

Disengagement From Care: Perspectives of Individuals With Serious Mental Illness and of Service Providers

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Objective: This study sought to describe reasons for disengagement from services and practical guidelines to enhance engagement among individuals with serious mental illness and high need for treatment. **Methods:** Qualitative interviews were conducted with 56 individuals with serious mental illness and 25 providers recruited from a larger project that used administrative data to identify individuals with serious mental illness who had disengaged from care. Individuals with serious mental illness and providers described reasons for disengagement and effective provider engagement strategies. **Results:** Individuals with serious mental illness and providers differed in reported reasons for disengagement. Reasons reported by individuals with serious mental illness included services that were not relevant to their needs, inability to trust providers, and a belief that they were not ill. Providers cited lack of insight, stigma, and language and cultural barriers as common reasons for disengagement. Strategies for increasing engagement were grouped into a framework of acceptable, accessible, and available services. Acceptable services reflect a partnership model that fosters support and instills hope; accessible services minimize barriers related to transportation and intake procedures; and available services address recovery needs in addition to treatment of general medical and psychiatric problems. **Conclusions:** Individuals with serious mental illness and providers often do not agree on reasons for seeking care. The framework of acceptable, accessible, and available services identifies opportunities for providers to adjust practices and maximize engagement in services among individuals with serious mental illness who are in high need of treatment. (*Psychiatric Services* 64:770–775, 2013; doi: 10.1176/appi.ps.201200394)

Large numbers of individuals with serious mental illness have difficulty accessing and remaining in care. The National

Comorbidity Survey found that in the previous 12 months, only 38.5% of individuals with serious mental illness had received stable treatment

(1) and only 15% received minimally adequate care (2). Several studies that surveyed individuals with serious mental illness indicate that up to 50% either are not engaged in care or have discontinued recommended services (3–5). Individuals are especially vulnerable to service discontinuation when initiating new services or transitioning between levels of care, for example, from acute inpatient to community-based care (6,7). Failure to receive care has been associated with repeated symptom exacerbations and with hospitalizations, homelessness, and incarceration (4,8,9).

Kreyenbuhl and others (4) and O'Brien and colleagues (5) reviewed predictors of treatment disengagement, including younger age, racial-ethnic minority status, co-occurring substance use disorder, symptom severity, and poor insight and awareness. Until recently, however, few studies described the subjective experiences of individuals with serious mental illness who disengage from care. Priebe and others (10) interviewed individuals receiving assertive community-based care and identified themes related to disengagement, including the wish to be independent and able, poor therapeutic relationships, and loss of autonomy related to the need for medications. Padgett and others (11) interviewed individuals with serious mental illness who were participating in a novel housing program after having been homeless. On the basis of the interviews, they

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generated a grounded theory of engagement in services that included person, system, and program factors. Person factors included mental illness severity and substance abuse, and system and program factors included perceived kindness, pleasant surroundings, access to one-on-one provider interactions, and fewer rules and restrictions.

In another qualitative interview study, Green and others (12) followed individuals with serious mental illness over time and found that recovery was associated with the development of consistent relationships with providers who supported “normal” rather than “mentally ill” identities. Similarly, qualitative studies by Ware and others (13) and Angell and Mahoney (14) have expanded definitions of treatment alliance to emphasize the importance of individuals feeling a sense of personal connectedness with providers.

This study used qualitative data to extend previous work and suggest practical guidelines providers can use to increase engagement among individuals with serious mental illness. We interviewed individuals who were identified by a quality assurance program managed by a state regulatory authority. The program targeted individuals with serious mental illness who had a high need for treatment but who had disengaged from care. We also interviewed providers who worked with this population. By collecting data from the perspectives of both individuals and providers, we hoped to gain a broader understanding of why individuals disengage from services and to propose effective strategies for improving engagement.

Methods

The study recruited individuals with serious mental illness who had high need for treatment but who had recently disengaged from services as well as providers working with this population. The participants with mental illness were recruited between July 2010 and October 2011 from individuals identified in the New York City Mental Health Care Monitoring Initiative, a quality assurance project designed by New York City and State

mental health oversight agencies to better understand service gaps and engagement opportunities for individuals with serious mental illness. The Care Monitoring Initiative used Medicaid claims and other secondary data to identify individuals with serious mental illness who may not have been engaged in adequate and appropriate services. Populations of individuals in high need of treatment were defined on the basis of prior service use, and notification flags were created to identify individuals who may not have been receiving needed services or who had used excessive amounts of acute behavioral health services (15–17).

Care monitors employed by a managed behavioral health organization contacted providers who previously served the identified individuals to review service history data and confirm whether the individual was currently engaged in care. During an 18-month period in 2010–2011, over 25,000 individuals with serious mental illness who met at least one of the defined flags suggesting disengagement from community-based services were identified. Care monitors reviewed treatment plans with providers for 7,623 individuals and confirmed that 3,504 were not engaged in services.

Recruitment and data collection

Individuals with serious mental illness. Of the 3,504 individuals who were not engaged in services, 2,361 met the following additional eligibility criteria for qualitative interviews: age 18–65 and a history of criminal justice involvement or mandated outpatient mental health services. These populations are among the most vulnerable and underserved in community mental health systems (18,19). They also encompass young adults between 18 and 24 years old, another vulnerable population.

Each month during the recruitment period, the managed behavioral health organization provided the research team with the names of 50 to 100 eligible individuals. Medicaid claims data were reviewed to identify providers who had served each eligible individual. Research staff contacted the provider to request that a

provider staff member present the project to the individual at the next contact. Providers were willing to attempt to contact the individual and present the study for 971 cases and successfully contacted 126 individuals. Providers presented the study to these 126 individuals during the 16-month recruitment period, and 77 granted permission to be contacted. Of these, 56 provided written informed consent after study procedures were fully explained and completed interviews. Two interviewers from the research team attended each interview, which was designed to last 60 to 90 minutes and was conducted at a convenient location in the community or on inpatient units for individuals who were hospitalized when recruited.

The research team developed a qualitative interview guide in weekly meetings during a three-month planning period. Qualitative questions prompted individuals with serious mental illness to describe interactions with providers, experiences accessing services in criminal justice and mental health settings, common reasons for failure to engage in or remain engaged in services, and strategies for use by providers to increase engagement. The schizophrenia outcomes modules (20) were used to collect self-reported demographic data and descriptive information regarding housing, legal problems, diagnoses, and mental health treatment.

Providers. Research staff also recruited providers working at agencies serving individuals with serious mental illness who had disengaged from services. The staff obtained the names of the agencies from the Care Monitoring Initiative and contacted agency directors or supervisors to request permission to interview staff. Research staff purposively recruited providers with various clinical roles, including intensive case managers, social workers, therapists, and clinical supervisors. Twenty-one agencies were contacted, and 25 providers from 14 agencies provided consent and completed interviews. Twenty-one (84%) providers were female, and four (16%) were male. The sample included three (12%) bachelor's-level case managers and 22 (88%) individuals with master's-level

Table 1

Characteristics of 56 individuals with serious mental illness who had disengaged from care

Characteristic	N	%
Gender		
Male	37	66
Female	19	34
Race-ethnicity		
African American	31	55
Hispanic	14	25
Caucasian	4	7
Other	7	13
Marital status		
Never married	46	82
Married or living with partner	8	14
Divorced or separated	2	4
Predominant housing in past month		
Independent living	24	44
Community residence	16	28
Inpatient or institutional care	13	23
Homeless	3	5
Current mental health treatment		
Inpatient	13	23
Intensive specialty Clinic or private practitioner	25	45
None	14	25
Previous mental health treatment		
Outpatient clinic	48	86
Emergency visit	47	90
Continuing day treatment	34	61
Inpatient	52	93
Case management	39	70
Assertive community treatment	13	23
Court-ordered outpatient (assisted outpatient treatment)	12	21
Psychiatric diagnosis (self-report)		
Schizophrenia or schizoaffective disorder	35	63
Bipolar disorder	30	54
Other	12	21
Unknown	5	9
Lifetime arrests		
0	2	3
<10	25	45
≥10	18	32
Data missing ^a	11	20

^a Young adults (ages 18–24) without known criminal justice history were not asked about arrest history.

or doctoral training. With the exception of one interview conducted at an agency, provider interviews were conducted over the phone and designed to last 60 minutes. Providers

were asked to describe their experiences working with individuals with serious mental illness who frequently discontinue services, common reasons for failure to engage in or remain engaged in services, and strategies to increase engagement.

Data analysis

The study was reviewed and approved by the research institute's institutional review board. All interviews with individuals and providers were audiotaped and transcribed verbatim for analysis. The research team used a thematic analysis approach that is based on the work of Miles and Huberman (21) and used the Atlas.ti 6.2 software system (22) to organize and analyze interview data. During weekly meetings, the research team reviewed transcripts and defined codes related to access to and engagement, disengagement, and reengagement with services. Code lists for individual and provider interviews used similar definitions. An iterative process was used, and codes were refined during the weekly team discussions.

After complete code lists were developed, three researchers coded the interviews. Reliability across researchers after blinded double-coding of a 10% sample of text was 83% for both client and provider interviews. Coding discrepancies between researchers were subsequently resolved in consensus discussions. The first author reviewed code reports and identified themes related to individual and provider perspectives on disengagement and to strategies to increase engagement. Strategies were grouped further into acceptable, accessible, and available services. The first author subsequently reviewed code reports to complete a content analysis documenting the numbers of interviews in which individuals and providers mentioned specific themes regarding strategies for improving engagement.

Results

Table 1 describes demographic and treatment characteristics of the 56 individuals who completed interviews. Their median±SD age was 31±12, and 20 were between 18 and 24 years old.

Individual perspectives on disengagement

Services not meeting needs. The reason most commonly reported by individuals for disengaging was that services were not relevant to their needs (N=17, 30%). Some individuals linked this observation to symptoms: "Some programs, I just don't find them suitable to my needs. . . . The activities are irrelevant for my disorder." Most spoke more globally about irrelevant programming. One client stated, "They referred me to a program at [facility name], and I've been there already. All they do is just sit around, talk, and draw. I didn't go because I didn't want to do the same thing." Another reflected, "I just got aggravated, because it didn't seem like the issues that I was having, anyone was really addressing them."

Difficulties with relationships and trust. Individuals also identified themes related to relationships with treating clinicians as reasons for disengagement. Sixteen individuals (29%) described experiences with providers whom they perceived as critical or negative: "Some doctors can be really the finger pointer, [doing nothing] other than giving you orders. I'd rather have suggestions, so when you start pointing your finger and telling me [what to do], I lose interest quick in people like that, so I just never went." Another individual reported, "One therapist used to say things, like, criticize me. I didn't like that. She used to criticize, say that I'm not trying to do the right thing. She wasn't giving me enough credit at all about nothing I did."

Eleven individuals (20%) noted lack of continuity with providers as a reason for disengagement. One individual reported, "Every time I get close to somebody, they just up and disappear. So I said . . . 'We're going to start talking about my problems, and then what? Two months later she's going to be gone?' That's when I said it isn't worth it." Another noted, "It's very hard to develop a rapport with a doctor, because you don't know how long they're going to be there." Twelve (21%) individuals insisted they had no mental health problems requiring treatment, and only two (4%) mentioned stigma as a reason

for disengagement. Individuals did not identify themselves as mental health patients and felt neither the burden of seeking care nor the negative consequences of being labeled.

Provider perspectives on disengagement

Coping with an illness. Whereas individuals with serious mental illness described disengagement in terms of service needs and relationship issues, provider reports reflected attitudes regarding individuals' difficulties coping with an illness. Nineteen providers (76%) described stigma as an impediment to engaging in services. One said, "The stigma from the community about having a mental illness . . . nobody wants to be thought of as crazy. It can keep you from being employed, which can keep you from feeding yourself, so that's number one is the stigma." Providers (N=17, 68%) also described lack of awareness of illness. "If they have no insight, there is really no helping them at this point, and if I can't really help them, I would have to refer them [to another provider]," according to one provider. Another noted, "Then you have your clients who really don't want to come. They just can't be bothered. They don't believe they have a mental illness, and they're axis II, so after a while they just drop out and we close their cases." In addition to identifying stigma and lack of awareness, which are patient-level issues, providers (N=7, 28%) also identified the system-level issue of a lack of continuity with clinicians as a reason individuals disengage from services.

Unstable support systems and logistical barriers. Providers (N=16, 64%) commonly identified family and cultural attitudes as barriers to accepting services. One provider noted, "A lot of times it's really not the client that has issues [with receiving services], it's the family members. Maybe it's the mother, or a sister, they feel 'Why is the client needing these services?' They don't see the reason why." Providers (N=21, 84%) also described transportation barriers (N=21, 84%) and changes in living arrangements or unstable housing (N=10, 40%) as commonly contributing to individuals' disengagement from services.

Strategies to increase engagement

Table 2 lists strategies to increase engagement identified by individuals with serious mental illness and providers. The strategies are grouped by acceptable, accessible, and available services.

Acceptable services. Fifteen individuals (27%) described providers who foster engagement as caring and noncritical. One individual said, "You want to know what makes me stay. Well, for me, it was the constant caring, the constant knowledge that came out of these people. It was like I find that if people are sincere and they really want to help you and they try, you can see that." Individuals (N=12, 21%) also endorsed a recovery approach. "They're not just listening to me," said one. "They're trying to help me to become a better functional person. I feel that they're serious in their desire to help me do the things I want to do."

Providers (N=15, 60%) also reported that clinicians with caring, noncritical attitudes were more likely to engage individuals. "It has a lot to do with having respect for the client and treating our clients like a person and not just somebody with a mental illness," said one provider. Another noted, "First it's listening to the patient. You can determine what is going to help them, and people like people to listen to them. One thing that helps me keep people engaged is just listening to what people have to say." Providers were more likely to describe approaches that include psychoeducation (N=13, 52%) and client choice (N=12, 48%). One provider noted, "The way to engage a client is to ask them 'What it is you think is your problem, or what problem or what issue do you think you have at this moment that I can work with you on?'"

Accessible and available services. Both individuals (N=13, 23%) and providers (N=17, 68%) endorsed the importance of transportation assistance, and providers emphasized flexibility of scheduling, both in time and place (N=17, 68%). A majority of providers (N=23, 92%) endorsed working with families to improve engagement, although none of the individuals endorsed family interventions.

Individuals noted the importance of help with activities outside treatment, including assistance structuring free time to avoid maladaptive behaviors such as substance use (N=12, 21%), and job training or assistance with entitlements (N=10, 18%).

Discussion

There are several evidence-based care coordination practices that improve service engagement for individuals with serious mental illness (23–29), but significant numbers of individuals still do not receive adequate care. This study focused on individuals with serious mental illness who had a high need for treatment and a confirmed pattern of discontinuing services, many of whom also had significant criminal justice involvement. Despite having established histories of disengagement, only 27% (N=15) of individuals acknowledged having been unwilling to participate in services. A majority endorsed the value of services but cited multiple reasons for disengaging. Many did not see themselves as ill, rejected notions of chronicity, and preferred to use behavioral health services on an "as needed" basis.

The findings from this study indicate that individuals with serious mental illness and providers working with them can have markedly different perspectives regarding reasons that individuals present for services. Providers should not assume that every individual is seeking treatment for an illness, and initial engagement efforts should aim to identify and clarify the individual's perceived needs (both immediate and long term) and understanding of the circumstances leading to the contact. Individual narratives in this study resembled those reported by Pescosolido and others (30), which described individuals who chose to seek care and others who used services only when coerced—via legal means or by well-intentioned family or support systems—or had unclear motives and were "muddling through" the mental health system.

Individuals and providers also differed in their perspectives regarding engagement. Providers underscored the importance of "breaking through the denial" and working through

Table 2

Strategies identified by individuals with serious mental illness and providers to increase engagement in mental health services

Strategy	Individuals with serious mental illness (N=56)		Providers (N=25)	
	N	%	N	%
Acceptable services				
Offer caring, noncritical listening	15	27	15	60
Employ hopeful, supportive, and strengths-based approach	12	21	12	48
Explain and educate client about services and illness	5	9	13	52
Emphasize partnership and client choice	3	5	12	48
Accessible services				
Transportation assistance	13	23	17	68
Flexibility (extended clinic hours, unscheduled appointments, and meetings in community)	8	14	17	68
Communication with other providers and facilitation of linkages	0	—	16	64
Available services				
Help client structure time outside treatment	12	21	3	12
Assist with job training or entitlements	10	18	6	24
Offer individual therapy (as opposed to only group therapy)	8	14	2	8
Provide peer supports or peer-oriented therapy	6	11	5	20
Provide family or culturally sensitive therapy	0	—	23	92

psychological conflicts, whereas individuals were more attuned to interpersonal aspects of relationships with providers. Individuals felt engaged when they perceived that their provider was listening carefully, valued the individual's overall well-being, and supported a strengths-based partnership. This perspective is described in the literature on recovery-oriented and shared decision-making strategies (31–36) and is also consistent with Ware and others' (13,37) description of connectedness, which involves the experience of a "common human-ness" in therapeutic relationships. Engagement should not be viewed as an event involving an individual's decision to adhere to treatment recommendations, but rather as a process that unfolds in the context of a helping relationship.

The contrasting perspectives of individuals and providers regarding

the relevance of mental health services may help to explain the high rates of disengagement in this population and also suggest that there are many roads to successful engagement. Both individuals and providers valued programs with a range of available and accessible services, suggesting that medical and recovery-oriented services can be complementary (38,39). Within this context, engagement is a dynamic process in which an individual's circumstances and motivations create a perceived need that aligns with specific services and treatments. Effective providers broker this process by becoming trusted expert collaborators and by helping individuals clarify their needs and make choices. Corrigan and others (40) described this process and proposed that the notion of treatment adherence should evolve to emphasize individual self-determination. Future

efforts should identify strategies that increase individual empowerment, self-efficacy, and self-determination and examine whether and how these characteristics lead to specific patterns of engagement and service use in this population.

There were limitations to this study, including the potential for selection bias related to our recruitment strategy. Participants were purposively, not randomly, selected, and only individuals who were willing to participate were interviewed. We also targeted high-need subgroups (young adults and individuals with a history of mandated outpatient mental health treatment or criminal justice involvement). The study sample, nevertheless, represents an important population of individuals in need of outreach and engagement. Finally, the project's cross-sectional approach also did not allow for tracking experiences longitudinally as has been done effectively in other studies (12).

Conclusions

Qualitative data can reveal subtle and dynamic processes that influence quantifiable risk factors and outcomes. The data from this study described important perceived needs and barriers to care among individuals with serious mental illness along with strategies to improve engagement. The framework of available, accessible, and acceptable services should be useful to providers looking to maximize engagement in services by highly vulnerable individuals.

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