

Research Article

Barriers Beyond Access: A Qualitative Study of Challenges to Care in an Urban Safety-Net Behavioural Health System

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ABSTRACT

Title: Barriers Beyond Access - A Qualitative Study of Challenges to Care in an Urban Safety-Net Behavioural Health System

Objective: This paper explores the experiences of patients with serious mental illness or substance use disorder receiving care in an urban safety-net behavioural health system - which serves large numbers of uninsured, Medicaid, and other vulnerable patient populations - in order to identify continuing areas of patient need beyond immediate access to services.

Methods: Interviews with 24 people receiving care at safety-net clinics in Metro Richmond, Virginia. Interviews elicited patients' experiences accessing care; their needs, preferences, and treatment barriers; and their suggestions for system redesign.

Results: Respondents identified interactions with clinic staff,

medication prescribing and diagnosing, characteristics of waiting room environments, and the availability of desired services as factors that either helped or hindered their experience receiving behavioural health treatment.

Conclusions: Behavioural health delivery system improvement efforts could benefit from in-depth assessment and inclusion of behavioural health patient perspectives and suggestions. Participants in this study both identified barriers unknown or not articulated by clinical staff and offered solutions to those barriers previously not included in redesign efforts.

MeSh Headings/ Keywords: Safety-net; Behavioural health; Patient perspective; Mental health; Health services accessibility; Grounded theory

Introduction

Mounting research demonstrates that increasing the availability and reach of safety-net behavioural healthcare services improves the overall health of low income, high risk populations [1]. As a result, system-level improvement efforts have principally focused on infrastructural and organizational enhancements to improve service capacity and access. The underlying assumption: more services for more people results in better care. Access to care is clearly an essential component for any effective healthcare system [2]. However, exclusively focusing on issues of access risks overlooking other patient-identified areas of need and may undermine a health system's ability to provide effective, long-term treatment to patients currently receiving care [3].

Research regarding the important role of social and structural barriers to access has been critical to the advancement of behavioural health services. Previous studies have identified extensive challenges faced by individuals with serious mental illness (SMI) and substance use disorder (SUD), including social stigma, lack of awareness regarding the need for treatment, limited financial resources, transportation problems, and the inability to navigate an often-labyrinthine healthcare system [4,5]. Such factors likely contribute to the startling statistic that people with SMI have life expectancies 25 years shorter than their peers [6,7]. Responding to this work, system redesign efforts have invested in increased screening to identify patients with unmet needs, and better access to services by creating

walk-in and 24-hour emergency services, and expanding hours of operation to evenings and weekends [8].

Some research has started to expose the potential for a mismatch between a health system's belief that they have adequately addressed patients' needs and patients' continued experience of these needs, especially within areas of high racial, ethnic, and socioeconomic diversity [9,10]. In Virginia, the mental health delivery system currently operates through community service boards, publicly funded agencies designed to provide mental health, substance abuse, and intellectual disability services to uninsured and Medicaid patients. While community service boards have been effective in providing certain emergency and case management services, many Virginia-based population centres still fail to meet the high demand for mental health services [11]. Efforts to strengthen the mental health system have been catalysed in recent years by the 2007 Virginia Tech Massacre and the 2013 Creigh Deeds incident, in which the State Senator's mentally ill son took his own life after his local community service board could not find him a psychiatric bed. In response, the Virginia General Assembly created a registry of inpatient psychiatric hospital beds, increased funding for the state's mental hospitals, and established a joint committee to study the state's mental health system over the next four years [11]. These initiatives have proved instrumental for improving Virginia's psychiatric institutions but do not fully address the gaps in community-based behavioural health interventions or the needs of its most vulnerable patients.

Despite improving access to the behavioural health system, further work is needed to align service delivery with other patient needs in community-based safety-net settings. This requires better engagement with vulnerable patient populations receiving services than provided by standardized satisfaction surveys [12,13], or studies linking patient perceptions of care to clinical outcomes [14]. Our study differs from such previous work as it explores, in-depth, patients' perspectives of care delivery in a safety-net behavioural health care system. We sought to understand continuing areas of patient need beyond immediate access to services, as well as patient-identified suggestions for continued system improvement.

Methods

Study sample and design

Between June and August 2015, we conducted twenty-four semi-structured interviews with people who were diagnosed with SMI and/or SUD and receiving care at one of four safety-net clinics or participating in the Mental Health Court Docket in Metro Richmond, Virginia. This interview study was nested within and informed Virginia's State Innovation Model design grant from the Center for Medicare and Medicaid Innovation. This award convened stakeholders from hospitals, safety-net primary care and behavioural health clinics, jails, courts, and housing and employment agencies to design regional integrated care models that could be scaled-up statewide to improve care and decrease costs for Medicaid and uninsured populations

	Number of instances	Percentage
Female	16	66.7
Heroin use	4	16.7
History of homelessness	14	58.3
Previous incarceration	13	54.2
Chronic comorbidity	8	33.3
Hospitalized in past year	10	41.7
Emergency Department use in past year	18	75

with SMI and/or SUD. Our interview study elicited patients' experiences accessing care; their needs, preferences, and treatment barriers; and their suggestions for system redesign. Interviews were conducted on-site among uninsured and Medicaid-covered populations that included the following characteristics: chronic physical comorbid conditions; opioid addiction; history of homelessness; previous incarceration; and multiple inpatient hospitalizations and/or Emergency Department visits. [For a complete account of participant demographics, see Table 1.] Capacity to consent screening was performed both before and after interviews to ensure participants were able to consent and retained decision making capacity during the course of the interview. All interviews were digitally-recorded and transcribed. This study was approved by the Virginia Commonwealth University Institutional Review Board.

Analysis

Key themes within interview transcripts were identified using a combination of template-based and emergent coding. The codebook included codes informed by and derived from the questions asked during interviews. Using grounded theory, the analysis team also read through the entire dataset, discussed emergent ideas, and developed additional codes specific to ideas represented within the data. Once the codebook was established and vetted through a consensus process, two members of the research team (Drs. Brooks and Tong) independently coded all transcripts and compared their coding, and resolved any disagreement through consensus. Having read and re-read the data, team members discussed patterns present within the coding and described the significance of those patterns through the development of themes.

This study explicitly asked respondents about the challenges they faced accessing and receiving care in the Metro Richmond behavioural health system as part of a broader, system-level quality improvement initiative. While respondents also spontaneously articulated the benefit and value of many services, interviews primarily focused on eliciting patients' perspectives on areas for improvement. Findings, or themes, are thus organized around respondent-identified challenges and suggestions for improvements.

Results

Wait times and clinic environments

Uninsured people and Medicaid members with SMI and/

or SUD living in the Metro Richmond, Virginia area currently have limited options for support and treatment. What options are available frequently require early morning arrivals for first come first serve appointments or scheduled appointments made far in advance. Once able to access support, the care settings were often perceived by patients as hurried and unfriendly. Waiting days, weeks, or months to schedule an appointment often exacerbated issues and weakened people's motivation to seek treatment. One respondent reported that although initially offered referral to behavioural health treatment by her primary care physician, "by the time they actually contacted me, I had completely forgotten that I had even asked her to do it, because it was probably more than six months before they contacted me."

After securing an appointment, inconsistent and inflexible scheduling undermined many respondents' ability to maintain treatment. Patients reported routinely waiting for over an hour to see a clinical staff member, a significant barrier for patients with limited transportation options or who are employed in hourly jobs. Others found the clinics' inflexible scheduling a challenge. One respondent reported that while clinic services were beneficial, "if you don't show up early enough for whatever reason, because life happens, traffic or something, you know, you're just totally screwed. If you don't make it, then you probably won't get another chance for a while ... I don't really like to think about what would have happened if I hadn't been able to see [my therapist] that day."

Respondents also described the social environment of waiting areas as "stressful," contributing to their feelings of exposure and vulnerability. "I just don't like the crowded front when you first come in," one man confided. Other respondents reported sometimes feeling bullied and ridiculed while waiting for appointments, leading one respondent to dub it "the waiting room blues." Another woman, recovering from a recent rape, felt especially vulnerable when men stared at or propositioned her. Attempts to avoid these public spaces by walking outside often resulted in missed appointments or censure from front desk staff due to being perceived as "rude".

Appointment types

Many behavioural health settings are interested in greater access and service availability. However, these are difficult to provide with limited resources. A common strategy used to overcome this in many health care settings is the group visit. Although abundantly available across clinic sites, some respondents bemoaned group therapy as an impersonal and threatening social space where their private struggles were made visible to other patients with whom they were unfamiliar. As one man said, "I just have anxiety issues being around people. I could be around two people but if there's more people in here, then I would want to leave."

Some respondents felt group therapy sessions could be more useful if individual sessions were also more available. However, respondents frequently cited a lack of individual therapy that addressed "real issues," or issues they felt particular to their lived experience. One respondent described therapy sessions as disappointingly focused on the "same old, same old." Another

described her therapy experience as a "maintenance type thing," suggesting that these sessions were overly focused on getting through to the next day but not oriented towards identifying and fixing the issues lying underneath. She emphasized its surface-level engagement by saying, "nobody sits down and have a real session with you. There's really no treatment. You know, nobody comes from way back and brings it up to the present and the stuff you've been through."

Interactions with clinicians and staff

Respondents identified interpersonal relationships with clinic staff as the most significant in-clinic determinate of their satisfaction with the services provided and their likelihood to continue treatment. While several respondents identified strong interpersonal connections with clinical staff, the majority of respondents' negative comments revolved around this area.

Many were frustrated by the lack of continuity among clinicians they saw in clinic. This contributed to feelings of disconnection and alienation. One respondent expressed clear irritation, saying, "Saturday, Sunday, Monday, you saw three different doctors... You never got to see the same doctor twice. You never saw the same nurse twice. You never saw anybody the same twice." This discontinuity can also undermine delivery of timely services, as highlighted by another respondent: "I'd like it to be consistent 'cause – like I didn't get to see [Dr.] today, so that means anything I wanted to talk with him about today didn't get done till next time, and there'll be something else next time."

Respondents also frequently criticized behavioural health clinicians with whom they felt unable to relate. They pointed out that clinical staff often had strongly dissimilar social backgrounds and sometimes relied on academic training at the expense of developing personal connection. As one respondent said, "I think one of the most difficult things I've dealt with is psychiatrists thinking they know what it's like to go through some of the stuff that we go through. Psychiatrists swear up and down they know everything, and you can't know everything if you ain't been through it." She continued, sarcastically mocking one of her therapist's attempts to handle her rape experience. "'Oh, well, I read it in my book that people get raped. [So] yes, I understand how you feel.' No, you don't. I don't want the fakeness. I want somebody who's real and honest."

Respondents routinely expressed frustration with behavioural health clinicians who appeared indifferent, aloof, or dismissive. Referring to a recent conversation with her doctor, one woman said, "You try to tell your problems, it's like he push you away and just gives you some medicine." During subsequent visits, the respondent reported that while clinic staff asked about the medication's effectiveness, they ignored her experience of the illness and treatment preferences. When staff asked about her status during a visit, she brusquely replied, "No, I ain't alright, cause you won't talk to me. I need somebody to talk to!"

The role of diagnosis and medication

Respondents often felt that physicians' first interest was in finding a diagnosis and medicating. This provided little room

for discussion of the patient's life and experience beyond those facts most closely aligned with symptomology. Some respondents complained that diagnoses were often made after a single visit, without the patient's input, and without searching for causal factors. One patient described frustration, "There's a lot of people that look at the diagnosis and... 'OK, this is what's wrong with you, this is what we need to give you.' ...they want to jump to the chase and diagnose you with something. They just don't find the problem." Rather than feeling like someone was investigating the underlying causes of their illness, respondents felt they had been reduced to obligatory pill takers.

Many respondents reported that attempts to resist or question a particular diagnosis were often dismissed. Some described encounters during which they were labelled as "drug seeking" without discussion. "You know, they wanted to stereotype me. I was like, 'I don't know how you get this from just sitting here, and not even talking to me for five minutes...No, I'm not here for the drugs. I need help!'"

Conversely, some respondents expressed frustration with the length of time required to receive an accurate mental health diagnosis. One respondent described years spent trapped in a physical medicine model, being referred to various specialists while his experience of symptoms was questioned. Eventually he received a diagnosis of post-traumatic stress disorder (PTSD). Reflecting on the cause of his experiences, he attributed the delay to his doctor's "ignorance and apathy" in the face of a "brutal system" that from the respondent's perspective fails to incentivize efficient and effective treatment of mental illness. "She's got four more people that she's got to see in the next hour and it's just not on her checklist."

Patients' suggestions for system improvement

While respondents primarily identified barriers to sustained or effective treatment, they also made several suggestions for system improvement. Respondents overwhelmingly valued the interpersonal connections that result from meaningful and repeated communication with familiar clinicians and staff members. Patients spoke fondly of case managers, social workers, and the occasional therapist who made a personal connection. They appreciated caregivers who, as one patient described it, had the capacity to simply "be there" with and for them in times of need. As one man remarked about his clinician, "He's never once seen me as a project or a throwaway client - he listens to me and he respects that it's a chronic illness that I'm dealing with." Similarly, many respondents suggested incorporating more treatment modalities focused on developing a positive relationship with clinical staff in one-on-one settings, as well as engaging in meaningful activities outside of a clinical setting, including home visits, art classes and being taken for "walks in the park." Others simply requested having a "safe space" to visit. Respondents emphasized a need to expand the use of case managers and to incorporate more peer recovery support services with people who "understand what it's like" living with SMI and SUD with whom they could relate and from whom they could learn.

Discussion

In Virginia, as in other states, efforts to improve the behavioural health system would benefit from explicit incorporation of patient experiences and insights [15]. Commonly used quality improvement efforts are often informed by explanatory models that focus on resource deficiencies (e.g., time, money, clinicians, clinics, training) [16] and social or structural impediments to success (e.g., stigma, poverty, low health literacy, and lack of motivation) [17]. These explanations do not consider whether parts of the system itself are not designed to effectively address patients' needs. Patient perspectives have the ability to expose unchallenged assumptions and to explain why the reach and effectiveness of behavioural health services are suboptimal.

Our study identified several lessons for future behavioural health system redesign efforts:

- Continuity of care and better rapport with patients may be achieved by expanding peer recovery support services and case management.
- Incorporating community-based activities, such as unstructured home-visits, outings to local parks, art classes, and safe-spaces in or near the clinic may promote more positive, informal, unscheduled interactions with others.
- Improved availability of one-on-one therapy with therapists trained across different modalities, including psychodynamic and trauma informed care, would benefit patient success.
- A singular focus on diagnosis and medication risks reducing people to their diagnoses thereby dismissing their experience and undermining their recovery.
- Educating all clinical staff, even those not responsible for delivering behavioural health treatment, facilitates recognition and respect for issues when they arise.
- Involving patients in diagnostic decisions, engaging them in shared decision making, and providing continuity of care with clinical staff can promote patient engagement and satisfaction.

While some of these lessons may have been mentioned in previous research, their differential impact on patient success is best understood through the experiences of those most impacted by the behavioural health system. Incorporating routine patient feedback into quality improvement efforts may allow for improved assessment of whether proposed and implemented changes are meaningful to patients. [3]

Conclusions

Respondents identified interactions with clinic staff, frustrations with medication prescribing and diagnoses, characteristics of the waiting room environment, and the availability of desired services as prominent factors that either helped or hindered their experience receiving behavioural health treatment.

While there is a growing recognition of the importance of engaging patients in their care processes and in broader systems redesign, [3,13] this movement has not translated into a sustained effort to engage patients with SMI and/or SUD beyond survey-based measurements of satisfaction. To ensure the success of current and future efforts to improve behavioural health delivery systems, it is imperative to include the perspectives of behavioural health patients in quality improvement efforts.

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