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What is This?
Factors Contributing to Engagement During the Initial Stages of Treatment for Psychosis

Katherine D. Stewart

Abstract

There is a growing international effort to improve the rate of engagement with young people needing early treatment for psychosis. In this article I describe how a sample of 30 young people, who successfully engaged in treatment for a first episode of psychosis, experienced the process of engagement during the initial stages of care. Using a grounded theory approach and purposive sampling, I found that the nature of relationships among young patients and care providers is a factor that influences engagement. I also found that the transition between initial treatment and community care is a critical time for engagement. The success of this transition is marked by contact with client-centered-care providers and a supportive peer group culture.

Keywords

grounded theory; health care, users’ experiences; relationships, patient-provider; research, qualitative; young adults

An increasing number of health professionals now agree that the optimal time for the treatment of psychosis occurs early in the course of the illness (Craig et al., 2004; Crumlish et al., 2009; Larsen et al., 2001; McGorry, 2000). McGorry, Killackey, and Yung (2008) found that, as a treatment strategy, early intervention prevents the development of severe symptomatic and functional impairment known to occur in illnesses such as schizophrenia. Despite the benefits of early intervention, a significant number of young people disengage during this critical stage of treatment (Edlund et al., 2002; Larsen, et al., 2000; Pelkonen, Marttunen, Laippala, & Lonnqvist, 2000). Early termination of treatment has been found to expose young people to a more chronic course of the illness, increase the need for hospitalization, prolong inpatient care, cause more profound levels of functional disability, and slow the recovery process (Addington, Van Mastrigt, Hutchinson, & Addington, 2002; McGorry, Hickie, Baune, Callaly, & Catts, 2008). Today dropout from treatment for first-episode psychosis is considered a significant clinical and systemic problem that challenges the quality of patient care and treatment outcomes (Berghofer, Schmidl, Rudas, & Schmitz, 2000; Killaspy, Banerjee, King, & Lloyd, 2000).

Noting the high numbers of young people leaving treatment prematurely, researchers have focused on the quality of service delivery for clues about the process of disengagement. For example, placing young people in treatment settings oriented toward traditional adult mental health care has been identified with dropout (Frueh et al., 2005; Kaplan, Busner, Chibnall, & Kang, 2001; Marriage, Petrie, & Worling, 2001). It seems that young people can experience a personal crisis when faced with the complex, insensitive, and alienating standards of care found in adult psychiatric services (Lincoln & McGorry, 1995; McGorry, 2007; McGorry et al., 1991; McGorry, Killackey, & Yung, 2007; Skeate, Jackson, Birchwood, & Jones, 2002).

According to Yung, Organ, and Harris (2003), care providers working in adult facilities have a tendency to focus on older patients with more chronic presentations, consequently neglecting the needs of young patients. Yung et al. concluded that the failure of care providers to assertively assess and actively follow up young patients results in a significant rate of treatment termination and delay, which then leads to a worsening of symptoms and subsequent need for longer hospitalization. Other researchers have found that hospitalization in adult psychiatric wards can place young people in situations that are frightening, unsupportive, abusive, and associated...
with adverse psychological effects that all factor in the termination of treatment (Etheridge, Yarrow, & Peet, 2004; Frueh et al., 2005; Kaplan et al., 2001; Marriage et al., 2001).

Early disengagement and delays in treatment have also been identified with the nature of the relationship between young people and care providers. For example, Busto (2002) found that even though young people needing treatment for mental health problems value the opportunity to build relationships with care providers, they are less likely to attend appointments or adhere to treatment if those relationships are experienced as negative. Interviewing 10 homeless young people with mental health problems, Darbyshire, Muir-Cochrane, Fereday, Jureidini, and Drummond (2006) found that disengagement was identified with the worst experiences of community treatment, in particular the development of relationships with care providers wherein young people believed that they were stigmatized, patronized, unwelcome, and unworthy. In general, disengagement is more likely to occur if young people experience care providers as intimidating, ineffective, demoralizing, frustrating, or lacking in understanding about the impact of the illness on a young person’s life (Boydell, Gladstone, & Volpe, 2006; Pelkonen et al., 2000; Tehrani, Krussel, Borg, & Munk-Jørgensen, 1996).

Conversely, researchers have found that the nature of relationships between young people and care providers also factors in the process of successful engagement. The overarching theme of engagement includes the young person’s desire to be understood, respected, and supported by care providers in a nonjudgmental manner (Darbyshire et al., 2006; French, Reardon, & Smith, 2003). In addition, young people need to have an understanding about the illness, be involved in treatment decisions, experience care providers as empathic and approachable, be listened to and cared about, and participate in conversations that are not limited by discussions about diagnosis and medication (Boydell et al., 2006; Busto, 2002).

Attrition rates reflect the difficulties of successfully engaging young people in treatment for a first episode of psychosis. Conducting studies across several countries, researchers have found that approximately a third of young people experiencing a first episode of psychosis typically delay treatment between 1 and 3 years, and up to 80% drop out within the first year of care (Larsen et al., 2000; Lincoln & McGorry, 1995; McGorry & Singh, 1995; Percudani, Belloni, Contini, & Barbui, 2002). There is little doubt that the percentage of young people terminating treatment necessitates more investigation. Nevertheless, the numbers of young people who remain and successfully engage in treatment also warrant a voice in this discussion.

There is a continuing need to build a body of literature that illuminates the experiences of young people who enter, stay, comply, and benefit from psychiatric treatment for a first episode of psychosis. How do these young people successfully engage despite the significant number of their peers who avoid or leave treatment prematurely? What enables the process of engagement? In this article I describe how 30 young people, who had successfully engaged in treatment for a first episode of psychosis, experienced the process of engagement during the initial stages of treatment.

Method

I used a grounded theory approach based on the work of Strauss and Corbin (1990) to understand engagement from the viewpoint of young people in treatment for a first episode of psychosis. Using grounded theory enabled me to capture how young people define events, realities, lived experiences, and ways of acting according to their beliefs about successful engagement. An additional benefit of using this approach is its strong association between a young person’s experiences that they express in their own words and the development of a theory based on the variability of those narratives (Chenitz & Swanson, 1986; Eaves, 2001; Glaser & Strauss, 1967). In this sense, grounded theory provided me with a systematic way to identify and assemble themes relevant to the process of engagement.

I also used purposive sampling to reflect the diversity of experiences within a group of young people all identified as successfully engaging with early treatment for psychosis. The process of purposive sampling starts with a purpose in mind and the participants are then selected according to shared characteristics of that purpose, even though they differ in other ways (Devers & Frankel, 2000). For instance, my purpose was to understand the process of engagement during the treatment of first-episode psychosis, and I selected young people who shared the experiences of successful engagement, knowing that they also represented a range of characteristics and diversity of background.

Procedure

I invited participants from a specialist early psychosis program (EPP) located in an eastern city of Australia to take part in the study. The EPP was established in 1995 as a comprehensive program aimed at addressing the mental health needs of young people with emerging psychotic disorders. I selected the EPP to position the process of engagement within a treatment context. Additionally, being a clinician of the service, I had a desire to expand my colleagues’ knowledge base about
engagement through a quality activity that included patient feedback. Conducting the study at the EPP also gave me the prospect of purposive sampling of young people who had successfully engaged. According to Catts et al. (2000) and Spencer (1998), who individually conducted comprehensive evaluations of the EPP, the service enjoys high rates of treatment adherence. Both researchers concluded that high adherence is attributable to a treatment model that includes a solution-focused client-centered therapeutic approach, a strong peer group culture, and the mobility of a clinical team to meet young people during the initial stages of treatment, particularly during hospital admission.

I had assistance from the EPP staff during the recruitment stages of the study. The first step required the EPP staff to identify young people aged between 18 and 20 years according to their level of engagement with the treatment program. The criteria included young people assessed as being highly involved with the EPP for more than 6 months. It was important that the young people had no prior history of psychiatric treatment, an absence of acute psychotic symptoms, and the ability to give informed consent. When a young person was identified, the EPP staff approached the prospective participant either in person or by telephone and explained the aim of the study. An introductory letter was then sent, containing a short explanation and the contact details. Young people then had the opportunity to self-select and contact me directly if they wished to participate.

Participants

There were 40 young people who received letters, and 32 nominated themselves for the study. Of those participants, one young person fell outside the age range and a second showed signs of an acute relapse during the interview and was hospitalized the next day. A total of 15 young men and 15 young women agreed to be interviewed. I ceased recruiting participants when the numbers reached 30 because of resources and time available.

During my initial conversation with each participant it became clear that this group of young people shared the experience of successful engagement, but differed in other ways. Gathering demographics from the initial conversation and reading case notes, I found that they reflected cultural diversity common to the area. Four participants were born overseas (Hong Kong, Greece, Spain, and Fiji) and 21 were first-born Australians whose parents migrated from Italy, Turkey, Scotland, The Philippines, Serbia, Germany, Malta, and India. The remaining 5 participants were from families of English descent who had lived in Australia for more than one generation. Reviewing the number of parents in each family household, I found that 20 participants were raised by two parents, 9 spent most of their lives in a household with only their mother, and 1 participant was raised in foster care.

At the time of admission to treatment all participants were assessed by a psychiatrist and given a diagnosis of acute psychotic disorder according to the International Statistical Classification of Diseases and Related Health Problems (World Health Organization, 1992), although the diagnosis changed over time. At the time of recruitment, 14 young people had been diagnosed with schizophrenia, 6 with schizoaffective disorder, 6 with depression, and 3 with bipolar disorder; 1 had experienced a brief psychotic episode that did not progress. Even though all participants were initially commenced on medication, 2 had ceased; the remaining 28 participants continued biomedical treatment, and 2 had additional electroshock therapy.

I obtained formal approval from the respective area health service and university ethics committees. Participants gave written consent prior to each interview. I took care to discuss confidentiality and gave assurances to each participant that his or her identity would remain anonymous. Each participant was encouraged to stop the interview if it became uncomfortable. All participants received a complimentary $2 lottery ticket as a token of appreciation.

Interviews

Each participant completed an interview that took approximately 2 hours. I developed the interview questions from an analysis of unpublished service evaluations, which had been collected by the EPP staff for more than 5 years. I identified two domains that defined the interview questions, including the experiences of initial treatment and the process of engagement. According to the service evaluations, it seems that many young people entered treatment through adult services and consequently suffered a number of personal difficulties. For me, it was important to decipher whether the group of young people participating in my study experienced similar difficulties and if so, to find out how they negotiated these problems and continued treatment. The young people who completed the service evaluations also identified that the process of engagement included relationships with EPP clinicians and peers who also attended treatment. Consequently, I became interested in the association between engagement and the nature of relationships found in the treatment environment.

I conducted the interviews either at the EPP site or the respective participant’s home. I based my interview style on the narrative practice of coconstructing discourse and transparency (Appleton, 1995). To encourage a narrative flow I led the interviews in a manner similar to an...
everyday conversation by openly discussing the aim of the interview, giving the participants the opportunity to ask about the nature of the questions, and soliciting feedback about my interpretation of the responses (Wimpenny & Gass, 2000). This manner of discourse is consistent with qualitative types of research in which the researchers set out to reduce a power relationship by inviting the participants to become experts in their own lived experiences.

By asking open-ended questions, I was able to explore multiple experiences, views, and meanings that the participants held about engagement. I used the questions as a guide, followed by a number of probes and prompts that encouraged a deeper exploration of the topic. As the interviews progressed, I modified questions from one interview to the next to become more specific with the discussion. For example, I was curious about the influence of parents on engagement, but soon found that this type of relationship was not strongly identified with the process and discarded these questions. At the completion of each interview I gave the participant an opportunity to consider his or her experience of the interview itself. The interviews were tape recorded, and additional information, such as emotional presentation and nonverbal communication, was documented through field notes. The taped interviews and field notes were transcribed verbatim, which aided me in eliminating biases in perception and recollection of the interviews.

Analysis

During the data analysis I used a combination of manual and computer-assisted methods. In the first instance, I manually organized the analysis of the interview transcripts. I first coded and interpreted individual paragraphs by underlining words or phrases that represented a particular picture of engagement, and then I listed them on large sheets of paper to scan more easily. By managing the data in this manner, I was provided with a visual perspective of the various narratives and themes. A parallel process was my own diarized interpretation of the transcripts, which revealed personal insights and interpretations of the circumstances associated with a particular text.

I then added a function for coding text and a more efficient way to manipulate, search, and organize data by introducing NVivo, a computer database software application designed to manage qualitative data (Richards & Richards, 2002). As I read, categorized, coded, and added the transcripts to the database file, I became more aware of themes. I then repeatedly analyzed general themes for more refinement. After consolidating the various themes I returned to the manual method by placing them on large pieces of paper and carefully searching for conflicting and disconfirming responses. Once themes were well established, I subjected them to a deductive analysis and organized summary tables according to consistent word sets, phrases, and patterns indicative of their correspondence to the process of engagement. Grounded in the data, I identified common factors associated with the facilitation of successful engagement.

Ensuring the Soundness of the Results

My dual role as clinician and investigator posed a number of challenges related to the execution and analysis of the data. To maximize the soundness of the results, I employed a number of methods to reduce the prospect of bias, increase the stability of responses, and promote a good fit between the data and explanations of the results. First, I was diligent with the data analysis. In particular, grounded theory methodology consists of a set of steps, the careful execution of which is thought to “guarantee” a number of themes. I also utilized techniques developed by Lincoln and Guba (1985) and strategies developed by Johnson (1997) to increase the soundness of the results.

Lincoln and Guba (1985) maintained that credibility, transferability, and trustworthiness are all essential when judging the quality of data, veracity of results, and accuracy of conclusions. Credibility is defined as the descriptive, interpretive, and theoretical validity of the research in terms of whether the participants’ views, thoughts, and experiences are truthfully understood and explained. Credibility establishes whether the results are correct, believable, correlate to the topic of the study, and then, when the theory fits with the data, are defensible. Transferability means that the results can be transferred to another context. Transferability and trustworthiness increase when the results are collected, analyzed, and scrutinized with a high degree of truthfulness. Therefore, other researchers are more likely to comprehend, value, and apply the results to a similar context.

According to Johnson (1997), a defensible study maintains the factual integrity of the participants’ accounts, reflects the majority of responses, and develops explanations that fit with the data. Therefore, the results should present as trustworthy enough to generalize to a different context. I used the following strategies developed by Johnson to maximize the soundness of the results: (a) I tested my impressions in conversations with the person who transcribed the audiotapes and another researcher experienced in qualitative research; (b) I practiced reflexivity as a method of critical self-reflection, which helped me to monitor and control for potential prejudices and presumptions toward the results; (c) I carefully and purposively searched for examples that might disconfirm the expectations or explanations of the response; (d) I openly compared the data to hypothetical control groups, other literature, expert opinions, and rival
explanations to decipher potential cause-and-effect relationships; (e) I reported verbatim quotes within the body of the results to illuminate and increase an accurate understanding of the inner world of the participants; and (f) I enhanced the consistency of the results by allowing steps, design, and methodology to be transparent and verifiable. This allows readers to make an informed decision about the generalization of the results.

Results

I found two significant themes emerging from the interviews: (a) young people are more inclined to engage during the course of a personal crisis brought about by the negative experiences of initial treatment in adult-oriented care; and (b) the process of engagement includes the timely introduction of clinicians and a peer-group culture that counters the negative experiences of adult care, and invites young people into client-centered relationships.

Engagement and Difficulties During the Initial Stages of Treatment

Reviewing the results, I found that a significant number of participants had experienced difficulties during the initial stages of treatment in adult-oriented care. It appeared that the high levels of distress, however, readied participants for relationships that helped them escape the problems they experienced early in treatment. Paradoxically, the culminating “hatred” for adult-oriented care sensitized participants toward relationships that assisted in strengthening their ability to cope. In particular, I found that the drive to escape the negative circumstances of hospitalization heightened the participants’ responsiveness to people who expressed a level of empathy, understanding, and guidance.

A total of 28 participants were admitted to adult psychiatric services in response to the emerging symptoms of psychosis. Out of the 28 participants, 25 entered treatment through a hospital admission and 3 were seen by private psychiatrists prior to joining the EPP. The remaining 2 participants received home-based treatment directly from the EPP, with the support of an acute care team. All 28 participants who were admitted to adult care revealed that engagement developed in the course of a personal crisis during the initial stages of treatment. The two greatest difficulties encountered by the participants included poor relationships with care providers and the stressful conditions of the hospital environment.

Participants identified the problems associated with care providers as including the clinical nature of the relationship, reinforcement of institutional rules at the expense of individual needs, poor communication about the illness and treatment, and an unsympathetic attitude toward the participant’s situation. Typically, participants described hospital care providers as clinically indifferent. The focus on medication led some participants to believe that the diagnosis was more important than themselves as people. Several participants disclosed that they often had a sense of being objectified and pathologized. Commonly, care providers were described as rude, judgmental, distant, tough, and abusive. The distress that developed during interactions with hospital care providers is summarized in the following quote from a young woman who was admitted to an adult psychiatric hospital in her teens:

The hospital was horrible. Being locked up in the “isolation room”; the way they just wouldn’t listen; their lack of compassion; their purely medical model. Thinking if I just took a pill it would all go away. The way they didn’t see me at all, they just saw the illness; and something else that was important: the lack of belief. The letter they wrote saying I’d never work again. The needles, like when they forced me to take the medication. Lack of support, and all the psychiatrists who wouldn’t listen when the medication was giving me bad side effects.

Added to the interpersonal problems with care providers, a number of participants also spoke of experiencing difficulties when confronted with the reality of the adult hospital treatment environment. The locked wards and unpredictably violent disposition of chronically unwell patients, plus coping with medication side effects, were all seen as adding another level of distress to the experience of treatment. The following quote describes the chaos and violence observed during one young man’s only hospital admission:

I was at [hospital] and the nursing staff were a bit nasty and a bit impatient. There wasn’t much to do there, so people were kind of getting worse . . . sometimes the nursing staff couldn’t control some of the patients, and that was a bit scary. I didn’t like it when people were cutting themselves and were stripping. It was horrible.

Participants developed a number of complex emotions and negative views about treatment as a result of the poor relationships with hospital care providers. They experienced increased senses of despair, guilt, anger, hopelessness, depression, and a loathing for certain care providers; for example:

The registrar [intern], she was a bitch. I did not like her very much. I did not cope with the registrar.
very well. I wanted to punch her face in. If my parents had not said no, not to, I probably would have.

Without adequate psychoeducation, some participants believed that they were to blame for the illness: “As if by getting unwell, I’d done something wrong. I had no idea what I was dealing with and they didn’t explain anything at all.” A few participants disclosed that the experiences during hospitalization exacerbated the symptoms of psychosis, decreased their ability to cope, and left them humiliated at the time of discharge. The anger and despair is evident in the following quote:

I didn’t cope when I was first in the hospital. I was worse going out of there than I was going in there. It was a complete misunderstanding about why I got in there because I wasn’t old enough to really defend myself and to have doctors patronizing me. To have people that don’t even know me, like nurses who don’t even know what happened, to be passing judgment over me was horrible, and then to come out and think that everyone knows where I’ve been.

It was clear that the majority of participants experienced difficulties during treatment and some considered dropping out. Even though the experiences of initial treatment were identified as difficult, paradoxically, many participants reported that the negative experiences motivated them to continue treatment and aim for recovery. I found that the worst experiences of treatment woke some participants to the reality of the situation, and that was what started the process of engagement: “I remember the acute ward. I really hated it but it really made me want to get up and get better. That’s where I made my first step in getting better.” Another participant’s decision to stay in treatment was motivated by the unpalatable idea of going back to hospital: “The acute ward. I especially hated it but it did help me. I don’t want to go back there so it made me try harder to get well, stay healthy, and look after myself.”

How the participants continued to negotiate the problems of initial treatment and successfully engage with the EPP points to two factors: the timely introduction of EPP staff who countered the negative experiences of initial treatment, in particular during hospitalization, and the development of positive peer relationships found within the community treatment environment.

Engagement as a Transitional Process

The transition between adult and specialist EPP community treatment was a significant point in the development of engagement. During this transition period all of the participants had contact with members of the EPP team and 26 identified that various EPP staff influenced their decision to stay with treatment. When I compared the attributes of staff identified with influencing engagement to those identified with early distress I found certain relationship factors associated with the engagement process. Participants dramatically preferred the accepting, genuine, optimistic, confident, flexible, and communicative characteristics of community staff when compared to the judgmental and unsympathetic characteristics identified with adult-care providers. One participant’s perspective can be garnered from the following quote. The use of the colloquialism “hitting your head against a brick wall” implies a lack of communication and a degree of frustration that was experienced with adult-care providers:

[EPP staff member], she’s very human, you know. She didn’t put up a wall between what’s professional and private, so she’s herself, whereas often with psychiatrists and nurses, it’s like hitting your head against a brick wall, whereas she was both very open and genuine.

Because of their attitudes, community staff were able to draw participants into a collaborative relationship in spite of the illness. In contrast, adult-care providers focused their clinical narratives on the illness despite the human needs of the participants. One participant’s interpretation of the different approaches is illustrated in the following quote. The open and transparent manner of conversing with community staff contrasts with the “narrow” and detached presentation of hospital doctors:

I liked the way [EPP staff member] used to let me describe what I was experiencing rather than saying, “Oh you have schizophrenia,” or “Oh, you have bipolar.” I think that sometimes with some doctors, the only way they can manage is by sticking to this narrow understanding so that they don’t really have any understanding of what you’re going through, what I was going through, but with [EPP staff member] I think it planted a seed that slowly grew where I started to feel like I was worthwhile.

One participant questioned whether psychiatrists or interns believed in the process of recovery, whereas she knew that community staff “wanted” her to believe she could recover. The recovery process included recognizing that she had to challenge the belief that the illness defined her as a problem, and then experience the illness as separate from her own sense of self and expectations about life:
I know my [EPP staff member] wants us to believe that we can get through this, but I don’t know if psychiatrists are ever aware or ever figure out that we can, like a physical illness, get healed. If you’ve got a broken arm, you can fix it, and whether psychiatrists ever think that we can ever get off medication. At first I was terrified that I was going to forever be an incapacitated person and I was never going to be able to achieve the things that I was potentially going to achieve before this happened. I had that feeling in the hospital because of the way that the doctors kept talking about it, that I’d be on medication for life. Really, that so countered everything that I believed was going to happen and it really terrified me, and it was really good to not be in there [hospital] and to be in the community program, where I quickly got from that, I’m not the problem, the problem is the problem. So I didn’t have to just be manic depressive you know; that I could actually be me who had this.

The momentum toward engagement during the transition from adult care to EPP could be attributed to the disparity between the negative hospital experiences and the positive encounters with EPP staff members. Many participants agreed that the early “bad” relationships in treatment seemed to sensitize them to the client-centered characteristics of community staff. It also seemed that their positive relationships with EPP staff prevented negative beliefs about initial treatment from generalizing across all staff relationships and defining future treatment experiences. According to one participant, the entire mental health system could be perceived as “bad” if it were not for some “good” experiences after being discharged from hospital:

The hospital experience was pretty bad. I do believe people need to be hospitalized, but the hospital experience is very bad, and I think if you don’t come out and get a good experience right after that, then that’s how you perceive the whole system.

According to the participants, the human relationship dimension of treatment was crucial to the development of engagement. Once contact was made with the EPP and community treatment proceeded, the participants found that the relationship with staff was a reason to continue in care. For example, the two participants who entered treatment directly through the EPP described staff as approachable, trusting, nonjudgmental, understanding, and empathic. The participant quoted below saw the EPP intern as able to build rapport by taking the time to talk:

It was really important that he [intern] came and saw me [at home] because I felt like I could identify with him really well as a person. He even didn’t put me in hospital, which was on the day I was determined to kill myself, but that’s like every other day. Yeah, well this is pretty much the trust you had to form and . . . there has to be that kind of trust, and somehow I just established this instant rapport with Dr. B. Or he managed to establish it with me. I had fun talking to him and seeing his spin [perspective] on what I had to say, so there was trust between us . . . . I felt like he was the only person who could do something for me.

The majority of participants identified that successful engagement was attributable to relationships in which clinicians taught them about the illness, guided them through treatment, identified and supported their personal strengths, and instilled an optimistic view of the future. They described these clinicians as genuine, unconditionally accepting, and comfortable with personal closeness. Clinicians who influenced engagement shared a rational understanding of problems and reflected a commitment to finding solutions. The participants’ ideas and insights were utilized in treatment, and the natural potential of each young person unfolded through support and guidance. They adopted a humanistic, client-centered approach to treatment that focused on the patient as a person rather than the illness:

She saw me and listened. She didn’t disregard my reality or my feelings. She stuck with me. She [EPP staff member] kept us going and—each person—she made us feel special like, normal, like she would treat normal people. She listened, never pushed on an issue, gave us ideas, an analogy, and left it to us. That was good. She always encouraged us.

Peer Group Involvement as a Factor in Engagement

Many participants added that the introduction of the peer-group culture found at the EPP served to solidify the process of engagement. The mixture of staff and peer relationships synergized a social dynamic that encouraged young people to stay in treatment:

I think it’s definitely got to be a mixture of the staff, and the pivotal point will be the staff and then the staff attract people. Like, the patients attract the other people, and so you have the combined pulling of the staff and patients who engage other patients,
who will stick around [stay in treatment] because the staff are so great as people. There’s some form of stimulus and entertainment and fun. Definitely “group” without the groups you wouldn’t have the social dynamic. You probably wouldn’t be able to get to know the staff as well as the other patients without group.

The dynamics of the peer-group culture that participants saw as encouraging engagement included normalizing the experience of the illness, reducing isolation, and increasing an ability to cope. By attending the weekly group meetings the participants were able to observe and measure recovery from the expertise and experiences of other young people who had also struggled with psychosis:

Going to “group” is very important; it was very important for me. First of all, being able to get an insight about the illness, being able to see people with problems and then, after realizing everything that I’ve got, actually staying in group and trying to help new people and reinforcing in myself the things that I’ve thought are helpful.

Many participants reported that meeting and gaining support from people with similar problems also reduced the negative impact of the illness on social development. For many participants, belonging to a peer group gave them a sense of friendship, an opportunity to talk in a positive and nonjudgmental atmosphere, and the chance to experience a collective determination toward recovery:

Definitely the groups [kept me engaged]. When we used to all just sit around there in a circle, it felt really warm and easy to talk, and I looked forward to it. I looked forward to going there and hearing other people’s stories as well. Sometimes it was comforting, and getting to know some of the other people that went along to the groups and the other groups that were organized as well, and I just felt a lot more positive.

Participants experienced group dynamics as shaping and normalizing the experiences of the psychotic illness, giving voice to problems, providing a sense of being valued by others, and helping define a purpose in life. In summary, group cohesiveness was based on the intrinsic act of giving and receiving insights and providing perspectives on life unimpeded by the illness. I found that the introduction of a patient peer culture added a unique level of understanding and support that encouraged the process of successful engagement.

Discussion

I interviewed 30 young people about their experiences of successful engagement. Examining the results, it is my theory that the quality of relationships engendered in the treatment process determines the success of engagement. Overall, the patient’s decision to stay in treatment is driven by relationships with clinicians who embrace client-centered perspectives and peers who have also experienced first-episode psychosis. The results resonate with a body of literature that emphasizes the importance of the therapeutic alliance and client-centered practices that articulate empathy, positive regard, genuineness, and focus on the patient as a person rather than the illness (Asay & Lambert, 2006; Frank & Gunderson, 1990; Horvath & Greenberg, 1994; Rogers, 1957).

The importance of peer support on the process of engagement is also expressed in articles that identify how the peer culture acts to capture patients who experience serious trust issues with authority (Lecomte et al., 2008). Although these comparisons are important, I note that early psychosis treatment services have purposely been designed to provide client-centered and humanistic interventions that focus on building a therapeutic alliance and supportive peer-group culture. In this sense, my results confirm best practice for the treatment of first-episode psychosis. Nevertheless, a result that needs more discussion is the timing of engagement, particularly during a young person’s hospitalization.

The idea that a personal crisis during hospitalization acts as an enabler to engagement suggests a significant extension to previous research. It is my assertion that the introduction of client-centered early intervention staff prior to hospital discharge is a landmark event in the process of engagement. The clinician and young person progressively improve their relationship during the course of the transition. Other researchers have also identified that the transition from institutional to community-based care is a critical time for engagement (Herman et al., 2000, Thornicroft & Susser, 2001). According to Herman et al., the success of this stage is dependent on social support and strong ties between patients and clinicians that are maintained past the point of hospital discharge. The additional introduction of the outpatient peer culture then acts to embed young people in a protective community of care through the transitional period. Entering a group culture, young people are able to see beyond the illness and the difficulties of initial treatment, create new truths that value their unique experiences, and develop competencies within a context of peer support.

I would add that a young person’s decision to stay in care is not a discrete event or private matter resting solely on his or her ability to respond to biomedical
treatment. Rather, young patients can be considered socially active agents who interact and construct accounts and meaning of an experiential world of treatment. In this context, I would define young people as actively involved in relationships and capable of construing and constructing realities about engagement regardless of their symptoms. I found that young people entering psychiatric treatment for the first time are not totally under the influence of the illness, but are capable of participating in treatment and the recovery process. Therefore, clinicians do not have to wait until the symptoms resolve before developing interpersonal interactions that influence engagement.

Limitations and Implications for Future Research

Although my article provides a useful picture with regard to one type of experience of engagement, the small sample size of 30 young people is a limitation. The use of a small sample raises questions about the ability to compare the results to other treatment settings and patient groups. Even though the results reflect the majority of responses, more in-depth exploration of the factors related to engagement would continue to add credence to the process. Additionally, the majority of the participants had a history of hospitalization. The large numbers of hospitalized participants were serendipitous to my study, but purposely selecting young people who successfully engage and avoid hospitalization would serve to test and develop an engagement model. The clinicians’ perspective of engagement would also add to the knowledge base of the topic.

I found that the analysis of the data did not reveal any overt evidence that consistently contradicted the reported themes; however, an improvement would be the addition of independent raters. Including a team of raters in future research studies could add greater dimensions and observations to the emerging themes. Additionally, research studies are needed to consider the viability of applying a model of engagement to the daily practices of psychiatric treatment, especially within adult psychiatric treatment settings. The question is whether a relationship model of engagement fits with various patient settings and what would differentiate the process between older and younger patients.

I have little doubt that the difficulties identified with hospitalization elucidate the need for more investigation. There are questions about the types of people who work in a hospital setting and the systemic or institutional influences on their behavior toward patients. I would be interested to know whether early psychosis care providers can retain the same abilities to engage patients if placed in hospital roles. I would also give more consideration to the mental state of young patients and the impact of that on engagement. Even though I found that the acute symptoms of the illness did not interfere with the patients’ abilities to observe and evaluate the circumstances of hospital admission, the dynamics of that phenomenon need clarification.

To date, mental health care providers have no clear definition of engagement or an approach known to reduce dropout. Investigating the human and social aspects of care has real implications for developing a model of engagement. Care providers now have the opportunity to initiate new narratives knowing that engagement is associated with the nature of relationships found within the treatment environment. I am always hopeful that future research will add to this important and necessary topic, while reducing the gap between results and clinical practice.

Conclusion

In February 2010, Press Ganey Associates published the Satisfaction Snapshot to provide evidence on what influences inpatient satisfaction. Drawing from a data base of 3.1 million surveys of recently discharged hospital patients, the report’s authors emphasized the importance of the patient–clinician relationship. Specifically, they found that what differentiates a high-performing hospital is not necessarily the clinical process but the emotional level of caring found within the patient–clinician relationship—in particular with nursing staff.

Regardless of demographics such as age and race, it seems that patients wish to be cared for as people, to be kept informed, to be talked to rather than be talked at, and to have the opportunity to participate equally in their care and recovery. Although the researchers at Press Ganey Associates drew the results from 2,000 acute care medical hospitals rather than psychiatric facilities, their findings give credence to the universal importance of the patient–clinician relationship on treatment engagement. It seems that all patients have a common need for real relationships with clinical staff to meaningfully engage.

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