Combining Peer Support, Emotional CPR and Open Dialogue Facilitates Recovery from Schizophrenia

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Abstract: In this study, we illustrate how a combination of peer support, Emotional CPR, and Open Dialogue have enabled a young man to recover from schizophrenia. The client had 15 psychiatric hospitalizations from 2011 through 2017. During that period, traditional clinical practice and medication did not reach him. However, in 2016 during his 13th hospitalization, a peer (Mateusz, the lead author), began a series of meetings with the client. The peer used his lived experience and Emotional CPR to meet the client at a nonverbal level. He developed trust and the client started to talk and engage in Open Dialogue meetings with his family and started to consistently take his medication. He has not been hospitalized for the last six years and he now works.

Authors’ Note: The ongoing peer support, Emotional CPR (eCPR) and Open Dialogue as well as the follow up interviews were all conducted in Polish. Dr. Fisher is very grateful to Ms. Zawisza and Biernat for translation and interpretation.

Introduction

One of the greatest challenges in the mental health field is how to engage persons with severe psychiatric conditions in mental health treatment. Traditional clinical mental health care fails to reach persons with such conditions. The traditional elements of diagnosis, psychotherapy, and medication seem pointless to people dealing with these conditions which shake the foundations of their world. The usual treatments fail to address the most basic need which is to be heard and understood, usually at a nonverbal, emotional level.
Typical mental health care depends on communication at the cognitive and verbal level. The psychiatrist and other mental health professionals are taught to ask a series of questions to pinpoint a diagnosis. But people in acute distress experience direct questions as attacks. Without meaning to, professionals also reinforce a sense of powerlessness by relating in an unemotional manner. Therapists are taught not to show their own feelings. But, in fact, when a person is in acute distress, they want to know there is a human being with them more than anything. Expressing feelings is the most convincing way to assure the person in distress that they are not alone.

The relationships between clients and professionals usually involve the professional problem-solving the client’s problems, which is disempowering. These experiences of powerlessness also diminish hope and motivation. To make matters even worse, clients are blamed for their lack of engagement and are coerced into treatments they feel alienated from. In contrast, people with lived experience have found that they can often more readily communicate with peers than professionals. The vulnerability and authenticity with which peers communicate reduces the power difference they experience with professionals. Instead of feeling hopeless, they are inspired by peers.

In addition, a new training, Emotional CPR (eCPR), is enabling peers and family members to engage with people in severe distress on an emotional level. This approach emphasizes connecting on a heart-to-heart level first, and with words second. People assisted through eCPR experience empowerment because they are encouraged to be equal partners in their care. The people assisting share their own feelings in a manner that makes their relating more authentic. The CPR in eCPR stands for Connecting, emPowering, and Revitalizing.

In addition, a group of Finnish psychologists realized that typical family therapy was not helping people with severe emotional issues. They have developed a highly respectful approach called Open Dialogue in which every voice is valued. Open dialogue was greatly enhanced by a combination of peer support and eCPR with a young man and his family, in Poland, as will be shown below. This combination of three approaches
helped the person in acute distress to have a voice in their family meetings, thereby enabling them to emerge from their monologue and enter the polyphonic community.

In summary, the unifying principles underlying peer support, Emotional CPR and Open Dialogue are compassion, love, understanding and hope. The person in distress and their family feel the team cares, they regain motivation to live, and they are revitalized.

D and His Family History

We share here the story of a young man "D" (we will use this initial to protect his identity) in his late 30s in Poland who has shown significant recovery from schizophrenia through the synergistic effect of peer support, eCPR, and Open Dialogue.

According to his twin sister "C", D was a very shy child. He had one friend in primary school. Teachers commented on his absenteeism, isolation from classmates, and lack of interest in meeting with peers. His condition worsened significantly after his older brother and sister moved out of the house. In high school, he began meeting with a psychologist once a week. Those meetings lasted for 2.5 years.

After a while, he stopped drinking liquids, eating, and lost a lot of weight. His hair was falling out. He didn't sleep. He sat in front of the computer. He was inattentive to self-care. D's mother asked to see the attending psychologist. The psychologist did not want to talk to the family. To the mother's concerns about weight loss and starvation, the psychologist responded: "Do you want a fat person in the house? My children don't eat either."

D did not socialize during high school and only attended the school prom for an hour. At age 18, D began studies at a university with a major in environmental protection. In January, he began to come home very sad, constantly lying in bed. He stopped eating again, and his hair began to fall out. In May, he came home announcing that he would not return to his studies. At the age of 20, he received a call to enlist in the army. After tests in the army, an initial opinion came out suggesting "schizophrenic
behavior." However, it was not a diagnosis but a description—and an opinion that none of the family paid attention to.

At age 21, D went to a psychologist who administered the MMPI and a Rorschach. Here are some of the results: D had a

sense of psychological discomfort, inner restlessness, persistent repetition of "proven" routines in behavior, inward-directed aggression, inhibition of activity, uncertain testing of reality, tendency toward social introversion, increased deep anxiety, low self-esteem, low self-acceptance, sense of low position in the social hierarchy, predominance of anxiety-based defense mechanisms, significant disruption of social contacts, strong internal normative conflict, sense of loss of control.

At age 22, a psychiatrist diagnosed depression and prescribed him his first medication. He did not experience any positive change. Another psychiatrist, Dr. H, concluded, "I have no doubt that this is simple schizophrenia. It develops very slowly, and it is the worst type of schizophrenia. You will have to take medication for the rest of your life because this disease lasts for the rest of your life." The doctor prescribed Solian, an antipsychotic medication. He discontinued the medication after about 2 years.

At age 24, upon recommendation by friends, D began day treatment. There were meetings with actors, cooking classes, and other activities. He was supposed to go there every day. One day, in the evening during a huge storm, he said he was going for a walk. He returned at 5 AM soaking wet. When asked where he had been, he replied that he had been for a walk—then left again. His older brother tried to stop him but to no avail. They found D in just his shorts three days later in the stairwell of a neighboring town. He was hospitalized for the first time at age 27 for 12.5 weeks.

This was the first of 15 hospitalizations during the next six years. During that time, he would stabilize in the hospital with support and medication but would never follow up with treatment in the community. D's sister, C, was desperate. She could see that traditional mental health care was not working. She was losing hope. C looked everywhere for a therapist, but
they only wanted to give him drugs—nobody wanted to try to reach D without drugs. D was hopeless, he was afraid of people.

Then, in 2015, C heard Daniel Fisher give a talk describing his own recovery from schizophrenia and his journey to become a psychiatrist. This talk gave her hope that D could recover. In the talk, Daniel described that peer support, Emotional CPR, and Open Dialogue can facilitate recovery.

**Peer Support, eCPR and Open Dialogue**

C encouraged Mateusz, a peer, with lived experience of recovery to meet with D during his 13th hospitalization. Mateusz could see himself in D—he, too, had felt oppressed by the system. He saw a person in pain who was nonverbal. His mother spoke for him. Mateusz decided he would be D’s voice. Mateusz was the first person to connect with D. Daniel became curious. He wanted to discover how Mateusz was able to connect with D when no other mental health worker had been able to do so. So, Daniel asked C, “How did Mateusz connect with D?” C said:

Mateusz saw D as a human being. He treated him as a normal person who could speak. Mateusz’s approach was different from traditional clinicians. Mateusz looked at D as a person in distress, because he looked beyond D’s diagnosis. He was not hopeless. Mateusz did not judge D. He was not afraid of him. Mateusz saw D as a normal person in an abnormal environment.

C felt hopeful when she met Mateusz because she could feel Mateusz’s hope. C felt that Mateusz understood D’s family situation. D did not want to live in the hospital and Mateusz supported that impulse. Mateusz was D’s megaphone. D was not talking when they met. Then he started to use words and, eventually, whole sentences. Peer support created an understanding and connection on an emotional level.

Once he felt connected to Mateusz, D joined the family in Open Dialogue meetings. These were conducted by Mateusz. Everyone was on an equal level, which allowed for a polyphony—that is, for all voices to be heard. Mateusz was available whenever the family wanted to talk. He was reliable. It was very important that Mateusz heard and valued every voice
in the family including D’s mother who had been excluded in previous meetings conducted by professionals. In Mateusz’s eyes, everyone was of equal importance. Mateusz never took sides—he walked in the middle.

To find ways that she could connect with D, C took the eCPR workshop. She said, “eCPR helped me to open up to my emotions, and it allowed me to start to talk about my emotions.” Mateusz also took the eCPR class. Daniel asked Mateusz what about his approach resembled eCPR. Mateusz said that the emphasis in eCPR on nonverbal communication was consistent with his way of connecting with D. He said eCPR helped him to put into words what he had intuitively used to reach D.

Mateusz said, “When I first met D, I met him as a person. I started with eye contact. I empathized with D. I could feel his sadness. I wanted to cry.” When Daniel asked Mateusz how he reached D, Mateusz said:

D actually reached me. I felt a tightness in my stomach and chest. When I shared this feeling, D said he also felt a tightness in his stomach. I felt D was telling people one thing but feeling something else. When D could not speak, I felt a tightness in my throat.

In sharing this bodily feeling, Mateusz formed a tight bond with D. Mateusz also used a religious metaphor to reach D. He suggested to D that he was a lost human trying to find himself. Then D started to comment on another patient’s tattoos. He was especially moved by a tattoo of a bleeding heart. D could feel it.

Once Mateusz had formed a trusting relationship with D, he felt he could conduct Open Dialogue meetings with D, C, and their mother. D’s mother wanted D to return to the hospital, but he did not want to go. C said that taking eCPR helped her to open up and express her feelings in the Open Dialogue meetings. So, when her mother wanted D to be back in the hospital, C could more readily express her anger and sided with D. She argued that he did not need to return to the hospital. C was also angry that her mother did not listen to what her children wanted.

Mateusz believes you have to have gone through a period of losing hope in order to connect with a person with D’s degree of distress. It is difficult for
the doctors to feel that degree of empathy because they often have not suffered to that degree. D met with Mateusz several times while he was in the hospital, and then the family met with Mateusz every two weeks for several years while D was living at home.

D has not been hospitalized since 2017. He has been working during the last several years, first doing cleaning then working at a sawmill with his father. He is attending a peer support group. D’s posture is better, and he is speaking up more. D is now better able to make important decisions in his life.

D and C respond to a series of follow-up questions

1. What did D experience during the first family meeting with professionals at the Centre for Neurology and Psychiatry before he met Mateusz? What feelings made it difficult for him to attend any other meetings with the following doctor?

In commenting on his first Open Dialogue meeting at the Centre for Neurology and Psychiatry in Warsaw, D said, “I felt judged. There was no ordinary conversation or dialogue. The facilitators were poorly prepared. They didn’t want to listen. C cried a lot.” D was not able to stay there. After this meeting, D didn’t want to attend the meetings with Dr. E because he anticipated that it would be the same—that there would be no conversation on an equal level; that they would not understand him. D felt anxious.

2. What feelings did D experience that allowed him to meet and connect with Mateusz? Did D notice any sensations in his body? Was it helpful that Mateusz was a person with similar experiences of hospitalization, medication, and psychiatric diagnosis?

The first meeting with Mateusz was organized by C during D’s 13th hospitalization. D stated that,

Mateusz and I started with a short, normal conversation as equals. I could see that Mateusz could easily communicate with the other patients and staff. Mateusz told me that I did not need to take medication. I felt that Mateusz knew my perspective. There was a
sense of understanding from another person that someone was on my side. I felt he understood me.

They made contact because Mateusz understood the perspective of a hospitalized patient such as being ambivalent about taking medication, constantly returning to the hospital, and experiencing a revolving door. D admired that Mateusz defied the psychiatric system.

3. What allowed D to stay and engage in Open Dialogue meetings with his family and Mateusz?

D said, “[in the Open Dialogue meetings conducted by Mateusz] there was dialogue, there was no judgment.” The relationship that was established, the simple conversation, and the lack of judgement were very important. D also saw that his sister and his mum were changing due to these meetings. They were starting to understand him. They understood that the whole system that D was locked into was sick.

The family understood that things could no longer be the way they were before—that the way of treatment had to be changed to a more social, people-friendly way. The meetings were also necessary for D because they changed the routine of D’s ordinary grey day, his boredom, and overreliance on medication.

4. Did D’s relationship with Mateusz help D stay in the family meetings run by Mateusz?

D experienced a change and an alternative, different approach during meetings with Mateusz. He no longer left the meetings. He accepted them because Mateusz was taking his side and feeling what he was feeling. Mateusz wanted D to be able to negotiate his way of taking medication. Even though everyone around D was pushing him to take the medication, Mateusz understood what it meant to take medication. Mateusz understood his perspective.

D felt Mateusz wanted to help him and was his voice in his relationship with his family. D felt he could finally say something. They could talk freely. There was dialogue. The family started to hear him, and they
stopped pushing for medication as the only treatment. They realized they didn't have to worry about D being sick and could go about their business.

They understood that it was not him who was sick, but the whole community that was making him sick. They understood that it was not an illness in the narrow medical sense. Instead, it was the result of difficult experiences with his family, school, university, and psychiatrist. It's not an illness—it's the result of traumatic experiences.

5. Did being with C help D when she spoke up more often at family gatherings? Did he feel that C and Mateusz were his allies?

At first, C made him very nervous because she, herself, was very nervous. Then she started to understand. C didn't want D to go back to hospital and that was important to him.

6. What is D's daily life like now and what has changed after his meetings with Mateusz?

D is living in harmony with each member of his family and community. He continues to meet with Mateusz and feels that he will be fine.

Conclusion

Here is the case of a young Polish man who was diagnosed with schizophrenia and hospitalized 15 times in a six-year period. Traditionally trained professionals were unable to engage him in individual therapy, case management, family therapy, or medication. He described the professional treatment as dehumanizing and disempowering.

However, through a recovery-based approach embodied in peer support, eCPR and Open Dialogue, the young man engaged in treatment. He has been free of hospitalizations and has cooperated with psychiatric treatment. He is working and free from delusions or hallucinations.

The young man and his family identify the more egalitarian relationships in these recovery-based approaches as crucial. They identified the conversational, personal approach of peer support as important in building
trust. By learning eCPR, the peer and the person's sister were able to reach the young man on an emotional level. Emotional expression was also important in allowing the peer and his sister to encourage the young man to speak up to his parents.

The goal of Open Dialogue is to make sure that every member of a family's voice is heard. When the "person of focus" (Open Dialogue term for the person with the most severe problem) has difficulty speaking, as was the case here, a combination of peer support and eCPR can be an excellent complement to Open Dialogue. Peer support and eCPR empower the person of focus and thereby ensure that their voice is as important as other members of the family. We recommend that Open Dialogue meetings be facilitated by peers, and that peers and family members learn eCPR as a unifying set of intentions.

**Additional Resources**

Information on peer support, ECPR and Open Dialogue can be found on the National Empowerment Center website: www.power2U.org

Awareness - rising information and examples of recovery on the Human Foundation website: https://human-foundation.eu/
Practical Alternatives to the Psychiatric Model of Mental Illness

*Beyond DSM and ICD Diagnosing*

Edited by

Arnoldo Cantú, Eric Maisel, and Chuck Ruby

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