

To live with a Schizoaffective disorder

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Abstract

This article tells about how it is to live with severe mental illness, but primarily it is a story about how to recover with the help of mental health professionals, friends and medication. The overarching aim is to convey a message of hope. Even great difficulties may be left behind. As a summary, four key points for staff members to reflect on are mentioned: Nurses should often encourage their patients and acknowledge their progress; Nurses should remember that there is hope, for everybody; Nurses should be encouraged to use their creativity when working with patients; If the alliance between nurse and patient is working well in a bilateral sense, nurses should have the opportunity to keep in touch with the patient as long as the patient needs and benefits from it.

KEYWORDS

cognitive and behavioural psychotherapy, hope and hopelessness, patient experience, psychosis, recovery

1 | INTRODUCTION

The key message for the readers of this article is that there is hope!

Despite tough problems and a severe diagnosis, you can find a way to feel better and to leave your difficulties behind you. Psychotherapy and medication, and not at least support from nurses are helpful according to my experiences. I have become healthier and my life has become better. Recently, I wrote a book (in Swedish) to tell my story and to convey hope to others in situations resembling mine (Arndtzén, 2019). This article mainly consists of excerpts from that book.

I was referred to a therapeutic treatment centre offering 24-hr services 7 days a week, with an orientation towards cognitive behavioural therapy (Perris & Skagerlind, 1994). I stayed at the centre for 1.5 years. Individual and group psychotherapy and vocational and physiotherapy were offered, as well as art therapy and different options for physical exercise. Afterwards, I met with my contact

person (a nurse) once a month for 17 years. This was very helpful in sorting out a lot of things in my life.

The care I received at this centre helped me to overcome my illness in a safe and reasonably quick way. It is important to preserve and develop this kind of care, and it makes me sad when I hear about reductions and restructuring of centres of this kind. For example, instead of accommodation 7 days a week, only group activities on Mondays to Fridays are being offered.

I fear that it would have taken so much more time to get better had I not had the opportunity to stay at an around-the-clock centre. Possibly, my admissions to a locked ward would have been longer and would have occurred more often.

My journey to recovery has been a long and sometimes tricky one. A condensed timeline of my life is presented in the following part. From this timeline, I hope you can learn a little of who I am, and I also mention what I perceive to be helpful and important regarding professional relations and interventions.

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1.1 | My life—a timeline

1.1.1 | Age 0–16 years

On 31 December 1964, my parents went to the maternity ward, and at 25 min past midnight I was born. I was the first baby to be born in the county of Västerbotten that year, so the event was mentioned in the local newspaper.

In summary, I behaved as a small terror as a child. Always on my way to new pranks. A friend of the family who worked as a child psychologist told my parents that a good whacking would be the only thing to do. My parents, however, did not believe in corporal punishment, so I escaped this. If a psychologist from today could travel back in time and diagnose me as the kind of child I was, it would probably be ADHD. But according to what was known and understood at the time I was a troublesome, disorderly child, a danger to myself, and to some extent a nightmare to my parents. This changed when I started school and met with my teacher, Ms Linda. In retrospect, I can see a magic transformation in just a couple of months. I guess Ms Linda was used to turning troublemakers into decent boys. Suddenly, I was sitting neatly at my school desk, raising my hand and behaving. My parents must have been enormously grateful for this change. Within a short time, I came to really like the school. Most likely due to Ms Linda's way of making everything fun, it was important to me to satisfy the teacher. However, something went missing, which later on would handicap me. In psychotherapy many years afterwards, we found that my instant metamorphosis from a ruffian to a model pupil was one of many reasons behind my developing a schizoaffective disorder. The mix of being a good pupil, being fond of the teacher, who also liked me, and having a somewhat challenging personality meant that I became the object of bullying. I only later understood that the bullying was devastating and harmful.

1.1.2 | Age 17

When I was about 17 years of age, the first more serious signs of mental problems started to surface. Until then I was a bullied, lonely child with a poor self-image and a destroyed self-confidence, and I was shunned by the community.

When I had my first panic attack, we went to the hospital. I cannot remember what the doctor said, but this is my first memory of having perceived anxiety. I did not understand what had hit me. Years later, I understood that this is how anxiety feels. I awoke with great fear, everything felt wrong, and an obsession grow in me that I had to go to a hospital as quickly as possible.

My anxiety back then, as today, becomes worse when among people. The worst thing is to be stuck in a room with a lot of people without any possibility to escape. In some way or another I made contact with Child and Adolescent psychiatry and I met with Peter, a clinical psychologist. I was also prescribed some medication, but

no one explained to me why I should take it, so I did not take very often. The sessions with Peter were, however, most helpful. I could tell him about everything that was difficult, and Peter instructed me on what to do and think in order to feel better. One problem, though, was that Peter failed to show me that my symptoms were connected to my anxiety. The concept of anxiety was unknown to me, and my view was that my life would end and that nobody understood what I was actually suffering from.

1.1.3 | Age 30–33

There is something about my personality that has made me awkward in many school-related situations, even at the university level. I have had to analyse my behaviour in order to understand how to fit in and avoid making enemies in the class. I am sure to have occupied too much of the space according to some people's taste.

I was a student at a folk high school when I finally realized that it was time to look for professional help. An encounter with two girls from the class and the counsellor of the school meant a lot of anxiety for me. A good thing about this meeting was that one of the girls asked me how I was able to keep going at all. She felt how tough things were for me. Her words were one of the reasons why I applied for funding to afford psychotherapy. It was not easy for me to realize how bad my mental health was. It is hard to admit that you are in need of help.

Psychotherapy at the institute I had chosen was very expensive, and it was nothing I could afford at that time. My application for funding was granted, and a couple of years of therapy started. The therapy meant that I could practice getting in touch with my feelings of anger, fear and sadness. I got the tools to handle these feelings and to let them out in a safe way. I had the same therapist during the entire time, which meant continuity and security and gave me the confidence I needed so that I could share what I felt. Later on, when I left this institute and its psychodynamic therapy to receive cognitive behavioural therapy, the advancements I had made in handling my feelings were continued, and it was a good basis to advance from. At the same time, a doctor prescribed an SSRI, which is an anti-depressive medicine. Actually, I had suffered from various degrees of depression and anxiety since the age of 19, but nobody had told me what anxiety was or what I was afflicted with. The fact that the implications and reasons for all my symptoms were unknown to me probably contributed to my not seeking help for all my difficulties until then. Finally, the psychotherapist said, "Your problems are too difficult for me to help you." I was referred to psychiatric services and was prescribed medication for psychosis.

1.1.4 | Age 34

I fell into a psychosis, heard voices and experienced tremendous anxiety and other nasty symptoms. Let me tell you about the psychosis—the medication did not work and sleep was no good; a

threatening neighbour was always on my mind. I got myself a long rope, and there was a hook installed near the balcony. If the neighbour had tried to force his way into my flat, I planned to put the rope on the hook and climb three metres down to ground to be able to escape and survive the attack. Other neighbours were also constantly present in my imaginary world. They could hear what I was thinking. There was no safe place anywhere. I checked the door all the time—it must be locked. I believed some of my neighbours were drug dealers and felt that they must have known that I knew. They made threats through the wall—“We know you know of our drug business, and if you report us we will harm you.” These voices were everywhere—threatening and frightening. Cars parked outside my building might mean danger. But when I went to do my shopping at the local shop, I became invulnerable—I had no fear or anxiety. I felt very special and more powerful than other small persons at the shop. The staff seemed frightened. I took walks at night to get away from my unsafe apartment. There was a certain unknown smell in my nostrils, like metal. I could feel the madness growing in me every day. I was lonely and had no friends. There was no safe space to go to. A woman who lived some floors above me attracted me. One night, at 3 a.m., I knocked on her door. She opened it, and I wanted to go in, but she wouldn't let me.

One night when I had had no sleep for a couple of nights, I felt the walls of reality fall apart; I became desperate and called the hospital from a public phone. I had no working cell phone because the enforcement bureau had stopped all my spending due to my debts. I talked to a nurse for at least half an hour until she realized that I was in such a bad condition that she called for a taxi to pick me up and drive me the 30 kilometres to the psychiatric emergency ward. In the car I calmed down—I felt that “the rescue is close.”

This was the first time I was in the need of emergency admission to psychiatry. I was brought to a room and had to give up my keys, belt and any sharp objects. They took care of me in a good way at the ward—it was a locked unit. I stayed at the ward for a month. The atmosphere in a locked psychiatric ward is very different compared with other places. In a way, it was a valuable experience to be an inpatient because I learned how it was and how it worked. The most important things were the meals, the meds and the sleep. My first nights at the ward were spent in a “room fit for a prince”—a single room that was used to assess the potential of the patient to make troubles.

During my time at the ward, I came to know several other inmates, good persons, who appreciated conversation. The staff cared for us, and sometimes, we had chats or played cards. At few times, I was offered to talk to the doctors, most often I had conversations with the nurses. The antipsychotic medication was generous, so the psychotic symptoms were subdued. This was a fairly safe place for me. Today, as I write about my experiences of being a patient in a locked ward, I feel happy about what was positive about being there. I did my best to stay there for as long as possible, and really did make an effort not to appear too healthy. A couple of odd things happened—a roommate asked “It's no trouble to you that I carry a knife?” and a female staff member entered my room late one

night and asked me if I could accompany her to a dance hall, as it was Saturday.

1.1.5 | Age 35–53

I was released from the locked ward and was offered to be a patient at a therapeutic treatment centre offering 24-hr services 7 days a week with an orientation towards cognitive behavioural therapy (Perris & Skagerlind, 1994). The psychiatrist connected to the centre diagnosed me with Schizoaffective disorder. The care I received at this centre and the safe home-like atmosphere helped me to overcome my illness in a quick and safe way. I was healed from the chaos that I had experienced in my apartment. Every day at the centre was scheduled, and this meant activities and a structure of daily living. I started to sleep at night and to be awake during the day. Gradually, it became easier for me to travel by bus, to cross a square and to stand still in a queue. The basic idea of the therapy was to provide me, the patient, with alternative ways of thinking. When the anxiety comes on, one should focus on subjects not related to creating panic. The treatment had a practical orientation. For example, I practised riding a bus a couple of times together with my therapist who sat a few seats away from me. Focusing on things outside the bus instead of what the other passengers might be thinking of me helped me to manage the ride. I was generally encouraged to expose myself to situations that awoke anxiety, and I had talks afterwards with the staff members and therapists. The staff at the centre often gave me praise, which had a positive effect on my self-image and my self-confidence. My impression was that the staff at the centre (the nurses, social workers, physiotherapists, vocational specialists and psychologists) had great opportunities to work independently, to make their own decisions, and to be creative. The psychiatrist visited once or twice a week and met with the staff to discuss treatment plans and medications. I was involved in most of the decisions about my treatment.

My relation with the centre came to last for a long time. After I moved out from the centre, I had meetings every month with my therapist (a male registered nurse with supplementary training in cognitive behavioural therapy) for 17 years. When needed, my access to the psychiatrist was easy. I just told “my” nurse that I needed to talk to the doctor, and he arranged it within a few days.

1.1.6 | Age 55

In the year 2019, I received therapy for my OCD (obsessive compulsive disorder) from a psychologist with a session every 2 weeks with the exception for the summer holidays. This was a good example of how well out-patient contacts can work. The psychologist's special competence in OCD problems in combination with a sufficient length of treatment allowed me to heal, and my compulsive thoughts and actions became much less bothering to me. Quantity as well as quality is important.

1.2 | Loneliness

Loneliness is a regular companion to those of us who are mentally ill. The feeling of being different, the feeling of being someone who does not fit in. My life has partly been very lonely. Years of bullying had effects on my self-esteem, my self-confidence and my view of myself. The feeling of not being good enough, not being cool enough to hang around with the boys and girls I wanted to. It is of utmost importance to be respected and to feel that you belong somewhere, and this was important to me during the years when I worked with children. To feel like one is loved and cherished makes you stronger and provides self-esteem and self-confidence, which is vital to handling your life in difficult situations and adversities. Thanks to my friends—and some professional persons—I have gained a value as a person and I have learned that I am important and can make a difference to others. Love from my girlfriends has taught me that I have a value and that I am good enough. The bullying and the loneliness that came with my illness made me uncertain about who I was and increased my symptoms. My weak perception of myself led me to have problems with my identity. I alternated between feeling like too important of a person to feeling too unimportant. There was an immense need to be at the centre, and to be uniquely important to many persons has always been important to me.

1.3 | Continuity

I realize that it must be exceptional to have endorsed such an extreme continuity of care at the personal level as what I was offered—a therapeutic relation lasting for almost 20 years. This might not happen too often and cannot be generally expected. But administrators and managers of services ought to consider the importance of continuity in long-lasting working relations between staff members and patients when planning for reorganization and restructuring of services. The centre where I got help to recover is not working in the same way anymore and cannot offer around-the-clock service. This is a general trend in the Swedish psychiatric service. The number of beds has decreased from about 5 700 in the year 2,000 to 3 000 in 2019 (SALAR - The Swedish Association of Local Authorities and Regions, 2020). In an international comparison of high-income countries, the Swedish number (37 beds/100,000 inhabitants) is close to the median for number of beds per 100,000 inhabitants. In England, the number is even lower at 22/100,000 (NHS Benchmarking Network, 2019).

1.4 | Getting better

It was a long way for me to feel better and to get healthier. It took a long time for me to realize that I was in need of help. As I can recall, nothing really happened until I was about 20 years old.

I have become extremely healthier, and I have learned to live with my schizoaffective syndrome. However, there are still situations that

I avoid. One problem gradually going away is my hearing of voices. I try to focus on the fact that the voices do not want to hurt me. The most complicated situation is when I become angry over what the voices are telling me. The moments just before and just after sleeping are the most difficult—my defence against the voices is weakest at those moments. Part of my disease is unwanted and automatic thoughts. When talking to a woman, the word “whore” might surface without this person in any way having caused any conscious thoughts of such nature. I do not say the word out loud, but the word is forced upon me.

1.5 | Disclosure

I am cautious about telling others about my schizoaffective syndrome. Many times people become shocked and seem frightened, and start to behave in a strange way. Other people who also suffer from this disorder might talk about it with persons they meet on the bus. In my opinion, you have to choose the right place and moment to tell about your diagnosis. The diagnosis is frightening, and there is a stigma attached to it. However, there should be no difference between having a mental illness compared to having a physical impairment—both are things that can happen to anyone. Being mentally ill often means that you only meet with other mentally ill persons as friends, and this might develop into a subculture of its own.

2 | CONCLUSION

My schizoaffective syndrome has not disappeared—it is only less tangible now. The risk that my personal circumstances should deteriorate is always lurking around the corner. And this is exactly why it is important that people around you are involved and give hints for when it is the time to seek help.

If I could wish for something, it would be that resources were spent on-around-the-clock treatment centres with a cognitive behavioural therapy orientation. They should have a home-like atmosphere, and the nurses and others working at the centres should be free to work in an individualized manner with every unique patient. Generally, psychotherapy ought to be offered more often and for extended periods. For persons like me with longstanding mental problems, continuity is important. If the relationship is functioning and if there is trust and a mutual understanding, it is extremely valuable to be able to meet with the same professional person for several years. This should be taken into account when planning for reorganization of services.

My journey to feeling better and becoming healthier has been a long one. It took a long time before I realized that I was in need of help. To look for help, especially psychotherapy, might mean that lots of alternatives must be examined. But there is help to get, and there is always hope—for everyone!

To sum it up, psychiatric nurses working with persons with longstanding mental problems might benefit from reflecting on the following four key points:

- Nurses should often encourage their patients, and acknowledge their progress
- Nurses should remember that there is hope, for everybody
- Nurses should be encouraged to use their creativity when working with patients
- If the alliance between nurse and patient is working well in a bilateral sense, nurses should have the opportunity to keep in touch with the patient as long as the patient needs and benefits from it.

3 | RELEVANCE STATEMENT

The key message of this article is that there is hope!

Despite tough problems and a severe diagnosis (schizoaffective disorder), you can find a way to feel better and to leave your difficulties behind you. Psychotherapy, support from nurses and medication are all helpful according to my experiences. I have become healthier, and my life has become better. I was referred to a therapeutic treatment centre offering 24-hr services 7 days a week, with an orientation towards cognitive behavioural therapy. The care I received at this centre helped me to overcome my illness. I was lucky to have the opportunity to continue with supportive out-patient contact with a nurse from the centre for almost 20 years, which helped significantly in my efforts to create a functioning daily life. A couple of sessions of psychotherapy as well as medications have also been (and are) necessary to keep me on the right track.

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CONFLICT OF INTEREST

The authors (M.A. and M.S.) are both members of the association Hjärnkoll Västerbotten, which is a non-governmental organization to

promote mental health in the community and improve mental health services.

ETHICAL APPROVAL

The article is based on of excerpts from the book *Att leva med schizoaffectivt syndrom* (in Swedish) written by MA, and published in 2019. MS has in cooperation with MA selected, translated and worked through the material. MA has commented on and after revision approved to the final text. Names of persons and places have been omitted to guarantee that no particular person can be identified. This is a first person's account—ethical approval not applicable.

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