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Family Member Engagement with Early Psychosis Specialty Care

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Abstract

Aim—Family members of individuals with early psychosis (EP) play critical roles in their engagement with EP services, but family member experiences of those roles are insufficiently understood.

Methods—We conducted semi-structured interviews with 18 family members of individuals enrolled in EP services during the Recovery After an Initial Schizophrenia Episode-Implementation Evaluation Study (RAISE-IES study), to better understand their experiences engaging with EP specialty care and their roles in client engagement in services.

Results—Family members described diverse experiences with the interplay among distress regarding their loved one's illness, uncertainty engaging with program staff, and highly valued facets of the clinical program. These included ongoing family outreach and support, frequent communication from staff, program flexibility, and individualization of care. They also described varied and stressful complexities involved in providing practical assistance and encouragement to support their loved one's engagement in care. Competing responsibilities, time and resource limitations, and the intricacy of providing support while fostering autonomy impacted their roles and experiences.

Conclusions—Given key family roles for most EP clients, understanding family members' highly individual experiences and responding to them in tailored ways is necessary to best support families in helping their loved ones engage in care and recovery as well as navigate their own worry and stress. Recommendations for engaging and supporting family members are highlighted.

Keywords

Family; treatment engagement; early episode psychosis

I. Introduction

Early episodes of psychosis (EP) typically occur in early adulthood, interrupting psychosocial development. 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” (1, p 589). Work on client engagement and retention with EP services e.g., (1-4) finds that family members are key. They are often instrumental in recognizing the need for mental health care and advocating for their loved one's needs (1-11) while coping with their own distress (4-7). They also support client engagement concretely – making appointments; providing transportation, reminders, and client history; offering observations; reinforcing the ill person's goals and treatment plans (1). Such roles are both rewarding and highly taxing (1-12), especially when the ill person is a minor.

Therefore, EP programs must actively engage and support family members as well as clients (13). While client and family-centered approaches are increasingly common, family members of people experiencing EP still often feel uncertain, unsupported and even disregarded by mental health providers and systems (1, 4, 6, 14, 15). In response, EP coordinated specialty services call for actively engaging and assisting family members (13) in ways that attend to caregiving stresses, cultural and developmental issues, and individual experiences with a collaborative person-centered approach (1, 9, 13, 16, 17).

Nonetheless, family members' actual experiences with these services are not well documented. To address this gap, we interviewed family members of individuals receiving EP specialty care to identify positive and negative factors that shape family members engagement and their role in their loved one's use of its services.

II. Methods

Study Context

Participants were family members of individuals enrolled in the Recovery After an Initial Schizophrenia Episode - Implementation Evaluation Study (RAISE-IES) in New York City and Baltimore, Maryland during 2012-2013 (13-15). RAISE-IES provided up to two years of coordinated specialty care (“the Connection Program”) to clients experiencing EP, combining best practices (8,9) of shared decision making (10), critical time intervention (7), patient-centered medication management, counseling, education and employment assistance, social skills training, family engagement and support, crisis services and outreach in a team format (13). Family-specific aspects of the Connection Program included ongoing family engagement, multi-family psychoeducational meetings, “family night” activities, and as-needed family consultation. Our research team is familiar with previous work regarding family engagement in EP care, but did not approach this study from any a priori theoretical model of family experiences. Rather we sought to ground it in the experiences of interviewees directly.

Eligibility, Recruitment, and Interviews

Procedures were pre-approved by the NY State Psychiatric Institute and University of MD IRBs; NIMH Data and Safety Monitoring Board provided oversight. Eligible individuals were a parent (or parental role), sibling, spouse, significant other, or family-like friend of a RAISE-IES participant. We sought to recruit half family members of well-engaged clients and half family members of clients not well-engaged with Connection services, as rated by the Connection Program team leader, for sample breadth.

For recruitment, clients were invited to suggest a family member for us to contact, or to freely decline, during a routine research appointment. We approached potential participants in person (waiting room) or via their preference of phone or email. One family member heard about the study and volunteered directly. Interviews were conducted after full informed consent by one of four trained interviewers.

Interviews asked participants about their engagement with the Connection Program, influencing factors, views of the program and staff, perceptions of their ill relative's experiences, and their roles in their relative's program engagement. Both facilitating and impeding engagement factors were queried. Participants received \$15 for their 30-60 minute audio-recorded interview.

Final Sample

The final sample (Table 1) comprised 9 family members of well-engaged clients and 9 family members of clients not well engaged in services; two reference clients were minors. Most (13/18) interviews were in person, 5/18 took place by phone at the interviewees' request. Nine additional family members were considered; 5 declined, 3 could not be reached, and the sample quota for one was filled before she was scheduled.

Data Analysis

We used inductive analysis (18) to capture participants' experiences and perceptions. Specifically, we used thematic analysis as distilled by Braun & Clarke (19) to familiarize ourselves with the data; generate initial codes; refine codes; organize the data into potential themes; review, develop and name themes; and organize them in relation to each other to address the research question. First, interview audio-files were professionally transcribed. Then, study RAs made preliminary memos of engagement experiences, facilitators, barriers and issues while proofreading, from which the team drafted an initial coding list after discussion; examples: "Team was engaging: competent," "Family help in client attending."

Second, two team members independently coded each transcript (using Atlas.ti 7.2) and compared results. Differences were minor, with occasional identification of a new code. We discussed these to consensus in both pair and full-team reviews, iteratively consulting the data, to make final refinements to the code list. Each transcript was then re-coded with the final code list.

Third, the first author integrated the codes/data into potential themes focused on engagement roles, obstacles, and facilitators. These were further developed with the full research team, including polishing theme definitions and making minor adjustments to coding. Then, led by

the first author, the team discussed relationships among themes and codes, using Atlas.ti “network view.” This yielded four major interrelated themes, shown in the Results. Lastly, we compared data between family of well-engaged vs poorly-engaged clients for meaningful differences.

III. Results

Below, the first three themes address participating family members’ experiences engaging with the Connection Program. The fourth describes their experienced roles in their relative's treatment engagement with EP. Note that we did find no meaningful differences in the data of interviewees of well engaged versus poorly engaged clients.

A. Direct Family Engagement: Family Distress and Uncertainty about Engagement

Interviewees described considerable distress and struggle regarding their relative's illness. They often had “no idea what to do” (multiple interviews), were afraid, and worried about “...what did I do wrong? What could I have changed?” (Interview 392). One parent said,

... to me it was like my son was dying and the child I had was dead and there was this new person so it was devastating, it was like the worst thing I've ever gone through. (Interview 162)

This distress shaped their Connection Program contacts over time:

In the beginning... we really didn't know what to do. We didn't trust anybody.... we were kind of like skeptical and ... and all this personal information that you have to give out.... We were kind of like ‘oh my God, *is* this something good?’ (Interview 928)

Interviewees were relieved to meet Connection Program staff, recalling reactions like “this just sounds like an answer to [our] prayer” (Interview 271). Yet, many remained uncertain whether and how to talk with staff about their concerns, saying “I didn't know that I could do that” (Interview 415) and “I'm not sure how much they want to hear from me” (Interview 338). Many wished for more pro-active communication from program staff to reduce family uncertainty.

B. Direct Family Engagement: Program Outreach to Family Members

The Connection Program included active family outreach: phone calls, mailings, meetings, informal contacts, invitations to events, home visits, etc. Interviewees found this engaging, especially because outreach continued beyond intake. They found staff-members’ warm, friendly, supportive manner set them at ease. Further, staff responsiveness to family needs helped interviewees stay connected. These qualities conveyed that the staff “really cares” and were willing to go “above and beyond” to help, which increased family members trust and value of the program. One said, “I'm happy that she's [daughter] in this study because... people genuinely seem to care. I get this aura that they care and they check up on her.” (Interview 141). At the same time, wanting even more outreach from Connection staff was a strong refrain from both family members of well-engaged clients and poorly engaged ones,

“...because sometimes we can be so involved in our daily routine life that we may need help to get more involved” (Interview 437).

Comments about Connection Program multi-family support meetings provide additional depth to this “yes but more” message. A few interviewees were not aware of the meetings despite staff report of widespread and repeated communication about them. Others had never or very rarely attended due to scheduling or other barriers (see below). Of those who had, meetings were experienced as helpful and engaging when they felt accessible and supportive; off-putting when they seemed inaccessible or stressful. Many liked the “chance to hear other parents”, informal contact with staff, new information, and discussing concerns. One interviewee (338) found their first meeting unpleasantly dominated by a distressed parent and did not return. Additionally, most interviewees wanted more direct services for family members, including individual counseling.

C. Direct Family Engagement: Program Characteristics

Interviewees described the Connection Program's structure as strongly influencing their engagement. Facets of the Program promoted engagement when they eased, reassured, validated, or clarified something for an interviewee, and impeded it when they increased stress, confusion, or hassle.

1. Program Flexibility & Individualization—The Connection Program's flexibility and tailoring to client and family needs was engaging. This included flexible meeting locations, scheduling, clinician access, understanding when life events interrupted attendance, and staff openness to diverse views and changes in needs or preferences. One prototypical example:

They are very flexible.... That's what I love about them. They don't say well, we have to reschedule him because he didn't make it... no, they [say]...as long as he makes it here, we're here, we'll be here. (Interview 518)

The Connection Program's model of medication management was the most common example interviewees detailed regarding flexibility, individualization, and engagement. First, interviewees praised the Program's providing medications onsite, without cost for uninsured clients, as stress-reducing. Second, they found the Program's family-inclusive shared decision making to be engaging and reassuring: “It makes a big difference having someone to actually sit down with, a doctor to talk to ... about his medication. Talk about the goals, talk about where you want him to be” (Interview 528). One parent detailed how this helped in a worrisome situation:

Recently he'd [son] been wanting to get off his medicine and I knew eventually he's probably go off anyway so I thought he might as well do it under controlled conditions. And so he had a team meeting, he set it up and I went and we talked about it, and they came up with a plan for him to go off and meet with them [regularly]. And so he's been off like five weeks or so, and he's struggling a little bit now with some depression. And he said he was going to go Wednesday and talk to them...about it. (Interview 162)

2. Program Effectiveness—Seeing their relative feeling and functioning better is the reason families engage with the Connection Program. A handful of interviewees made explicit what others implied: seeing results supports engagement. They noted effects on their ill relative's engagement (e.g., “She feels supported and comes out feeling better after she meets with [staff]” Interview 600) and on their own engagement (e.g., “When I noticed that she was being helped, I realized that it was a good program” Interview 415).

3. Competing Priorities and Program Logistics—Family engagement with the Connection Program was often complicated by employment schedules, caring for children, distance, finances, and the physical or mental health concerns of the interviewed family member or other relatives. One interviewee said, “So, there's more there that we could've taken advantage of and didn't... we have just other things come up” (Interview 271). Despite flexibility, program logistics impact family engagement, including location, transportation, physical space characteristics, and program or schedule changes. For example, several described giving bus money to their loved one to get to the Connection Program but then not having transit money to attend a family meeting.

D. Family Member Roles in Client Engagement

Interviewees reported substantial practical and motivational roles supporting their ill relative and his/her engagement in Connection Program services.

1. Practical Assistance—The most common roles they described were also the most concrete: providing transportation, appointment and medication reminders, helping staff contact the client, helping the client articulate needs and preferences, and supporting the client's goals and treatment plan. One mother described it this way:

“[I say] you know you got an appointment tomorrow. [He says] ‘I know,’ and then when you go to wake him up it's like ‘I'm going, I'm getting up.’ I have to constantly make sure he gets up to get down here to do what he needs to do.”
(Interview 518)

Interviewees not involved with the client's day-to-day (e.g. if living apart) had much smaller practical roles. One said, for example, “it's hard for me to tell [how much daughter is engaged]There are details I can't really like observe you know like from a distance” (Interview 715).

2. Encouragement to Engage—Intertwined with the practical, interviewees described encouraging their ill relative to engage with the Program: pointing out positive aspects of it, urging attendance, reminding the client of things they liked in the program, and expressing hope for and belief in the client. One parent (Interview 141) articulated how intricate this role can be:

I had to convince [daughter] of the benefit of the program and how it can help her.... [I said] ‘let's not go in with a closed mind, let's go in open minded and if you're not feeling it, we'll stop it and we'll leave.’ And so I really tried to convince [her] this was her decision because she's an adult now. So I try to remove myself from that process, but I needed to get her *to* the water to drink, if that makes any sense?

3. Autonomy Dynamics—As reflected above, most interviewees, especially parents, wrestled with wanting to foster their loved one's independence while deeply wanting to help and protect them. For example, Interviewee 338 wanted her son to enroll but felt “it's not really my business because he is twenty, he's of age,” so instead of talking to staff directly she “provided his cell phone number.” Another (Interview 600) limited her contact with staff out of concern that it “would take away some sense of confidentiality that's important to [son].” Others grappled with the dynamic very differently:

... he was like 21 or 22 when this started and they [Connections staff] are not allowed to do...anything without his consent, which, I mean, he's *sick*.the patient shouldn't be making decisions.... in a case like ours like we [parents] should be making decisions. (Interview 242)

Connection Program staff could not eliminate these tensions, but interviewees reported appreciating staff listening, respecting, and engaging with them in its complexity.

IV. Discussion

This study confirms and extends existing literature on family experiences with early psychosis by documenting the experience of family members with the Connection Program, emphasizing the range and diversity of family member experiences and needs. Some themes were universal – such as appreciating the Program's ongoing active outreach, warmth, and flexibility. However others, such as autonomy dynamics, varied sharply across interviewees. Similarly, interviewees commonly called for additional family support but differed markedly on what forms they preferred.

This study's results corroborate previous research that family engagement is crucial to EP coordinated specialty care (17, 20-24) regarding both practical and emotional support to clients (25). They also underline family members own distress and needs (26, 27). Further the results validate that the RAISE-IES model of active on-going family outreach, support, and inclusion (while navigating client autonomy and privacy) is effective (13, 15, 26, 28), while also highlighting the importance of individual tailoring within the model.

These themes echo client EP treatment engagement findings (15, 23), which also emphasize the importance of individualized empathic care while fostering autonomy (29). Much of that literature has focused person-level variables rather than program attributes (23), so this corroboration is important.

Additionally, these interviews illuminate that even the family-active RAISE-IES model (13-15) is not enough to fully meet family member needs. Interviewees wanted even more communication, invitation and engagement options, and even direct counseling services for family members. Some programs may grapple with whether or how to provide direct family care (versus referring out) while maintaining focus on the individual with EP. Others may consider partnering closely with community-based family-support organizations. Regardless, our results reinforce that family member outreach and support is core to EP clinical care. Specifically, our interviews indicate that clear and *repeated* information and invitations for family members to engage with the program/staff are needed and would be welcome.

Family members opposed to psychiatric treatment or entirely disengaged from the Connection Program are not represented in our sample, although we were open to interviewing them. This limits the data, but also focuses it on the most common experience: family desire to find effective services for their loved one coupled by uncertainty and worry. Also, while RAISE-IES and the Connection Programs engaged Spanish-speaking family members, everyone in this sub-study spoke English primarily. Therefore our sample is missing the perspectives of primary Spanish-speaking family members.

Overall, these interviews underline the centrality of warm, active, individualized care in EP treatment that includes family in individualized ways. To serve clients and families well, EP staff need the resources and time to develop and maintain truly person-centered and family-centered care.

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Table 1

Interviewee Demographics

	Family of Well-engaged clients n=9	Family of poorly-engaged clients n=9	Totals
Age			
25-34	1	1	2
35-44	0	2	2
45-54	1	4	5
55-64	6	1	7
65 +	1	1	2
Gender			
Female	5	7	12
Male	4	2	6
Race			
African American	3	5	8
Asian, Pacific Islander	2	2	4
White, Caucasian	4	2	6
Other	1	0	1
Ethnicity			
Hispanic / Latino/a	2	2	4
Non-Hispanic	7	7	14
Highest Education			
Some High School	0	1	1
HS Grad / GED	1	0	1
Some College	1	1	2
College Grad or higher	7	7	14
Family Member Role			
Mother	5	6	11
Father	3	2	5
Sibling	1	0	1
Cousin	0	1	1