Title: Remarkable lives: Spencer Insley in conversation with Jerome Carson.

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Abstract

Purpose - The purpose of this paper is to provide a profile of Spencer Insley.

Design/methodology/approach – Spencer gives a short biographical account and is then interviewed by Jerome. Areas covered in the narrative are the misery of mental illness, the prodromal signs of illness, hospital admission and discharge to supported accommodation.

Findings – Apart from the losses resulting from a diagnosis of major mental disorder, Spencer also talks about the loss of friendships. His admission to hospital was especially traumatic, leaving him frightened and confused and feeling he was treated like an animal.

Research limitations/implications – While Spencer’s is only one story of many, his experiences have a sorry familiarity to them.

Practical implications – Too long denied in the history of psychiatry, service user narratives help us understand the nature of mental suffering and the often inadequate nature of service responses to mental distress.

Social implications – Involuntary admissions to hospital need to be handled in a more therapeutic manner.

Originality/value – So often it is nurses and occupational therapists who have the most impact on the lives of those with lived experience. Psychiatrists were felt not to be interested in Spencer, whereas his community mental health nurse “Had a genuine interest in what I was doing and how I was getting along.”

Keywords - Recovery Narrative Hospital admission Psychosis Supported accommodation

Paper type – Case study

Introduction

Spencer was one of several students to tell me of their own mental health problems, perhaps because he knew I was a clinical psychologist and would perhaps be more likely to understand his difficulty. However it was only in constructing this account that I was given a full insight into his background. My colleague Ian McMillan recently said in a workshop that he no longer came into contact with people with mental health problems since I left the NHS. I mentioned to him later that earlier that week one of my own students showed me her Home Treatment Care Plan. She was being visited by mental health workers twice a day at home. Other students have also disclosed mental health problems. Some staff feel that many students come into Psychology hoping to learn more about their own problems. I do not know if this is the case. What I do know is that education can provide a base for recovery, as people try to rebuild their lives after what Bill Anthony calls the “devastating effects of mental illness” (Anthony, 1993). Spencer’s story shows how education is helping him rebuild his life.
Brief biography of Spencer Insley

When life is good and things are going our way we tend to forget about what miseries may be lurking around the corner. Mental illness is a misery. Mental illness can stop us in our tracks. Recovery from a psychotic episode may take years and recovery is not as simple as it may sound; perhaps for some of us it is more of a discovery or rediscovery of the self.

To some people recovery might mean getting back to how they were before they were ill, to the person they were before the misery began. But it is difficult to pinpoint just when the illness happens. It may come on suddenly or it may take weeks, months or years for a person to become unwell. Everyone is unique. Sometimes it takes the friends and families of those experiencing a psychotic episode to notice the signs of illness, sometimes nobody may notice. I was lucky in the way that I had my family around to notice when I was really becoming ill, even though at the time I really couldn’t see it myself, or I just refused to admit that I had a problem.

In 2007 I was diagnosed with schizophrenia and was hearing voices, quite delusional, convinced that I was being hunted by the KGB and receiving personal messages from the television and radio. Up to this point I had been living with my parents at their home after living in rented accommodation in Manchester and every time the psychiatrist and social worker came to the house to try to see me, when the appointment time approached I used to run away. This avoidance didn’t help matters and eventually I was sectioned and spent two months in a secure psychiatric unit. Up to the point of being sectioned I was self-medicating myself with various drugs and alcohol in an attempt to block out what was really happening to me. I was living under the illusion that everything was ok, but it wasn’t.

My friends at the time were not very sympathetic, partly I believe because they didn’t really know what was happening to me either. I remember one friend saying that he wanted the “old Spencer” back and I kind of knew what he meant but it was an impossible task, without help simply just to revert back to the “old me”. It was obvious at this point that something was wrong, something about my old self and me not being myself, and that it was clear to people who were close to me although I couldn’t really see it myself. I wasn’t looking after myself properly and I didn’t know what was happening to me. This was a very frightening part of my life, a real low point. I was miserable.

Also, the way in which I was admitted to hospital was not very pleasant or dignified. I was at my parents’ house in the kitchen when the police turned up. There were three police vehicles. They led me out to a police van and put me inside what can only be described as a cage where I was locked in. It felt as though I was being treated like an animal and by the time I reached the hospital I was afraid and disorientated.

It eventually took a Psychiatrist to convince me that I had schizophrenia and I was put on medication in hospital, olanzapine which really seemed to help control the voices and other symptoms that come with schizophrenia and I continue to take it to this day.

I didn’t have a job and I had no place I could call my own. Upon discharge from the psychiatric unit I was referred to supported housing or rehab as some people like to call it. I
spent a year in supported housing, which I did not enjoy. I had a tiny room with a single bed and a sink but I preferred it to being in hospital. The house I was sharing with several other patients had a shared kitchen and one of the problems we had was that food was being stolen from the refrigerator. This resulted in the funders of the project having to shell out for several new refrigerators that could be shared by two people, each of which had a key to their fridge, which remained locked when nobody was using it, presumably so that if any food went missing it was obvious who the culprit was.

Apart from the problem of stolen food, I really did not enjoy my stay in supported accommodation and I don’t really believe that it helped me much on the road to recovery. I was greatly relieved after spending a year there, to hear that my community psychiatric nurse at the time had found me my own flat. After fourteen months of feeling rather unsettled to say the least, at last I had a place that I could call my own and I moved in January 2009 determined to stay well. I was recovering and rediscovering myself, perhaps part of it was the “old me” but I was feeling much better within myself and the misery had already begun to disappear. I was happy with the present situation and the way ahead seemed much clearer and brighter than it had been for a long time.

I believe that the misery of mental illness can be overcome and we can get better as we rediscover ourselves on the road to recovery even if we experience many negative things along the way. Support is essential. I was lucky enough to have my family around me, and an exceptional community psychiatric nurse available to support me. Without this support I really don’t know what I would have done.

In September 2010 I enrolled at the University of Bolton on a part time undergraduate degree course in Psychology and I am currently studying in my final year. I feel that I have come a long way from being sectioned in a secure psychiatric unit seven years ago, to being on the brink of achieving my undergraduate degree.

Spencer in conversation with Jerome

Jerome: You are studying for a Psychology degree. What do you hope to do after you graduate?

Spencer: Hopefully I will graduate successfully in summer 2015. It would be great to carry on and train professionally in clinical psychology if at all possible after graduation or just to reach the point where I can look at the options that are available to me at the time and then choose what route to take. It would be nice to work in research but it would also be nice to stay in education.

Jerome: Can you say a bit more about your hospital admission and how it was handled?

Spencer: I remember the experience of going into hospital well. It was not a pleasant experience. I was in the kitchen at my parent’s home and was preparing some food when
three police vehicles pulled up outside the house. I can’t remember exactly how many police officers there were altogether but there were quite a few. I quickly realised that they had come for me and when I opened the front door, one of the police officers stood blocking the doorway with his arms folded so that I could not escape. I did not know what was happening as I was led down the path to a police van. The officers put me in the back of the van. Inside the back of the van was a cage and there were no windows to see out of. As the van drove towards Tameside Hospital I had no idea where I was going, as there were no windows to see out of and it was impossible to have any sense of direction in the disorientating environment of the back of the police van. When the van reached its destination, I was pulled out of the back and marched into the Psychiatric Unit at Tameside Hospital. Initially nobody explained to me what was happening and I was abandoned at the hospital with nothing in my possession except the clothes I was wearing. It was a harrowing experience and I do not like to think about how many other people suffering with psychosis have been through the same thing. I was treated like an animal. Surely there is a better way of sectioning someone? The experience left me feeling frightened and confused. Then, I had to adjust to the new environment I was in, which was difficult as I quickly discovered that my freedom had been taken away from me. Gradually I adjusted to life in hospital and was eventually released after two months.

Jerome: You mentioned in your story about the “old Spencer.” What has happened to the friendships you made before you became unwell?

Spencer: Most of the people I was friends with before I became unwell have drifted away now and I don’t see them anymore. None of my old friends were particularly sympathetic when I needed support the most, including when I was diagnosed with schizophrenia. I suppose the friendships have ended now and I have not seen any of them for years.

Jerome: What changes would you like to see in mental health services?

Spencer: I would like to see mental health professionals, especially psychiatrists, make an attempt to get to know their patients better. In my own experience, sessions with a psychiatrist last only a few minutes and the same questions are asked at every session. It is like they are not really interested in the patient and they are just going through the motions of the job. People are still human beings even if they have psychosis and should be treated with respect.

Jerome: What are your views on the use of medication for mental health problems?

Spencer: I don’t believe that medication is the answer to everyone’s mental health problems. It depends on the person. In my case a small amount of olanzapine taken every night seems to work for me. For some people medication might not work at all and may be useless. It is bad that many people out there have tried different medications and suffered various distressing side effects without experiencing any benefit whatsoever. I think that I have found the right medication for me. Of course it would be wonderful not to have to take medication at all, but for the moment I feel that I need to take it in order to continue to stay well.
Jerome: How do you think services can best help promote recovery?

Spencer: Support is essential if we want recovery to happen, and personal independence is also important. By personal independence I mean for a person to be able to live independently outside of the hospital environment, which needs to involve services by getting the people who work in these services to help people on the road to recovery by supporting them with issues such as benefits, housing and medication.

Jerome: Have you been inspired by any mental health professionals?

Spencer: Yes, the mental health professional that has inspired me the most is Lyn Cotterill. She worked as a Community Psychiatric Nurse (CPN) for the Early Intervention Team in Tameside. She was my CPN at the time and it was wonderful how she always had time to listen to me when she visited me, and she always had a genuine interest in what I was doing and how I was getting along. Without her support I don’t know where I would be now. If more people who work in mental health services were more like her, I am sure they would see better progress in people who are recovering from serious setbacks in their lives. I don’t know if Lyn is still working with the Early Intervention Team at present, as the last time I heard there had been some serious cuts to jobs within the service. I hope she is still working with the team because I know she can make a big positive difference to people’s lives.

Jerome: In terms of people with lived experience, which individuals have impressed you?

Spencer: The first person that immediately springs to mind is Peter Bullimore, and the way he has managed to survive horrific personal life experiences and still come through to the other side with an extremely positive attitude towards life and mental illness amazes me. Another person is Peter Chadwick, his story about transvestism and mental illness and how the two things were mixed together at certain points in his life really interested me. Both these people are unique individuals who have much to offer mental health professionals and service users alike. I admire them both.

Jerome: What challenges lie ahead for you? What do you most want to achieve in the future?

Spencer: If it is at all possible, I would like to study further and even train in clinical psychology so that I can try to positively help others who may find themselves in a similar situation to the one I found myself in a few years ago.

Jerome: What would you most like to be remembered for?

Spencer: I’m not sure that anyone will remember me! But if they did I would like to think that they would have seen me as a human being, who treated other people like human beings.
Conclusion

I have argued elsewhere that the development of service user narrative has constituted a revolution in psychiatry, (Carson, 2013). Thirty years ago when I was training as a clinical psychologist we read case studies written by professionals about their patients. Now patients are writing their own stories. It is staggering to reflect how the patient voice has gone largely unheard in the history of psychiatry, with very few exceptions (Russell, 1997). The present account also has implications for the training of police officers and how patients are brought into hospital against their will. While the late Janey Antoniou trained thousands of police officers in how to work with people with mental health problems, Spencer’s account of his admission suggests much work still needs to be done.

References


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