Client Views of Engagement in the RAISE Connection **Program for Early Psychosis Recovery**

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Objective: This study assessed factors that facilitated or impeded clients' engagement in services offered by the Recovery After an Initial Schizophrenia Episode (RAISE) Connection Program for youths and young adults experiencing early psychosis. It was part of the larger RAISE Implementation and Engagement Study.

Methods: Thematic qualitative analyses of data from inperson, semistructured interviews with 32 clients were used to examine experiences of program services, staff practices, clients' engagement behaviors, and related factors, such as expectations, family involvement, illness, and setting. Eighteen clients were well engaged with services, and 14 were not. Thirteen were interviewed early in their program involvement (two to nine months after enrollment) and 18 others later (12 to 24 months after enrollment).

Results: Four domains of factors influenced engagement: individualized care, program attributes, family member engagement, and personal attributes. A central factor was the program's focus on clients' life goals. For many interviewees, engagement hinged substantially on receiving what could be considered nonclinical services, such as supported education and employment. Other key factors were individualized services and staff interactions that were respectful, warm, and flexible; engagement of family members; and a focus on shared decision making.

Conclusions: The findings help explain the Connection Program's effectiveness regarding client engagement and deepen understanding of treatment engagement for youths and young adults experiencing early psychosis. The individualized, flexible, recovery-focused, and assertive model of services and client-staff interaction, incorporating shared decision making and a focus on client life goals, should be implemented and sustained in services for this population.

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Treating psychosis early can optimize the affected person's recovery, functioning, illness course, and well-being (1). Care delays and gaps may increase the likelihood of prolonged disability. Engaging people in treatment is a multifaceted process affected by logistical (service availability, location, transportation, and costs), psychological (health beliefs), interpersonal (client-provider fit and communication), and other factors (2,3). For young people coping with first or early episodes of psychotic experiences (early psychosis), engagement is further shaped by relative maturity, understanding of their experiences, legal status, autonomy needs, prior experiences with care, and family relationships (4,5).

The RAISE (Recovery After an Initial Schizophrenia Episode) Connection Program is an innovative multiservice intervention for teens and young adults experiencing early psychosis suggestive of schizophrenia. The program combines critical time intervention (6), best practices regarding early-psychosis treatment (7,8), shared decision making (9), and ongoing engagement outreach. It offers counseling, medication management, vocational and educational assistance, case management, and crisis services with a highly individualized, client-centered, community-based team approach. Details of the program are available on the Web site of the National Institute of Mental Health (NIMH) (10). The programming, implementation, and effectiveness of the Connection Program were evaluated in the RAISE Implementation and Evaluation Study (RAISE-IES) (11,12). Among its aims, RAISE-IES evaluated the Connection Program model's recommended practices for engaging and retaining clients in treatment. Fewer than 10% of clients dropped out of Connection Program services during their treatment period of up to two years. This is a lower rate of dropout than reported in the literature. Other studies of first-episode populations have reported an average of 30% disengagement over three to 30 months; disengagement varied by study (13).

This study was designed to understand how clients experienced the program and its practices. The study focused on engagement in order to contextualize the RAISE-IES retention rates. Specifically, it aimed to identify engagement facilitators and barriers among individuals with early psychosis.

METHODS

The engagement study used semistructured interviews with Connection Program clients, their family members, clinicians, administrators, and outside referring-agency representatives. Only client interviews are presented here. The institutional review boards (IRBs) of the New York State Psychiatric Institute and the University of Maryland approved all study procedures. The NIMH Data and Safety Monitoring Board provided study oversight.

Sampling Frame, Eligibility, and Recruitment

This study involved participants from among the 65 clients enrolled in the two RAISE-IES Connection Program sites (Baltimore and New York City). RAISE-IES inclusion criteria, recruitment procedures, and client demographic characteristics are reported elsewhere (11). To create a broad-based sample for the engagement study, we sought to interview some Connection Program clients earlier in their program involvement (two to nine months after enrollment) and others later in their enrollment (12 to 24 months after enrollment). We also sought to enroll clients who were "well engaged" and others who were "not well engaged" in Connection Program services; engagement was rated by the site's clinical team leader just before recruitment for this engagement study. This approach created four groups of participants—two tenure levels by two engagement levels-roughly half from each site.

Clients were eligible for this engagement study if they were enrolled in the New York City or Baltimore Connection Program while it was a research study, fit into one of the four tenure-by-engagement groups, cleared by the team leader as clinically stable enough to participate, and willing and able to give informed consent. Research staff approached clients at the end of a research or clinical appointment for the parent study or by phone. Funded by a federal contract, RAISE-IES was conducted under a National Institutes of Health Clinical Exemption from the Paperwork Reduction Act (PRA). This engagement study was also conducted under exemption of the PRA because we interviewed nine or fewer individuals in each of our four participant groups.

Interview Procedures

In-person interviews took place from May 2012 to April 2013 in a private setting using IRB-approved informed consent procedures and conducted by trained, experienced interviewers who were not involved in providing Connection Program services. They followed a semistructured guide focusing on client experiences and opinions about the Connection Program services, staff, practices, family engagement, and clients' own engagement with services. Each audio-recorded interview lasted from 30 to 60 minutes. Each participant received \$15. At the close of each interview,

interviewers offered to send participants a copy of the interview transcript to keep and invited them to submit comments and corrections. A total of 25 participants requested and were sent transcripts, and none returned comments.

Data Analysis

Interview audio files were professionally transcribed and then proofread by one of three research assistants (RAs) supervised by the first author. Proofreaders made preliminary notes of engagement facilitators, barriers, and other issues in each interview, from which two authors (AL and JS) with two of the RAs drafted initial coding categories. Examples of the categories include "Team was engaging: competent," "Symptoms and engagement," and "Client feels obliged to attend." This initial code list was revised and refined during the steps described below.

Analysis was completed in two phases. First, using Atlas.ti 7 (14), pairs comprising the first author plus one of the three RAs independently coded all transcript passages that related to services engagement in each transcript and compared their results. Differences were minor, with occasional identification of a new code. After pairs discussed differences and reached consensus, the code list and definitions were refined accordingly and the final coding of each client transcript was double-checked for errors.

Second, in close discussion with other members of the study team, the first author consolidated codes into categories focused on the study purpose of identifying factors affecting engagement, specified as "facilitators" or "obstacles." This phase involved refining coding structure and definitions to encompass all data; combining codes to increase parsimony; and checking code and quotation distributions in Atlas.ti for anomalies, errors, and completeness. Next, again led by the first author, members of the team examined the relationship of all codes to each other in terms of their effects on engagement, both by discussion and by exploration via Atlas.ti "network view." This led to grouping the codes by topical families that formed the domains described below.

This process also included frequent comparison with the transcripts; independent comment on the transcripts by a RAISE-IES investigator (SME), which we considered in our analysis; and ample team discussion. Atlas.ti software was used to track coding changes, interpretation notes, and code interrelationships. [A table in an online supplement to this article provides details on the specific codes in each engagement domain and theme.]

RESULTS

Final Sample

We interviewed 32 of 65 Connection Program clients: 18 well engaged with Connection Program services and 14 not; 13 early in their Connection Program involvement and 18 later. Table 1 presents data on demographic characteristics. Fourteen additional clients were considered but not interviewed: four declined, four could not be reached to invite. two were not cleared by the clinician, and four did not fit a sample group for which we were seeking participants.

Four domains of factors influencing client engagement emerged from the procedures described above: individualized care, program attributes, family member engagement, and personal attributes (see box). All domains and subthemes were robustly represented in the client interview data, and quotations used below and in the online supplement are drawn from all participants.

Individualized Care

According to the interviewees, the highly individualized care that the teams provided was pivotal to their engagement in three ways: focus on life goals, effectiveness, and warm respect.

Focus on life goals. Most (N=27) of the 32 interviewees said that the Connection Program was engaging because staff took their life goals seriously, "helped me out with some of my life problems," and seemed dedicated to helping them "get back on track." Most goals were related to relationships, jobs, or education. For example, one interviewee said, "What I like about the program is that it covers a lot of places, like they help you look for a job, they help you go look for school if you're in school, they cover like everything that's going on in your life." Or, as another phrased it, "You have some clear goals, you're struggling with some things really energetically, you're trying to go places. The Connection team [asks] are there ways that they could help you?" These life goals were also important to the initial engagement of individuals who did not see themselves as needing psychiatric care.

Paradoxically, a small portion (N=7) of the 32 interviewees also described life priorities as competing with program engagement. For example, one client said, "Sometimes I struggle with like the actual [services] that they want me to partake in because I'm really focused on like finding a job and that to me is a high priority for me and my family."

Effectiveness. Many of the 32 interviewees (N=18) described positive results as engaging. They said things such as, "I want to keep coming because it just helps me. It's as simple as that." "After a while I got to realize how the program was working for me . . . so that's when I really got into it." Some cited specifics, such as, "I feel a lot healthier." "[The program is] help[ing] me to feel okay with who I am right now." "[I'm] not feeling constantly anxious." "[I'm] realiz[ing] that I don't really need [smoking marijuana] to keep on." "They have changed my medicine, which was [is] better." Conversely, not perceiving effectiveness reduced engagement. For example, one client reduced the frequency of her appointments because she said, "I didn't feel that much was coming out of my sessions with [a new clinician]."

TABLE 1. Demographic characteristics of 32 participants in the RAISE Connection Program^a

Characteristic	N	%
Age		
<20	7	22
20-24	16	50
25–29	7	22
30-34	2	6
Gender		
Female	11	34
Male	21	66
Race		
African American	16	50
Asian/Pacific Islander	1	3
White, Caucasian	10	31
Other	5	16
Ethnicity		
Hispanic or Latino	7	22
Non-Hispanic	25	78
Education		
Some high school	6	19
High school graduate or GED	3	9
Some college	15	47
College graduate or higher	8	25

^aRAISE, Recovery After an Initial Schizophrenia Episode

Warm respect. The Connection Program model emphasizes staff warmth and respect for clients. Interviewees (N=28) described a staff combination of friendliness, interest, patience, and sincerity as very important to their engagement. They cited experiences in which staff "take my opinion seriously" with "no judgment at all" as strongly engaging. This was conveyed by staff doing things that showed that they "listened," "really cared," were "very helpful," and would go "above and beyond." Having access to crisis services 24 hours a day, seven days a week with familiar staff members was mentioned several times. Clients (N=17) also perceived staff and program flexibility, especially regarding appointment times, locations, and late arrival, as embodying respect and as facilitating rapport and trust. One interviewee said, "They were there for me. . . . If it was just another program I wouldn't have honestly cared, I would have just disappeared. ... But ... they put the time and effort into trying to help me [and] all they ask from me is just to be better... to see how I feel.... So I did understand, like I really do got to shape it up and come in." Another recalled, "They are very kind people and very inviting, very caring, very genuine, very—like soft spoken Just their demeanor that made me feel comfortable and their intentions. Their intentions were pure, they really wanted to help me."

Program Attributes

Characteristics of the program itself also had an impact on engagement. Interviewees (N=17) described an overall positive program atmosphere where things "run smoothly, things happen as they say it will" and yet are "relaxed and flexible" with no "negative feel." More specific program attributes are described below.

CLIENT ENGAGEMENT FACTORS IN FOUR DOMAINS Individualized care

Focus on life goals Effectiveness Warm respect

Program attributes

Team structure Setting and location Medication management Active outreach

Family member influences

Promoting engagement Deterring engagement

Personal attributes

Ambivalence Self-concern Self-reliance Symptoms

Team structure. The multiservices team approach was highly engaging. Interviewees (N=12) spontaneously mentioned that being able to access multiple services through a "one stop shop" reduced strain and encouraged attendance. For example, one client said, "Knowing that there was a team available and everybody had their own, their own specific role to help me with my life . . . gave me ease of mind." A few (N=5) said they found meeting with the whole team at once could be overwhelming, especially at the beginning or when feeling unwell.

Setting and location. Interviewees described concrete attributes, such as location (N=23), setting (N=5), and transportation (N=18), as affecting engagement. How nearby, easy to get to, safe-feeling, and pleasant the program location was affected the ease with which interviewees were able to engage. Similarly, transportation was described as either facilitating or impeding engagement, depending on how stressful, affordable, safe, and convenient it was for each person. A few clients (N=4) noted that symptoms can make riding public transit and driving stressful and even prohibitive. A few (N=5) emphasized that the more institutional, hospital-like, and "psychiatric" they found the location, building, or décor, the less engaging it was, especially if they had negative associations with it, such as having been involuntarily hospitalized in the same building.

Medication management approach. Most clients (N=23) described the Connection Program model for managing medication as very engaging. A handful (N=6) commented that having medication services within the program facilitated

access and that by paying for medications not covered by insurance plans, the study reduced hassle and expense and conveyed caring.

Many interviewees (N=17) emphasized that the medication shared decision-making practices promoted engagement. They liked the fact that staff (especially psychiatrists) discussed medication concerns nonjudgmentally, saying such things as, "[The psychiatrist] works with you more, like instead of just kind of telling you what your needs are, she [says] we'll see what we can do together." Being able to be frank, to be taken seriously, and to get sincere responses were key. For example, one said, "I told them I wasn't taking my medication and they didn't press me like you [have to] take your medication or you shouldn't do that . . . but I kind of realized that I really do need it." Conversely, interviewees felt less collaboration when medication interactions felt less open: "I wish it was a little bit more compromising . . . like you get a little bit more of your say and less of their . . . agenda."

Active outreach. The Connection Program model stresses active ongoing outreach. About one-third of interviewees (N=10) commented on the relationship of outreach and engagement. They found staff outreach to be persistent, individualized, sometimes surprising, and highly effective in keeping them involved on a practical level. For some, the calls, visits, and offers of assistance also increased their desire to engage because of what outreach conveyed. For example, a client said, "They would make the effort, and I like that. Instead of waiting for me to come to them, they would come to me, call me, ask me what's wrong you know. . . . So now I like to come, and I look forward to talking with them."

Family Member Influences

Family influences interacted with the factors above, and many interviewees (N=18) described family influences as important to their engagement. Almost all of the 32 interviewees had at least one family member (usually a parent) in contact with the Connection Program team, reminding them of appointments, encouraging attendance, providing transportation, or expressing concern about their well-being. A few (N=3) reported enrolling in the Connection Program primarily to reassure "my family that I was doing something to try not to have them worry about me."

Promoting engagement. In most instances, family impact on engagement was positive and involved practical assistance and emotional support: "My mom comes with me every time. . . . I actually like her support. . . . Having my mom come makes it feel less of a struggle."

Deterring engagement. Occasionally family involvement could also be an obstacle, especially when relatives were not supportive of mental health care. For example, one client described her mother's involvement as embarrassingly argumentative with staff, saying, "I almost gave up. I was like I

actually don't want to come here anymore." Interviewees who reported family tensions (N=8) said that Connection Program staff often educated family members and helped the clients form their own opinions, listen to family members, or navigate family relationships and boundaries.

Personal Attributes

Most interviewees (N=23) described personal attributes that affected their engagement. Ambivalence about engaging in treatment was often an obstacle for some (N=11), combining worry and fear about symptoms, unfamiliar mental health concepts, stigma, an uncertain future, and past negative experiences. At the same time, self-concern regarding symptoms and functioning led some interviewees (N=10) to want services, highlighting that distress can facilitate engagement. One succinctly expressed this tension, "Really, really I didn't want to get involved with the program, but I knew it was going to better me so I had no choice but to go to the program." Interviewees described information, reassurance, patience, and focus on getting help with personal life goals as helpful in overcoming ambivalence. Some acknowledged a conscious decision: "I'm already used to the program, I just got to open myself up I guess. . . . It's just if I want to do [that]

A few clients (N=6) described self-reliance as affecting their engagement. The effect was described in two ways: self-reliance defined as taking responsibility for one's health prompted engagement, but self-reliance defined as striving to solve problems without others' help could discourage it. For example, one person said, "I was [at] a really low point where I didn't think I could really help myself. That's why I was seeking professional help and trying to use resources to the best of my ability." Another declined some services: "So far what they've offered I've just been kind of like I guess I can do it myself."

In addition, some clients (N=11) described symptoms, delusions, depression, fears, lethargy, and self-consciousness as making engagement difficult. Individual examples included sleeping a lot; being unable to attend cognitively; and feeling disoriented, irritable, or paranoid.

DISCUSSION

This study aimed to better understand the engagement experiences of clients experiencing early psychosis who were enrolled in the RAISE Connection Program. Results add to the understanding of engagement for this population in general and have several implications for services. First, prioritizing clients' life goals was fundamental to engagement. For many interviewees, engagement hinged substantially on receiving what could be considered nonclinical services, such as supported education and employment, especially during early program tenure. Although these services were built into the Connection Program model, they were more crucial than anticipated, likely because of their link to clients' personal growth (15). Second, in keeping with

other studies of engagement and retention in care (4,5,16), the results indicated that staff flexibility, mobility, patience, warmth, and stamina over time helped clients navigate ambivalence, illness, and life challenges and stay engaged with clinical services. In a similar vein, staff members' nonjudgmental active outreach conveyed caring and respect for clients, their families, and their complex situations and helped ameliorate barriers to engagement (4,8). Third, the focus of the Connection Program on shared decision making was experienced by clients as more engaging than adherence-focused clinical programs that they had attended. As in previous studies (2,16,17), staff openness to discussing concerns, especially regarding medication and even discontinuation, was described by interviewees as respectful, helpful, and adherence promoting.

These three areas—the focus on life goals, staff flexibility, and the focus on shared decision making—embody a youth-tailored, client-centered, active, and empathic program and staff approach that echo and add specificity to the growing literature on services engagement among youths with early psychosis (4,15–18). As discussed by Wilson and Deane (5), Edwards and colleagues (18), and others, such approaches can support clients in using their young-adult drive for autonomy and identity development and thereby promote engagement with services and mental health recovery.

This study's context is relevant to interpreting its results and implications. First, because interviewees were enrolled in the Connection Program, our sample excluded people who never made contact with the program. Thus the study may have been especially well suited to identifying engagement facilitators but less able to give a full account of barriers. Second, some clients conflated the parent study's clinical encounters and research encounters, and the research process may have played some unexamined role in engagement. Third, a limited number of participants who fit our four categories of interest were available for interview, and thus we did not interview all clients. Finally, the applicability of this study's results to other settings and client samples will need to be evaluated in future qualitative and quantitative work.

CONCLUSIONS

It takes considerable personal effort to approach mental health services (19), making each facet of the experience a potential barrier or facilitator to successful engagement. The Connection Program was designed to engage young people experiencing early psychosis, a group usually very hard to involve in services. In the parent RAISE-IES project, the Connection Program teams were able to achieve very high rates of client engagement and retention (11). The results of this related qualitative study help explain how and why the rates of retention were achieved and deepen our understanding of engagement for this population. The results suggest that to maximize engagement, early-psychosis treatment should provide services and staff interactions that are highly individualized, respectful, warm,

and flexible, giving prominence to clients' life goals and preferences and family member engagement. Although doing so is challenging, such services offer hope for maximizing recovery.

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