Engagement and Retention in Services among Formerly Homeless Adults with Co-Occurring Mental Illness and Substance Abuse: Voices from the Margins

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This qualitative study analyzed 72 interviews with 39 formerly homeless psychiatric consumers to develop a grounded theory model of engagement and retention in mental health and substance abuse services. Person-centered themes included severity of mental illness and substance abuse (the latter also conflicting with programmatic abstinence requirements). System-related themes inhibiting service use included program rules and restrictions and a lack of one-on-one therapy.

Those promoting service use were acts of kindness by staff, pleasant surroundings, and the promise (or attainment) of independent housing. Implications of these findings are discussed in terms of integrating consumers’ opinions about services to enhance treatment engagement and retention.

Keywords: homeless, severe mental illness, substance abuse, service utilization

Engagement and retention, regarded as key factors in mental health recovery, remain among the greatest challenges confronting providers seeking to help the severely mentally ill (Blackwell, 1997; Brunette, Mueser, & Drake, 2004; Calsyn, Klinkenberg, Morse, et al., 2004; Laudet, Magura, Cleland, et al., 2003; Watkins, Shaner, & Sullivan, 1999). When such individuals have co-occurring substance use disorders, the odds of treatment dropout are even greater (Brunette et al., 2004; Minkoff, 2001). Perhaps hardest to reach and retain are homeless mentally ill adults, where trust-building is considered essential to successful engagement (Rowe, Fisk, Frey, & Davidson, 2002). Given a pattern of cycling in and out of services before finally engaging (Hopper, Jost, Hay, Welber, & Haugland, 1997; Watkins et al., 1999), it is important to understand consumers’ views on the services designed to help them.

In this report, we focus on engagement and retention in mental health and substance abuse treatment services using qualitative interviews with 39 formerly homeless mentally ill persons who participated in the New York Services Study (NYSS). In keeping with an inductive perspective (Glaser & Strauss, 1967), we used grounded the-
ory analyses to identify key themes in engagement and retention in services.

**Engagement and Retention among Homeless Persons with Severe Mental Illness**

Both the intensity and duration of engagement are considered strong predictors of treatment success in general (Fiorentine, Nakashima, & Anglin, 1999) and among the homeless mentally ill in particular (Cohen, Onserud, & Monaco, 1993; Pollio, Spitznagel, North, Thompson, & Foster, 2000). Yet there is little consensus on how engagement is defined, with most indices conflating cause and consequence, e.g., treatment attendance, working alliance, and client satisfaction (Dearing, Barrick, Derme, & Wallitzer, 2005; Hser, Evans, Huang, & Anglin, 2004; Yatchmenoff, 2005). While “engagement” implies mutuality between provider and client (Yatchmenoff, 2005), “retention” derives its meaning from provider recommendations and clients’ acceptance or rejection of them (Brunette et al., 2004; Calsyn et al., 2004; Klinkenberg & Calsyn, 1996).

Engagement and retention present a greater challenge when severe mental illness co-exists with homelessness and substance abuse (Blackwell, 1997; Brunette et al., 2004; Calsyn et al., 2004; Laudet et al., 2003; Minkoff, 2001; Rowe et al., 2002; Watkins et al., 1999). Treatment and services for these individuals typically entail hospital stays lasting days or weeks at a time, living in residential care facilities for prolonged periods, regular attendance in outpatient treatment, and taking medications with powerful side effects. The intensity and duration of commitment expected of such patients is extremely high—few if any medical conditions require as much effort or loss of autonomy.

A “continuum of care” approach dominates the landscape of services for the homeless mentally ill (Allen, 2003; Greenwood, Schaefer-McDaniel, Winkel & Tsemberis, 2005; Herinckx, Kinney, Clarke, & Paulson, 1997; Monahan, Redlich, Swanson et al., 2005; Nose, Barbi, & Tansella, 2003). At entry level, such programs typically offer temporary housing in dormitory settings with the requirement that the person will become and remain clean and sober, attend treatment programs, and obey house rules regarding personal hygiene, curfews and proper behavior (Tsemberis, Gulcur, & Nakae, 2004). In addition to these “terms of engagement,” compliance with prescribed medications is considered essential to progressing along the continuum toward independent living (Klinkenberg & Calsyn, 1996).

Empirical studies exploring non-retention in mental health services reveal the significance of individual characteristics such as male gender, co-occurring substance abuse, low motivation for change, and rejection of the psychiatric diagnosis (Brunette et al., 2004; Koekkoek, Van Meijdal, & Hutscheaekers, 2006; Laudet et al., 2003; Nose et al., 2003). Successful programmatic approaches are low-demand, use assertive outreach and seamlessly integrate substance abuse treatment (Brunette et al., 2004).

Missing from services research on the homeless mentally ill are consumer perspectives in their own words (Everett & Boydell, 1994; Ware, Tugenberg, & Dickey, 2004). With this in mind, we asked participants in this qualitative interview study to tell us about their experiences as service recipients over their life course. Our research questions were:

1. What enhanced or impeded participants’ entering and remaining in treatment for mental illness and substance abuse?

2. How (if at all) did their life histories of homelessness affect services use?

3. What salient events stand out in their accounts as positive or negative aspects of service utilization?

**Methods**

**Sampling and Recruitment**

The sample was drawn from a group who had completed participation in an earlier experiment (1998–2002), entitled the New York Housing Study (NYHS). In the NYHS, 225 participants were randomly assigned to “housing first” vs. “treatment first” conditions to assess differences in these approaches for homeless mentally ill individuals (Tsemberis, Gulcur, & Nakae, 2004). Individuals in the NYHS had documented DSM-IV Axis I diagnoses of severe mental illness and were either currently homeless or had been homeless during the past 6 months. Although not an inclusion criterion, 90% also had documented histories of substance abuse. Further details on the NYHS can be found in Tsemberis et al. (2004).

For our sample selection, 56 participants were ineligible due to unknown whereabouts (n = 19), death (n = 17), movement out of the greater New York City area (n = 16), or they had not signed a release for future contacts when the NYHS ended (n = 4). This left 169 eligible for study participation.

“Maximum variation sampling” (Patton, 2002) was used to ensure inclusion of participants from both “arms” of the earlier experiment as well as representing differing levels of functioning. Two members of the study team who had been experienced NYHS interviewers drew on their own notes and reports from the earlier study in order to rate each participant as having “positive,” “negative” or “neutral/unsure” outcomes based on housing...
stability, psychiatric status and control of substance use. Criteria for a "positive" rating included the following outcomes at the end of the NYHS: stable housing arrangement, absence of psychiatric hospitalizations in the previous year, and low or no substance use. The initial inter-rater agreement rate was 78%. Through further case review with the study team, the list was assigned to four groups ("housing first" positive, "housing first" negative, "treatment first" positive, and "treatment first" negative) with 100% agreement on assigning individuals to one of these categories after omitting individuals rated as "neutral" or "unsure.

Within each category, individuals were prioritized based on expected likelihood of making contact, potential richness of the interview, and gender (in order to over-sample females). Interviews were conducted by recruiting equally from the four categories until the targeted sample size of 40 was reached; no individual contacted refused to participate. With the loss of one person too impaired to continue, 39 persons constituted the final sample. These included 21 from the housing first group and 18 from the treatment first group, roughly evenly split between positive and negative outcomes.

The sample had an average age of 48 years and was predominantly male (n = 26; 67%). Race/ethnic composition consisted of 41% (n = 16) African American, 41% (n = 16) white, and 15% (n = 6) Latino/a; one person was of Arab descent. The most common psychiatric diagnosis based on earlier records was schizophrenia (56%) followed by bipolar disorder (22%), and major depression (22%); 33 of 39 reported lifetime substance abuse. None of the participants was homeless at the time of the interviews in this study.

Data Collection
Four interviewers were trained in building rapport and conducting in-depth, minimally structured interviews. The study included two interviews occurring about a month apart, each lasting one to 2 hours. Interviews were conducted at a setting chosen by the participant—usually their own residence or the study's offices. All participants gave informed consent and received $30 for each interview; all study protocols were approved by the first author's university Institutional Review Board.

Participants were told that they were part of a study that sought to understand the service system from their perspective. We adhered to a standard technique in qualitative interviewing in which we used open-ended questions and follow-up probes (Patton, 2002). In the first interview, participants were asked to tell their life stories, paying particular attention to major events and their significance. The second interview focused on capturing specific experiences with services, including positive and negative events and reasons for their satisfaction or dissatisfaction. Examples of probes included:

- Did you ever get treatment [for drug abuse]?
- How did you get to _____shelter?
- What happened while you were there?
- What influenced your decision to leave drug rehab early?

In total, 72 interviews were conducted (five participants did not have a second interview due to health problems or to having supplied sufficient information in the first interview). Interviews were tape recorded, transcribed verbatim and entered into ATLAS/ti software for analysis.

Coding and Grounded Theory Analyses
Procedures for coding and interpreting the transcripts followed those of grounded theory (Charmaz, 2006; Strauss & Corbin, 1990). First, four members of the study team independently coded a single transcript and met to develop an initial list of open codes. Second, two senior members of the team independently coded 3 more transcripts, thereby adding codes and refining the list. A final set of codes was complete (saturated) by the tenth co-coded transcript. Using this code list, all transcripts were co-coded separately by two members of the team—all discrepancies were discussed and consensus reached.

In the next stage of analysis, selective coding and constant comparative analysis (Strauss & Corbin, 1990) were conducted by the first author in consultation with the study team in order to yield core categories (also called themes). Selective coding involved "systematically relating core categories to other categories" and validating these relationships by confirming and disconfirming examples (Strauss & Corbin, 1990). Thus, themes lacking sufficient grounding in the data and/or linkages to other themes were not included in the model. When the selective codes and core categories (themes) reached saturation, i.e., no additional information or countervailing evidence emerged, the final grounded theory model was developed. In keeping with grounded theory procedures, an audit trail was used to document analytic decisions (Padgett, 1998).

Results
Figure 1 displays a grounded theory model of service use developed from the data and comprised of seven themes (two person-centered and five system-related factors). As shown by the arrows, person-centered factors...
(mental illness and substance abuse) are related to service outcomes directly as well as through their interaction with system factors.

Lack of service use was explained by three themes located in the lower portion of the diagram—one person-centered (substance abuse) and two systemic (lack of one-on-one treatment and rules and restriction). The upper part of the model shows the themes linked to service engagement and retention, i.e., one person-centered (mental illness) and three system-related (acts of kindness, access to housing, and pleasant surroundings). The curved arrow connecting the outcomes in Figure 1 reflects the episodic, on-again off-again nature of service use in this population (Hopper et al., 1997).

**Person-Centered Factors**

**Mental Illness Severity.** When symptoms of mental illness became overwhelming, e.g., auditory hallucinations, participants entered treatment and remained until stabilized. Although this sometimes occurred involuntarily, study participants also "owned" their decision to get help. As one man noted,

> My schizophrenia started coming out. And...I got to a point, I can't take it no more. I'm going to the hospital.

When asked about a particular hospital stay, another participant stated,

> that's where I wanted to go, because I knew I could get the help. I could talk to a psychiatrist, you know, they feed me...get some medication, whatever.

**Substance Use/Abuse.** Participants acknowledged that drug or alcohol addiction made service engagement extremely difficult or impossible. One man recalled such difficulties,

> sometimes they couldn't stabilize me 'cause I kept on drinking. I was drinking and I was wondering why medication wasn't working.

When substance abuse conflicted with abstinence requirements, service use was prevented by the program or ended when the client went AWOL. One participant noted,

> They said they were afraid that I was drinking too much. They take people with problems, so I don't know why they turned me down. It was the same with the four other places I went to.

Another participant reflected on his tendency to go AWOL,

> I don't last too long in a hospital. I was in a program... I used drugs... When I started using I said, "Oh my God what am I in this place for?"

**System Factors**

**Rules and Restrictions.** Aside from prohibitions on substance use, programs enforced rules that often discouraged engagement and/or retention. Associated with congregate care, these rules typically included medication requirements, curfews, close supervi-
sion, attendance at treatment groups, signing over one's disability check, and postponing the pursuit of housing or employment until deemed ready by staff. As one participant explained,

I skipped out...because I would not want someone to be in charge of my money. Also there and at some of the other places, they put you...in classes where they lecture to you for 6 hours a day. I mean that would be like jail.

An older woman recalled life in residential treatment.

You're cleaning the houses...And they can come any time they wish, without you informed. Go through these urine tests. Insist on taking the medication in front of them. Money management...they give it to you when they feel like it.

Another participant described being "put on restriction" for rules infractions,

You know during the week sometimes people would be allowed to go to the store and go to the park. And then all those things would be cut out except for appointments. You couldn't watch TV, you couldn't play the radio...it was all group, group, group. I mean all day and almost all night long they would have the groups we would have to go to...they were very rough on me.

Participants also felt constrained by a lack of power,

it was like a totem pole you know, and clients are at the bottom and the staff they've got the top and they have their laws or this rule or that rule...and they're very, very controlling, these people.

Lack of One-on-One Therapy.
Participants expressed frustration with the lack of individual "talk therapy" to help heal the emotional wounds of mental illness, addiction and life on the streets. One woman exclaimed,

I've been asking for a therapist for goddamn years! I don't know why, it's the wrong thing to say!

The dominant modality of group treatment also raised fears of losing one's privacy when disclosing intensely painful information. A younger woman who had an abusive boyfriend and a drinking problem stated

I'm quiet in groups cause, you never know who can turn against you and throw it up in your face...one on one is better for me, because I could talk.

Pleasant Surroundings. This theme refers to quiet, clean facilities where patients had privacy and the surroundings were calming, all in contrast to the brightly lit, noisy, and sometimes dangerous hospitals and crisis centers to which they were accustomed. A young woman had fond memories of a suburban psychiatric hospital.

It looked like a kingdom...it's like the trees and then the grounds and everything, they were like beautiful. I was like, Oh my God! I've never seen a hospital like this.

In addition to comfortable amenities, these facilities also afforded patients privacy without intrusive supervision. In ___ Hospital they let you be yourself. They give you your privacy. They give you your freedom. And if you don't want to relate to these people that's there with the same problems, you don't have to. If you want to you can.

Having access to such facilities represented a rare experience of being offered an open bed in a hospital or treatment program normally reserved for private patients.

Access to Independent Housing. As noted earlier, a subset of study participants had been enrolled in a "housing first" program and thus had the unusual experience of gaining immediate access to an apartment without abstinence and other requirements. One man who had spent the previous four years in a state psychiatric hospital related how getting his own apartment set the stage for a more stable life.

They said we're going to give you an apartment with a phone and a TV. And I never had one. It had cooking things and everything there and it was great. I'd go to my meetings, do a little poetry or go to a movie with my girlfriend.

The goal of obtaining independent housing was a powerful incentive to engaging and remaining in services even when its achievement was elusive.

I was going to the doctors and the social workers that I was seeing, and I kept talking to them about you know, giving me help for housing and stuff like that. Cause that's what I was interested in. I was already taking my medicines, I was doing everything else, you know.

Acts of Kindness. This theme refers to staff who showed warmth and humanity and/or made extra efforts on a participant's behalf. There was, for example, a staff psychiatrist who gave patients rides on the expansive hospital grounds—and let them sit in the passenger seat of her car. One young man recalled a social worker who went the extra mile on his behalf,

P___ said to me I should get a job off the grounds. And that was a wonderful thing she did right there, man. Cause she brought me to this thing called ___ where you go to get a job coach, people help you with a job and stuff, help you maintain a job.

Another participant spoke with gratitude of a hospital case manager who stayed in touch with him long after he was discharged.

When I first came home, he [case manager] was there for me day and night...He told me that you know, if you stay out of the hospital, I'll take you out to dinner. Me and him go out. Walk around. Have breakfast.

These incidents were memorable because of their rarity amidst a norm of
routinized (and sometimes dehumanizing) encounters with staff.

We note that the relationships shown in Figure 1 are not solely linear. As is known from previous research, mental illness severity may influence and be influenced by substance abuse (Drake et al., 2001). Similarly, the two-way arrow at the bottom of Figure 1 shows that non-treatment can be a consequence of substance abuse and can also exacerbate it (along with mental illness).

Discussion

Taken together, these results comprise a grounded theory model of participants' subjective experience operating at personal and systemic levels and with differing valences. Thus, individuals experiencing active symptoms of mental illness are more likely to enter treatment—favorable treatment settings, acts of kindness and access to independent housing enhance the likelihood that they will remain. In contrast, co-morbid substance abuse is an impediment to service use as are inflexible program rules and the absence of individual therapy and support.

The person-centered themes in these findings are consistent with previous research on the detrimental effects of co-morbid substance abuse (Brunette et al., 2004; Calsyn et al., 2004; Laudet et al., 2003; Minkoff, 2001) although in this study they were inductively derived from participants' own words. It is the system-related themes in these findings that are noteworthy for their relative absence from the literature. One of these has received a moderate amount of attention, i.e., rules and restrictions have been portrayed as impinging on consumer choice and undermining cooperation with service delivery (Allen, 2003; Greenwood et al., 2005).

The remaining themes present a rare glimpse into the subjective experiences of formerly homeless psychiatric consumers as they navigated a multifaceted and often daunting service system. They appreciatively recalled pleasant treatment surroundings that starkly contrasted with dangerous shelters, stringent drug rehab programs, and crowded public hospitals. Unusual acts of kindness extended by overworked providers were remembered as welcoming signs of humanity and compassion. Participants expressed a longing for "one-on-one" therapy to address past traumas confidentially. Finally, the long-sought but elusive goal of attaining permanent independent housing was a powerful incentive to engagement and retention.

Perhaps not surprising given earlier writing on the subject (Dearing et al., 2005, Hser et al., 2004), we found it difficult to disentangle "engagement" from "retention" in participants' narratives. With homeless services in particular, "outreach," "engagement" and "retention" typically form an overlapping continuum in which the longer-term promise of housing is leveraged to enhance engagement and retention in the short-run (Rowe et al., 2002; Monahan et al., 2005).

This study has both limitations and strengths. Study participants were experienced research interviewees and may have given "rehearsed accounts" that were less authentic or candid. Similarly, their experiences in a large urban metropolis may not be transferable to smaller towns and cities. A benefit of our sampling strategy was that participants were not drawn from treatment settings (where service users are disproportionately represented) and were not skewed toward the higher functioning. Our strong emphasis on rapport and trust made it unlikely that the participants misled us about their service experiences, although negative events are sometimes more memorable in retrospect.

The grounded theory model in this report represented deep immersion in over 1,200 pages of transcripts, numerous analytic memos and many hours of team discussion. Specific strengths include the deployment of strategies for rigor (Padgett, 1998) such as independent co-coding, team debriefing and interviewer supervision, two interviews per participant and use of an audit trail to document analytic decision-making.

The results from this study have direct implications for the delivery of services for mentally ill adults with histories of homelessness and substance abuse. Policy and practice recommendations emerging from these findings are consistent with calls by consumer advocates for sensitivity and flexibility in helping patients (Deeghan, 1988; Fisher, 1994). Programs featuring "housing first" are likely to attract and retain clients unable or unwilling to conform to more restrictive environments. Studies of this model have shown cost effectiveness as well as more stabilized lives compared to traditional approaches (Culhane, Metraux, & Hadley, 2001; Gladwell, 2006; Padgett, Gulcur, & Tsemberis, 2006). Finally, the results point to a need for treatment options such as individual therapy and stronger emphasis on patient privacy and self-determination.

The momentum for recovery-driven mental health services has grown rapidly in recent years and a central premise of this movement is the inclusion of consumers' opinions in program and policy decisions (Anthony, 1993; Department of Health and Human Services, 2003). Persons suffering from severe mental illness, substance abuse and homelessness are among the most vulnerable and hardest-to-reach within the consumer population (Drake et al., 2001) and much can be learned from...
their personal narratives. The success of the delicate negotiation beginning with outreach and engagement depends upon the fit between consumers' needs and the service system's "offer." Policies and practices that integrate consumers' opinions are more likely to make an offer that is not refused.

References


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