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Treatment of Youth with Bipolar Disorder and Substance Use: The Youth ACT Care Model and Self Determination Theory

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Abstract

Youth Assertive Community Treatment (Youth ACT) is a rising novel community based care model for youth with pervasive psychiatric illness. This type of intensive treatment follows specific principles which include an interdisciplinary team, small caseloads, 24/7 access to the team, and treatment given in the patient's home or community. A variety of studies have reviewed outcomes and generally report that patients have statistically significant improvements in symptoms. However, much is still not well understood about how this model works, how it is applied, or about the clinical significance of the models. There have been relatively few case studies written outlining how patients respond to the Youth ACT interventions. To better understand Youth ACT, how it works, and what patients may benefit from this level of treatment, a clinical scenario is discussed. This clinical scenario involves a 15-year-old male youth with bipolar 1 disorder, psychosis and ongoing substance use. This case is indicative of the severe psychiatric symptoms that the Youth ACT teams address in the community. After case presentation, outcomes are discussed and significant clinical improvement is reflected upon.

Introduction

Youth Assertive Community Treatment (Youth ACT) is a model of care that is popping up in certain areas of Europe, Switzerland, Australia, and now the United States[1,2]. The Youth ACT model of care has largely been fashioned after adult assertive community treatment, with 9 core components that include small patient caseloads, an interdisciplinary team, crisis management, 24/7 access to team, clinical flexibility, medication management as needed, and of course, community based care care[2]. Youth ACT consists of a multi-disciplinary team in the community that interacts with the identified patient and family in their normal environments- home, stores, schools, or even outside. The team consists of clinicians, clinical support staff or case managers, family or youth support staff, a psychiatric nurse practitioner (NP) and a team leader. Assertive treatment for this team means reaching out consistently and without reservation to the youth and family to set up frequent visits during which the staff go to the patient, rather than the other way around.

Youth ACT has an evidence base indicating that youth with both psychiatric and substance use concerns have statistical improvements in symptoms and substance use after they engage with the program[1,2]. However, some authors do well to note that statistical significance does not always equate to clinical significance[3]. While many scales and rating systems do well to capture clinical change, clinical improvement on a Youth ACT team is still difficult to quantify[3]. It remains important for adolescents to function successfully in society

and achieve developmentally appropriate milestones as key aspects of clinical improvement. So the question remains, how exactly does a Youth ACT team facilitate neuronormative development and improved functioning in youth with severe psychiatric disorders and substance use? Does the quantitative data truly capture improved quality of life and what does that look like for the youth that qualify for this treatment? These are the considerations for the discussion of the following clinical case scenario.

In addition to this query about treatment modality, there is a pressing need for psychiatric care for youth in the community. Less than two thirds of young people presenting with a psychiatric illness get the care that they need[4]. This further contributes to poor outcomes, impaired functionality, and substance use[4]. Many barriers including systematic and individual characteristics, such as transportation or mistrust of the healthcare system[4,5]. These factors contribute to the difficulty of youth with psychiatric needs and substance use to access treatment[4,5]. Despite bipolar and substance use often starting in the adolescent years, we have huge gaps in reaching our target population and engaging them in treatment. As many as 38% of young patients report not receiving treatment[6].

Case Presentation

The patient for this case is a 15-year-old male, with no notable medical or physical illnesses. He came into Youth ACT with the diagnoses bipolar 1 disorder and unspecified substance use. When he first came to Youth ACT after stabilization in extended inpatient care, he was slow to respond, monotone speech, had slow movements, and appeared groggy. He responded minimally to questions, providing one word answers after long pauses. He had been hospitalized for risky behaviors, delusional thinking (paranoia that dad was poisoning him and ascribing meaning to mundane objects), and manic behaviors (decreased need for sleep, increased agitation). He was diagnosed as having bipolar 1 disorder with psychotic features at that time, which was less than 1 year prior to Youth ACT admission. This hospitalization also identified substance use, with the youth testing positive in the hospital for cannabis and benzodiazepines. Prior to this he was engaging minimally in outpatient treatment, which he started only a few months prior to hospitalization. During this time, the youth frequently stated "I don't need therapy." Therefore, the referral was made to Youth ACT treatment for improved engagement. Previous therapists had described the family as "cold" and "distant", stating that the youth reported not feeling close to either parents. This youth remained in Youth ACT treatment for roughly one year and was successfully discharged to a lower level of care without specialized substance use treatment (youth refused this). During the year, he received treatment as detailed in the following sections.

Engagement

Most visits took place in the youth's home or in the youth's school. Communication and regular contact occurred with parents throughout treatment as well. The initial task on the team's radar, in addition to assessing youth and family needs, is to build rapport with the youth. Adolescent patients can be unique and challenging in that they often do not want to be in treatment. They also want to have age normative experiences and resist having more adults telling them what to do. The team promoted youth engagement through open ended questions, prioritizing youth and family goals, and offering incentives when possible (such as trips to fast food restaurants as part of therapy). In the beginning, the youth was hesitant to interact with the team, but as time progressed the youth talked more with the team and made his preferences and goals known. A key aspect of engaging this youth was accepting his statements of not needing therapy and focusing on concrete supports with a goal of discharge if he maintained stability in the community.

Psychotherapy

Psychotherapy focused on safety planning, crisis management, communication skills, supporting youth-parent relationships, positive reinforcement of coping skills and good communication. The team also provided encouragement around age normative tasks such as doing well in school, meeting parent's expectations, taking driving test or obtaining a job. The team primarily used supportive therapy techniques that focused on promoting a sense of belonging, unconditional positive regard, and acceptance. Due to this, the youth was able to freely speak on his concerns and goals.

Case Management

The clinical support staff provided case management services for the team, youth and family. In addition to connecting with educational services to offer our support at school, this member of the team assisted the youth in finding employment and developing practical strategies for being safe in the community. During the time in the Youth ACT program, the youth was able to obtain his driver's license and employment while also remaining successful in school despite some school suspensions for suspected cannabis use at school. Clinical support staff also supported the team with treatment planning and keeping on target with the youth's individualized goals.

Family Support

The family peer advocate supported the team and the family stay on track with treatment goals and supported the parents in learning how to support their child on the Youth ACT team. For this family, there was a considerable

discrepancy between youth and parents due to difficulty engaging in open communication. To be more specific, this family received education on strategies to communicate with each other and build closer relationships. Parents learned ways to show empathy so that the youth would feel less isolated from the family.

Parents were given space and time to process their concerns and then discuss with youth through a more open and accepting dialogue. The Youth ACT team were able to be flexible and respond to family needs and crises events as they came up, such as substance use situations or school suspensions. The family prioritized belonging and acceptance rather than focusing on the youth challenges, which ultimately improved youth motivation to do better in school and social functioning.

Medication Management

This youth came to Youth ACT treatment on risperidone 0.5 mg and lithium carbonate extended release 1200 mg daily from his extended inpatient stay. Initially, the youth was sleepy and groggy during meetings. Father reported that the youth has been sleeping more often than usual. Father reported that he was sleeping throughout the day and during the night, which was highly unusual for the youth. Youth had also not been interacting with peers at all, despite being a very social individual at baseline. Therefore, risperidone was stopped lithium was reduced to 900 mg daily following labs. These changes improved his alertness. Lithium blood levels remained above 0.6 mEq/L throughout his treatment time with Youth ACT on this reduced dose. While this prevented any acute mania, the youth and father still reported low mood after 3 months with Youth ACT. Youth was not convinced that medication could help, but he agreed to trial lurasidone 40 mg daily. After 4 months he appeared to have an improvement in mood, but he insisted that he did not need the medication and no longer wanted to take lurasidone. He stated that he was using strategies to improve mood, and that the medication made him shiver and feel more cold than normal. Although this is not typically a known side effect for this medication, the shivering did stop after the medication was discontinued. Therefore, collaboration was used with the youth and the medication was discontinued. This helped to build trust and therapeutic alliance with the medication prescriber. The prescriber (Psych NP) maintained clear communication with dad to relieve his any potential stress regarding the youth requesting less medications. This was processed with dad and symptoms to monitor for were discussed. This built on the dad's developing skills of communicating and collaborating with his youth. With this support, the youth did not experience any acute manic or psychosis events will in Youth ACT.

Substance Use Treatment

This youth continued to use substances recreationally when with peers, and his willingness to discuss substance use did fluctuate throughout his time with Youth ACT. Six months into Youth ACT care, the youth was in his room and not responding to parents knocking on the door. When parents did get into his room, the youth seemed very sedated at first and then when they were able to awake him, the youth became aggressive and punched his father. The following day a toxicology screen and labs were completed to identify contributing factors. The youth complied, and this allowed for an open and honest conversation (with youth, father, and psychiatric NP) around edibles and pressed pills that the youth had used and what outcomes may be from these substances (lab results showed many THC and benzodiazepine varieties). After this, the Psychiatric NP was able to facilitate harm reduction conversations which included testing substances for fentanyl, not driving while under the influence, and never using alone. Father was also provided with Narcan in case of emergencies, though this was never used. At the time of discharge from Youth ACT, the youth was able to remain safe in the community and while around friends without completely committing to abstinence, using this harm reduction approaches with the Youth ACT team.

Goal's set by the youth and parents included items like the youth being successful in school, wanting to avoid future inpatient hospitalizations for youth, and increasing youth's independent function. Therefore, the Youth ACT team worked to educate youth on the effects of substance use on these goals and how this did not match where he wanted to get in life. Due to this, youth was able to engage in conversations with the Youth ACT team about substance use and minimizing risks without completely committing to abstinence.

Psychoeducation

The psychiatric NP and other team members also provided education to the youth and father throughout Youth ACT treatment. This included a discussion of medications, psychiatric symptoms, laboratory results, and the youth's unique presentation. At the time of discharge, father and youth were having open conversations successfully. Youth was reporting a safety plan to communicate with dad if he noticed delusional thinking patterns similar to what he noticed prior to previous hospitalization. Youth demonstrated good insight into his illness and risk of hospitalization by following safety plan and meeting with providers even when he didn't necessarily want to. After a year in Youth ACT treatment, father and youth reported an increase in their ability to manage youth's conditions in a lower level of care, so the youth was discharged successfully to outpatient psychiatric care.

Wellbeing Framework: The Self-determination Theory for Youth

The Self-determination theory considers sources of motivation and what an individual may need to reach their full potential. This theory was selected for its synchrony with the goals for this treatment team. These goals were not simply the absence of psychiatric symptoms, but improved functionality and the completion of age normative tasks (as a sign of improved mental health). This theoretical framework indicates that each individual has 3 broad categories of psychological needs that need to be met in order for them to feel intrinsically motivated to engage in positive activities and promote their own individual growth and wellness[7]. Based on this theory all individuals need competence, autonomy, and relatedness to improve motivation and engage in their own care[7]. This is to say that all people need to feel a sense of belonging and connection to others, they need to feel some sense of control over their own life, and they need to develop a sense of competence in navigating the nuances of their own life. This can sometimes be difficult to navigate in young patients. In this youth, the acceptance and empathy from the team provided a foundation of belonging for the youth and family. The work with the family allowed for focus on family inclusion and empathy first during times of disagreements, which promoted youth's sense of relatedness and belonging within the family. This also improved parents sense of competence in resolving difficult situation. The family peer worked with parents on shared decision making to build autonomy and competence, which was also modeled by the medication management discussions with the psychiatric NP. This will be further illustrated in the assessments listed below.

Assessment Tools

This youth and his family were assessed thoroughly upon admission and discharge using the Family Assessment of Needs & Strengths version 3 (FANS) and Child and Adolescent Needs and Strengths – New York 6+ version 2.0[8,9]. These assessments cover a variety of topics and spheres of functioning for the youth such as functioning at home or school, functioning in social settings, substance use, and functioning around basic hygiene. Lower scores reflect less needs. This youth scored 79 upon admission to Youth ACT care (showing needs in areas of social settings, home settings, with sleep and with substance use practices). Ultimately, youth improved to a score of 68, with marked improvements in areas of family functioning, sleep, school functioning, and engagement in social settings. Youth voiced an interest in wanting to be involved in decision making for his own care.

The FANS assessment started at a score of 13 and progressed to a score of 4. The FANS assessment showed weaknesses in caregiver self-efficacy, caregiver stress or burden, caregiver ability to communicate and caregiver optimism or hope for the future. Parents verbalized that they wanted to learn about how to better engage their son into the family milieu. Parents also reported wanting to be able to have open and honest conversations with youth while also maintaining their own integrity based on family values.

In addition, the youth completed the Mood Disorder Questionnaire (MDQ) upon initial assessment indicating a history of both manic and depressive symptoms. Lastly, Patient Health Questionnaire 9 (PHQ-9) and Generalized Anxiety Disorder 7 (GAD-7) scales were also used to monitor symptoms. were completed at admission and discharge, which indicated an improvement of 14 and 11 to 2, respectively. These assessments helped guide the team through specific interventions along the arc of treatment and were done every 6 months. The youth was able to work on goals of being involved in medication management and diagnostic decisions. The family and youth were able to work through communication goals and skill building. Additionally, youth worked on connecting with peers and engaging in harm reduction conversations regarding substance use and risks (such as understanding potential side effects and the importance of not using substances alone).

Patient & Youth ACT reflections

Overall, this family was appreciative of how accessible this youth's mental healthcare was. Family voiced appreciation for the accessibility of the Youth ACT team and their constant monitoring of youth progress. This youth himself voiced that he did not need traditional therapy modalities and his concerns were validated throughout the treatment. His concerns relating to medications were also validated and used to inform care. Youth ultimately stated that he did not need such intensive treatment, but appreciated that this program helped to prepare him to remain successful in the community by developing plans to communicate to family if he experienced any increases in symptoms. Youth ultimately did have an increase in motivation, finishing his junior high school year successfully, learning to drive, engaging with peers, and obtaining a job.

Youth ACT team members saw immense value in the program's ability to build on family and youth strengths. Parents and youth were very insightful throughout their time with the program and clearly articulated concerns. In congruence with the literature, team members saw the Youth ACT level of care as being appropriate for youth who struggle with psychiatric symptoms and substance use.

Discussion

This clinical case was presented to highlight the

many aspects that are important for complex psychiatric care in youth. By reviewing this case study, healthcare professionals can identify ways in which they may need to be more flexible and assertive with adolescent patients, who often do not choose of their own volition to engage in care regardless of severe psychiatric symptoms. A flexible response to resistance can promote good outcomes in youth who may not see the purpose of healthcare visits.

Limitations of this article include the discussion of only one youth at this time. However, this is fitting to the small caseloads of assertive community based teams. Additionally, assessment of the youth and family do not include information from 6 month follow up after leaving the Youth ACT treatment (this time frame had not passed at the writing of this article). Despite these weaknesses, this is a unique case that is worth considering as it includes early onset bipolar symptoms and substance use in a youth that does not see any potential in psychiatric treatment. However, with intensive community supports, he was able to do well with the Youth ACT team. Strengths of this case study include the use of assessment tools, and the inclusion of patient experience.

This team built trust by being reliable and listening to the youth when he was advocating for himself. This included making compromises and helping parents to realize that youth need to feel heard to be successful and active in their own care. This teaches them to listen to their own bodies and allows them to develop confidence in their ability to understand their own symptoms and communicate these to others. This youth reported a mistrust of his parents prior to being admitted to Youth ACT. Through treatment, the family peer advocate and other team members were able to encourage parent communication styles and increase their confidence in facilitating open discussions with their child. Ultimately, this contributed to the youth's sense of belonging in the family. This safety and sense of belonging allowed the youth to become more vocal and involved in his care needs and what services would be helpful to him.

This was helpful because throughout treatment, the youth developed a safety plan for remaining out of the hospital that he took ownership of. This plan included communication with dad if youth were to experience any hallucinations, mania, or delusional thinking. In remaining out of the hospital, this youth was highly successful despite the fact that he did not engage in traditional psychotherapy or agree with every medication recommendation. Allowing the youth to have a voice in treatment promoted autonomy and competence. Harm reduction interventions as a strategy also helped the youth feel more at ease discussing his use through radical acceptance. This approach also allowed the parents to help keep the youth safe. The mechanism of action that promotes these outcomes are hard to quantify in rating scales and the clinical significance is individual to each patient, thus making patient scenarios critical to understanding how these flexible treatment teams exert their effect. The Self Determination Theory allows for the identification of what mechanisms may be useful in Youth ACT teams.

Conclusion

It is often hard to identify how the Youth ACT programs are successful with a wide range of youth and young adults. One key factor is the way in which they encourage youth to partake in their own treatment decisions which develops a sense of autonomy and competence as patients are experts on themselves. This is done while also remaining with the patient and family through difficult times in their lives- contributing to a sense of belonging. Through these mechanisms, this team was able to help a particular youth with psychiatric illness and substance use disorder transition back to living at home after an extended in patient hospitalization stay. He also increased motivation to be successful in school, learn to drive, and get a job during his time with Youth ACT. Teaching skills and listening to the youth when he had concerns built up his confidence until he no longer needed extensive community-based services. In this way, Youth ACT can assist with treatment for substance use disorder with psychiatric illness. Ultimately, this youth displayed an overall improvement in function that was clinically significant for both the parents and the youth. This was determined by taking into consideration youth and family goals, their progress towards those goals, and their perception of the progress made. Patient and family outcomes were then reviewed in the light of a wellness based framework to better understand the functional underpinnings of youth assertive care.

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