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Too Late and Too Little: Narratives of Treatment Disconnect in Early Psychosis

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Abstract

Schizophrenia and other psychotic disorders are a source of significant morbidity, both for patients and caregivers. The first 2–5 years after the onset of psychosis are a critical period wherein treatment might effect disproportionate improvements in long-term outcomes. Specialized services have been developed with the goal of providing early and effective treatment—however, engaging young patients in these services remains a challenge. In this study we sought to uncover possible reasons for this finding by collecting participants' narratives of their early treatment experience. We conducted in-depth, semi-structured interviews with 11 patients currently enrolled in a first episode psychosis program in Connecticut. Transcripts were analyzed using inductive thematic analysis. Participants reported that prior to them entering specialized treatment services, their initial contact with psychiatric care was brought about by abrupt behavioral changes that were noticed by others, and that this led to treatment that was disconnected from their own concerns, which centered around more everyday challenges. This initial contact did not serve to engender trust or facilitate engagement in further treatment. Additional examples of disconnect were noted even after participants had entered specialized services, and these centered around the patients' preference for conceptualizing their difficulties, treatment and recovery in multi-dimensional terms that emphasized social inclusion and vocational achievement. Participants in our study highlighted several areas of disconnect in the course of their early treatment. There is an opportunity to enhance early engagement by offering patients concrete evidence that their treatment priorities are understood and will be addressed.

Keywords

Treatment engagement; Early psychosis; Schizophrenia; Patient insight; Recovery

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Introduction

Schizophrenia and other psychotic disorders represent a significant burden for both patients and family members, causing an estimated 15 million disability adjusted life years in 2010—an increase of 43 % since 1990 [1]. According to this metric, the burden of schizophrenia is similar to that of Alcohol Use Disorders, a remarkable fact given that schizophrenia is a comparatively rare illness. Furthermore, these measures of disease impact do not include the impact of the illness on family members, which is thought to be considerable [2]. The first 2–5 years after the onset of psychosis have been described as a critical period wherein treatment might effect disproportionate improvements in long term outcomes [3]. Aside from a wealth of observational data supporting the intuitive appeal of early intervention (EI), several experimental approaches have established the effectiveness of 2 main elements of EI services: (1) Early Detection or shortening delays in entering treatment, measured as the Duration of Untreated Psychosis (DUP) and (2) First-Episode Services (FES) which use specialized teams to deliver packages of empirically supported treatments adapted for younger patients and their families. These efforts to optimize the *timing* and the *quality* of care, respectively, for early psychosis patients have produced significant improvements in clinical symptoms, functioning, quality of life and economic costs [4, 5].

Despite evidence of clear benefit, EI services like many others, struggle to engage and retain young patients in their services, with data from two such programs indicating dropout rates of 23 % at 18 months [6] and 31 % at 30 months [7]. A relatively recent review exploring rates of disengagement in a variety of mental health settings reports that although varying, on average around one third of patients disengage with treatment at some point in the course of their care [8].

Why do individuals fail to take advantage of demonstrably effective services? Specific risk factors for poor treatment engagement that have been identified including positive symptom severity, childhood exposure to violence, lower scores on ratings for negative symptoms and substance abuse [7, 9]. A large study conducted at a FES in Australia found that the primary predictors of disengagement were a prior forensic history, not living with family at the time of discharge from hospital, less severe illness at the time of diagnosis, and persistent substance use [6]. While such approaches can direct clinical attention to particular subgroups, they are less able to illuminate the interaction amongst several factors that determine engagement with care.

Studies that seek to understand personal narratives are showing promise in supplementing these traditional approaches. One proposal is for investigators to widen their conception of insight from congruence with clinical assessments to a complex and multi-dimensional concept [10] that widens inquiry toward an exploration of patients' broader and more distinctive understanding of their situation. A young person may have an acute awareness of symptoms or functional losses, but when faced with a treatment plan that seems tone deaf to their individual and sometimes idiosyncratic priorities, may choose to disengage. A 'complex and generally misunderstood [patient] storyline' may need to be 'given voice' to allow for effective engagement [11]. A related exemplar used phenomenologic approaches to elicit participants' experiences of social relationships during the early treatment period [12].

Participants felt they had lost contact with the friends they had prior to the onset of their symptoms, and sought connection to a peer group that might understand their experience and predicament. This highlights the need for services that can provide a ‘menu’ of options, including social or recreational components, that might better engage a heterogeneous group compared to traditional pharmacologic or psychotherapeutic modalities. More recent qualitative work has highlighted the continued role of stigma and poor understanding of mental illness as barriers to service engagement [13].

In this study, we extend the use of individual patient narratives to explore two major challenges in providing early intervention for psychotic illnesses: prolonged DUP before and poor engagement after entry into treatment. We used in-depth interviews of young patients in an exemplar FES based in a U.S. urban community mental health center to elucidate key themes in their variable trajectories of engagement with care.

Methods

We conducted semi-structured interviews with 11 people currently enrolled in the clinic for Specialized Treatment Early in Psychosis (STEP) based at the Connecticut Mental Health Center (CMHC). The sample included ten males and one female, with an age range of 20–35. Participants were referred by their primary clinicians. Interviews were recorded, transcribed, and analyzed by the author GVS using QSR nVivo. We employed the use of inductive thematic analysis, whereby the data were subject to repeated rounds of coding during which themes were allowed to emerge organically [14]. The use of this analytical approach allowed us to organize the data without imposing an existing framework for understanding these ideas. This, in combination with the use of open-ended questions (see Fig. 1) maximized our ability to give voice to the perspectives of our participants. At several stages during the process of analysis, the coding process was reviewed by the co-author LD in order to improve validity. Themes were subsequently organized into hierarchies, and emphasis was given to themes that emerged consistently across the sample. Approval for this study was obtained from the Yale Human Investigations Committee. After complete description of the study to the subjects, informed consent was obtained.

Results

The most prominent themes that emerged from participants’ experiences are organized into two phases—specifically, before and after enrollment in the STEP clinic. The themes under each phase are shown in Fig. 2.

Before Entering STEP

Brought to Hospital Due to Others’ Concerns

Participants provided diverse responses to the question of how they initially came into contact with mental health services. The most common description was that of being brought to the emergency room by police in response to disruptive behaviors. One participant described an episode of aggression:

Participant 3: Eventually, when I had a final portfolio to finish and they started calling me an asshole, I was in [the college] computer lab and I got really upset and I slapped a wall and I made a dent in the wall and I got arrested because of it, and that was the last straw. After that I broke down [and] said I needed to get help...

And, similarly,

Participant 6: Well, I guess there was an argument between me and my neighbor. I guess I got a little bit too aggressive towards her. I guess she felt threatened, so she felt the need to call the police. And that's when they put me at [the psychiatric hospital] for the first time.

In other instances participants were encouraged to seek help by their families

Interviewer: How did you end up in hospital then?

Participant 4: My mom recommended me to go... I was staring at walls and not thinking. I was fasting at the time. So I was in a low energy state and I was hoping that would control my thinking and it didn't. And I ended up staring at walls. I quit my job at the time. I had nothing going for me.

In yet other instances family members took action alone: "My family called because I just couldn't get to sleep and I was running around acting very strangely. And they didn't know what to do."

Participants' Did Not See the Same Problems

All of these situations, in which participants accessed help either partially or entirely due to the concerns of others, were accompanied by a stark change in behavior. However, when describing what they considered to be the sentinel problem, participants more often referenced difficulties functioning at school or work:

Participant 2: I was in college at the time so my first semester I had a 3.5GPA and then started getting – the voices started coming and it was hard to concentrate. It was hard to focus. It was hard to even have a conversation with people, listen to people, and I slowly disintegrated.

All participants described delays between the onset of what they considered (in retrospect, at the time of the interview) to be symptoms and their initiation of treatment. A reason offered by some participants was that they initially felt that their unusual thoughts were based in reality:

Participant 3: I had a number of odd things happen to me and because of those odd things I believed that – and still do believe that people who – I can't really explain it whether it's telepathy or technology or whatever it is – were able to access my mind and were able to make me hear them say the word asshole over and over again. So I said, "Well this isn't a psychiatric problem. Maybe they'll just leave me alone after a while."

Another participant thought that the symptoms would go away by themselves, and his family supported the idea that nothing was wrong:

Participant 8: I thought maybe it would go away. I thought maybe I just – it was very unusual thought. I thought to myself, I was like, what’s going on. Why am I hearing stuff? And I didn’t tell anybody right away. I kept it to myself. And after a while, I told my mother that evening. And she told me that there was nothing to worry about.

Initial Contact Did Not Facilitate Engagement

An additional prominent thread was that several participants failed to become engaged in treatment following an initial hospitalization or outpatient visit:

Interviewer: Did you have that [symptoms] some time before you first came to treatment?

Participant 4: For about nine months.

Interviewer: Okay. And in that time did you think about coming to treatment soon?

Participant 4: Before coming here [to the STEP clinic], I was actually admitted into the hospital three times. The first time was January 2012 and the second time was March and the third time was March again. And I didn’t go diagnosed – I didn’t get diagnosed with anything because I didn’t tell them. I didn’t talk about what the problem was. But it was apparent.

Another participant even described her hospital experience as posing a barrier to further treatment:

Participant 10: I kind of felt like people might think, “oh, she’s crazy.” And not listen to me about anything because that’s how I was kind of treated at the hospital when I went to the hospital... they just ignored me and put me in restraints and stuff like that. It was a really terrible experience. I don’t like to think about it that much.

In a similar vein, other participants described having the sense that nobody understood their problem initially:

Participant 5: I had become very anxious. I had trouble focusing at work and different things. I stopped caring about my personal – like, my appearance and stuff. You could tell something was going on, but nobody could exactly pinpoint what it was.

Finally, one participant described how he had initially hoped to receive treatment focused on anxiety, rather than psychosis:

Participant 10: Someone from the [STEP clinic] approached me. And at first I didn’t want to do anything with the program because I, at that point, still thought I was okay. And that it was just that I had no sleep. And I wanted to call a different study about anxiety because I thought it was just anxiety. And the study rejected me because of the psychotic episode. They thought it was something more and that I should see somebody else. And they referred me to different places. And eventually I did call the [STEP clinic]...

Although only one participant described this as a barrier to accessing specialty care, such differences in perspective between those of the participants and those of the staff at the STEP clinic were presumably common and will be discussed in the next section.

After Entering STEP

The Importance of a Relationship with a Professional

A majority of participants described their relationship to a therapist as being central to their treatment. They described this relationship as a source of social engagement and support, as allowing for an honest discussion of personal difficulties, and, at times, as a source of well-informed advice. For example, in response to a question about what he had found to be helpful in the STEP clinic, one participant responded:

Participant 3: Just talking about what I'm going through. It'd be even worse if I was going through it alone. I don't hold anything back when I come to therapy. I tell them everything that I'm experiencing; some of it is embarrassing, some of it is degrading, but I tell them everything just to get their perspective from another human, an intelligent human who knows what, has the training, and all that is helpful.

The importance of feeling heard also emerged in the participants' narratives:

Interviewer: You spoke a bit about things are better with [new clinician], so what was helpful?

Participant 3: Well, she really listens to you when you talk. She really understands what you're going through. And she doesn't miss things. She pays attention to the details of what you're saying...

A Focus on Everyday Problems

Participants emphasized the value of the assistance they received with their basic needs, such as in relation to housing and employment:

Participant 8: Well, help me with making sure I have a safe place to live. Making sure I have clothing, I have food, I have shelter. [They] also helped me with ... employment. They got me assigned to an agency, which helps me find work...

When asked how things were going, many participants responded to this open ended inquiry by describing a sense of social isolation. For example:

Participant 6: Before when after I got out of the hospital, I didn't even want to get out of the apartment. For the first couple of weeks I didn't even want to leave the apartment ... Because I just had this stigma that people had this view about me... And I really felt like maybe it wasn't the best time for me to actually go outside and try to find work. Maybe I should just think about what it is I should be doing. And what I ended up doing was making it worse. Alienating myself from the public, not being outside, I really found out that instead of this helping me, it got worse.

The same participant described his experience of the STEP Program as follows:

Participant 6: I've had two clinicians. The first clinician... he was cool. He really knew what I was going through when I was trying to find work, the struggle about it. Getting up, getting your clothes on, going to interviews, coming back home, doing follow-ups... He really sounded like he could actually relate to what it was I was going through. And he gave me advice on how to talk to girls, how to fix a car, simple things.

This tendency to focus on everyday problems on occasion had the effect of making participants apprehensive about attending a state psychiatric facility. For example, one participant expressed a concern that people would "label me as a lot worse psychologically than I actually am... like the worst mental health of anyone you've ever met," while he viewed himself as "just a regular guy who was a slight condition, who gets overmedicated all of the time."

Multiple Sides to Recovery

Participants provided detailed narratives of how things had improved for them since entering the STEP program. Seeking or returning to employment (or school in certain cases) was frequently raised as an important example:

Participant 8: It's been good lately. I'm very fortunate to have a full-time job. I have benefits there, so I'm very comfortable there. And like I said, I'm just lucky to have a 40-hour a week job.

Another participant offered additional indicators of increased social engagement and a sense of doing something meaningful:

Interviewer: You don't seem anxious now.

Participant 6: No, not anymore. And that takes years. It's not something automatic. You have to learn to cope with your problems... and talking helps. Being out in public helps. But for me the most important thing I tell people is that you have to do something that makes you feel you accomplished something

The above references suggest that participants emphasized psychosocial factors when describing their difficulties, and concordantly described their treatment as primarily involving talk therapy. A significant number of participants mentioned the importance of having their psychotic symptoms alleviated:

Participant 2: Because the fact that I was hearing voices almost every day of my life and it was annoying and disturbing, since I've come to STEP I only hear voices now and again for a few minutes and then it's gone. The medication works well.

Overall this aspect of recovery was less emphasized, and in one instance a participant described how too narrow a focus on medications had been detrimental to her engagement:

Interviewer: What was it like when you would talk to him about medications generally?

Participant 10: He would, I think he would put me on too much medication, or would push medication more than just therapy at the time.

Interviewer: But how was the negotiation about that?

Participant 10: So it kind of, it helped to talk with him about it. But it took a lot of convincing for him to put me on lower doses of things because my body is sensitive and I know that. But I guess the normal dose for something, maybe of my body weight or whatever was what he was trying to give me.... It was very stressful and kind of scary because the medication would make me feel weird...

Later in the interview, when the participant was asked if she had ever considered not coming to her appointments she responded:

Participant 10: I think most of the time that I thought about not coming to my visits was with the other doctor.

Discussion

This study of patient narratives revealed several important themes relevant to understanding prolonged DUP and the quality of treatment engagement (Fig. 2). While some of these themes have been reported earlier, our results highlight an early disconnect between what patients think is happening to them, and the actions of family, criminal justice, and healthcare systems. In some instances this is perhaps best understood as a temporal ‘phase disconnect’—specifically, providers were advocating treatment for a psychotic illness before the participant even considered themselves to have an illness at all. Another manifestation of this was the finding that while young patients would start by framing the initial problem and treatment goal in normative terms of social inclusion and vocational achievement, the interventions of various caregivers including family and the healthcare system emphasized behavioral and symptom control.

A subsequent example of a phase disconnect relates to the way initial contact was made with mental health services. It is tempting to see this as a setup for failure—a young person who may be preoccupied with concerns about their declining performance at school or work is brought to an emergency room by the police, and then hospitalized and started on medications. These types of interventions might understandably appear out of step with the individuals’ perception of the problem. Given this situation, it is unsurprising that participants reported having several hospitalizations before being engaged in comprehensive outpatient treatment.

These findings point to the hypothesis that greater engagement in early treatment could be facilitated by finding ways to more closely align treatment approaches to the experiences and concerns of patients, for example giving them concrete and immediate evidence that help is available for what they perceive as their most pressing difficulties. This description is consistent with the previously described ‘misunderstood storyline’, which, if not given voice, may have detrimental effects on long-term engagement. What our results serve to highlight is an early disconnect between what patients think is happening to them, and the reaction of family, criminal justice, and healthcare systems.

A second and related disconnect emerged when patients eventually came into contact with treatment. Even as patients became aware of their psychiatric diagnosis and started taking

medications, they continued to frame their difficulties in terms of more everyday losses in school or work functioning. Similarly, most prominent in their characterization of treatment at the STEP program was the use of the more normative term “therapy.” Participants described the importance of a trusting relationship and receiving commonsense advice and psychosocial support with housing and employment. These interventions were more clearly connected to the challenges that participants first noticed, in contrast to psychiatric hospitalization that in this view is at best irrelevant and at worst a barrier to the achievement of these goals. When asked the simple question about how things were going after a variable amount of time in the early psychosis program, most participants responded by referencing improvements in relationships and their employment situation, and appeared to view this as a more prominent factor than the state of their psychotic symptoms.

Another significant example of a disconnect was the rich narrative provided by a participant who felt that she was being pushed to take medication by her provider; an experience that made her sufficiently uncomfortable to consider disengaging from care. This example is of particular interest. When patients who are acutely psychotic are averse to taking medications these behaviors are often interpreted as due to a lack of insight. However, in this case the patient was not totally averse to taking medications, and apparently had some sense of her diagnosis. Nevertheless, she continued to prefer for her treatment to be focused more on therapy, suggesting that she continued to view her difficulties in more normalizing terms. This illustrates the value of a broader construal of insight [10], in this case within the developing narrative of the individual patient. An approach that contextualizes insight within a developing, individualized narrative might allow providers to differentiate instances in which patients are making poor decisions owing to their illness from those in which they are simply asserting current preferences within shared treatment goals.

Additional sources of disconnect related to patients’ own stigma about the facility where they were receiving treatment. Although the patients in the STEP program would by many other metrics be considered severely mentally ill, it was clear that by their own metric they were not so ill as to be counted amongst the mostly chronically mentally ill receiving care at CMHC. One participant simply felt out of place with people he considered being more impaired than himself. But of great interest was another participant whose concern extended to the fear of being labeled as more mentally ill than he really was; it was of importance to this participant that he be seen as a regular guy with a slight “condition.” This finding is consistent with the growing number of quantitative studies exploring the issue of self-stigma in schizophrenia [15], as well as more recent qualitative work [13].

Encouragingly, several participants chose to continue attending their appointments despite these barriers, and described a sense of significant benefit from the clinic. While symptom resolution was important, equally often participants mentioned the importance of improved ability to engage in work and school, as well as improvements in their social relationships. These results echo work that has suggested the need for assessing multiple dimensions of recovery [16].

In using qualitative methodology, and more specifically, the use of open-ended questions and inductive analysis, we hoped to collect data in a way that would allow our participants’

views to emerge with minimal constraints and direction. Our results would suggest that this approach proved successful, in that it revealed aspects of the early psychosis experience that were not evident in prior reports of disengagement. Traditional approaches have focused on symptoms, behavioral changes and other measureable features that might define risk for prolonged DUP or disengagement. The narrative approached used here offers a better understanding of those aspects of particular significance to the patients.

Our study possesses a number of limitations. Firstly, it could be of significant value to explore the early psychosis period from the perspective of clinicians and family members. Doing so could help us understand whether these areas of disconnect represent fundamental differences in priorities or rather an issue of perception, where the underlying motivations of family members and clinicians may be in line with those of the patient but this is not apparent to the patient in the early period of crisis management. A further limitation of our study was that we were only able to recruit one female into our study, and that we were of course unable to interview people who had definitively disengaged from treatment—an important perspective that will likely remain elusive.

Participants in our study described a number of issues that are consistent with previous theoretical and empirical findings in the literature. Most prominently, our results are consistent with the work by Judge et al., who reported that young individuals with psychosis identified “changes within themselves” but did not attribute these to a mental illness. Furthermore, the authors describe how participants identified “domains of recovery” that did not always involve the alleviation of symptoms, limiting the potential role of medication treatment and acting as a deterrent to seeking professional help [17]. Our findings echo the sentiments of others in describing the ‘misunderstood storyline’ [11] as referenced in the introduction. The value of our study is the way in which we were able to describe the common thread of a patient narrative that was often at odds with the way the patient was being offered treatment or the health care system’s response to them. Encouragingly, participants described many examples where services appeared to be in line with their expectations, most often referencing relationships with clinicians who were willing to listen carefully to their stories and to offer commonsense advice that was well-pitched to their preference to normalize their needs for care. Nevertheless, further research exploring comprehensive strategies for bridging this divide could have potentially significant impacts across this critical period for preventive intervention.

There are significant areas of disconnect between the experiences of patients and the response of the family, medical, and criminal justice systems. Participants appeared to favor conceptualizing their experiences in everyday terms. This disconnect is of clinical significance as it appeared to have the capacity to delay entry into treatment and act as risk factor for subsequent disengagement. The next steps are to consider ways in which this divide may be narrowed, as well as to enhance our understanding of this disconnect by exploring the perspectives of other role players.

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Biographies

Gerrit Ian van Schalkwyk, MB, ChB is a PGY-3 adult psychiatry resident in the Yale University Department of Psychiatry. Gerrit has a particular interest in early adulthood, with clinical work and research experience exploring mental illness in this population. In particular, Gerrit is interested in the experiences of young adults with Autism Spectrum Disorders, psychotic disorders, and the complex intersection between these conditions. In

addition, Gerrit has interests in research mentorship, and LGBTQ issues related to psychiatry and mental health.

Larry Davidson, MD is involved in research and consultation/training work focuses on processes of recovery from and in serious mental illnesses and addictions and the development and evaluation of innovative policies and programs to promote the recovery and community inclusion of individuals with these conditions. We utilize mixed qualitative and quantitative methods, and typically conduct our research in a participatory and inclusive fashion that involves people in recovery in all aspects and phases of the research process.

Vinod Srihari, PhD Dr. Srihari's clinical and research interests are focused on the evaluation and treatment of individuals with psychotic disorders. He directs a clinic that provides a specialized model of care to individuals who are early in the course of a psychotic disorder. The clinic for Specialized Treatment Early in Psychosis (STEP) is based at the Connecticut Mental Health Center where Dr. Srihari is a staff psychiatrist. Dr. Srihari's teaching efforts are focused on the use of the Evidence-Based Medicine (EBM) approach as a tool for making clinical decisions and keeping up with the scientific literature.

1. How have things been going?
 - a. What things?
 - i. At home?
 - b. What have you been up to?
 - i. How has that been going?
 2. What has it been like working with the people here at CMHC?
 3. What have you found to be helpful?
 - a. What is helpful about that?
 4. What about coming here has been hard?
 - a. Practical issues?
 - b. Stigma at home/in the community?
 - c. Perception of benefit?
- A lot of people who initially get seen at STEP end up not coming to their appointments. We are interested in finding out why this is.
5. Have you every thought about not coming?
 - a. If yes, why?
 - b. Do you have any ideas about why others might not come?
 6. What happened that first led you into contact with mental health care?
 - a. What things were difficult around this time?
 - b. What things were helpful?

Fig. 1.
Interview guide

Fig. 2.
Summary of themes