e., participants completed the measures at intake and after 6 months of treatment), the data on number of treatment visits were collected retrospectively. There are also a host of factors that may be confounding, mediating or moderating the findings we observed and that we did not measure including language spoken by family, geographical proximity of family, or quality of family relationships. Further, the independent variable, family engagement, is limited by lack of information on the quantity, type, or quality of family engagement as it was simply measured as a binary variable (families that attended one psychoeducation visit were grouped with families that attended multiple therapy visits). The sample size, particularly for discrete variables such as races other than White and Black/African American, reduced statistical capacity to examine certain analyses. Future analyses within the larger EPINET dataset will help us to understand which of our results are replicable.

Another key limitation relates to our restricted geographical location; the entire study sample came from clients engaged in CSC treatment programs in Minnesota, reducing the generalizability of our findings to other CSCs in the United States and internationally. Finally, this study looked at the 6 month period of time

following initial enrollment in the CSC. Some clients are acutely symptomatic when first presenting to CSC and family engagement may be delayed either due to client preference or family levels of distress. It will be important for future longitudinal studies to consider what family engagement looks like over the duration of enrollment in CSC, as well as how family engagement at different time points might differentially impact outcome variables.

Conclusions

Family engagement in CSC is associated with many benefits to client engagement including increases in both intention to attend visits and actual participation in most treatment interventions. Families of White clients were significantly more engaged in treatment services than families of Black clients, as were the families of clients who were younger and living with family. Rates of medication adherence as rated by both clients and clinicians were remarkably high across the entire sample. Future research should endeavor to replicate and expand upon these findings with particular emphasis on identifying better ways to engage the families of Black clients, examine the effects of family engagement on psychiatric and functional outcome variables, and explore factors associated with high medication adherence rates.

Abbreviations

CSC	Coordinated Specialty Care
DUP	Duration of untreated psychosis
EPI-MINN	A Minnesota based hub of EPINET
EPINET	Early Psychosis Intervention Network Study
FamEng	Clients whose families were engaged in their treatment; NofamEng: Clients whose families were not engaged in their treatment
IRT	Individual Resiliency Training
MBC	Measurement-based care
SEE	Supported Employment and Education
TAU	Treatment as usual

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Author contributions

SV and PMK conceptualized and acquired funding for this study. Data curation and formal analysis were performed by MF. The investigation was conducted by several Psychometrists and Site Leads (see Acknowledgments), including authors MD, CA, AWW and JL. Project and lab management were provided by NO and AC. Supervision was provided by NO, AC, MF, MD, JL, PMK, and SV, and other Site Leads. All co-authors were involved in drafting, reviewing and editing the manuscript, and approved the final manuscript.

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Data availability

This data has been shared with the NIMH Data Archive through the EPINET National Data Coordinating Center, and while the dataset is not publicly available at the time of publication, access to the data can be coordinated by contacting the corresponding author.

Declarations

Ethics approval and consent to participate

The institutional review board (IRB) of the University of Minnesota reviewed and approved this study (STUDY00009334). Written informed consent was obtained from the participants and/ or their legal representatives for their participation in the study before the commencement of the study.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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