

## Commentary

# Personal experiences and perspectives of psychiatric intensive care and recovery

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## Abstract

Two stays in different psychiatric hospitals left me with very differing experiences of severe mental illness. The impact of the more severe episode was much reduced due to the positive way in which staff interacted with me. Recovery was impeded during the first episode by the paucity of therapeutic relationships with staff and the absence of control over one's medical choices. The role of being a patient was very much a negative experience and the memories of which are still with me ten years on. A positive outlook can be enormously helpful when relayed from staff to patients.

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## Keywords

Communication; recovery; therapeutic relationships

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## INTRODUCTION OF SELF

I am writing now as a woman of 34 years of age and I have been a patient in both a general and an intensive psychiatric unit in two different EU countries. I am writing also to support practitioners' understanding of the most helpful way to provide care and recovery services to patients who are experiencing an episode of illness. Torrey et al. (2005) called for insights of people with such experiences as my own, to inform the field.

Prior to the age of 24 I knew nothing of mental illness, nor did I know anything of its devastating potential. Back then I was a postgraduate student, living in Dublin. Immediately prior to this point I had completed a 4 year degree course upon leaving school and I was enjoying life as a postgraduate student.

## DIAGNOSIS

I have a diagnosis of a severe mental illness. It is a good time in my life now to write, for it is ten years on since I was first diagnosed. When I first learnt of my diagnosis I was devastated. I am obviously mad, was all I could think. I no longer thought of my name or my occupation or my personality as words to describe me, my diagnosis was too damning and all powerful. The very words seemed to consume me and to diminish me to a neat phrase. I attributed a meaning to my nightmares, the journey through fear, emotional numbness and depression that I had been on. At the time these experiences seemed pointless as my own interpretation and meaning had been squeezed out of my experience through my diagnosis, which is a common concern (Slade, 2009). I thought my life was over and when I heard the diagnosis all I felt was that I was a danger to others. I very rarely actually reveal my diagnosis. It makes me feel too vulnerable and too open to others'

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judgment to utter the words the psychiatrists use. It's the most personal information I possess.

And yet my life is richer, happier, I am more loved and I love much more than before I became ill. I believe in myself, in what I do and the way that I do it.

## FIRST EPISODE

### Events leading up to first episode

The ending of a long term relationship a few months previously, being over-worked, and a trivial incident that brought on nightmares resulting in four days of staying awake which was followed by psychosis.

### Hospitalization and timeframe

Length of stay approximately 7 weeks, responded to medication. November 2000 to January 2001.

### Things that helped

Occupational therapy: cooking, woodwork, and having friends and family coming to visit, talking to other patients in the hospital, jogging, listening to music (U2's *All That You Can't Leave Behind* album), knitting a cardigan.

## SECOND EPISODE

### Events leading up to second episode

Commuting to an IT based job, working long days, a bladder infection, no break over Christmas followed by submission of DPhil.

### Hospitalization and timeframe

Approximately 10–12 weeks stay in hospital; I didn't respond to medication March–May 2004. I had a course of ECT treatment as I had become catatonic.

## RECOVERY

What aids recovery? Smith (2000) set out six factors as being critical for recovery and these are: a group of supportive people, the right medications, meaningful activities, a sense of

control, determination towards recovery and a positive outlook. While Torrey et al. (2005) talked about the role of service users as self-practitioners and mutual helpers who can support patients on their recovery journey. Having support in the form of friends or medical professionals who can just be with you and walk with you on your journey. Having a friend to talk to, someone who can really listen as well as talk.

## WHAT HELPS

Empathy, understanding, concern, time, slowed conversations, counseling.

My concentration is often poor when I'm depressed. I may have trouble reading or absorbing information. Therefore, having people around me to talk slowly and gently helps greatly. It worries me even more if my family is worried about me, for I'm then worried about their worry. If they are concerned that is quite alright with me however. I guess I feel guilty for causing them worry.

In November 2006 I had a number of weeks off work with depression. The local crisis team made regular visits to our house. I had counseling and this helped me enormously. The depression lifted out of the blue one night. I now place a huge value on being listened to and the healing power of feeling heard. The doctors thought I would need another round of ECT, but the counseling helped me enormously, it was gentle and empowering. I felt like I had finally put something right in my emotional development and maturity, like the pieces of the emotional jigsaw of my life had finally fitted into place.

## WHAT DOESN'T HELP

When people are too probing and simply pierce your emotions with their questions; for one's wellbeing is especially fragile in depression and during the following recovery. It also doesn't help when people are over stimulating when you need quiet and peace.

When you can't get a meaningful answer out of staff as to why you're in hospital in the first place, 'But you're not well Suzanne' was what I was told by staff, over and over again. I didn't understand what their statement meant or that I was depressed, I just felt trapped surrounded by strangers (patients and staff). Here was the voice of the professional, who knew what was best, being told this made me feel stuck in my depression with no hope of a return to normal emotional functioning. While the professional had a monopoly on knowing what was best for me (O'Hagan, 2009), I felt I had little input into my own recovery. I did not feel that I had any resources within myself or that I had any self-righting capacity. Time spent in hospital was like time in a waiting room, the medical staff told me we were waiting for the medication to work. As Slade (2009, p.41) neatly phrased it when he talked about hope and recovery: 'The possibility of a good future is rarely communicated by mental health professionals'.

While Slade (2009, p.55) suggested that: 'The way that mental health staff work with people in the "patient" role may be as important as what they do', I would argue that the way mental health staff interact with their patients is central to the patient's recovery. Essentially their way of communication is more important than what they actually do, because their way of communication defines a role for the patient.

Whilst Janner (2007) argued for talking therapies, these may not always be offered depending on one's previous diagnosis and this is highly frustrating for patients who are trying to recover. During the first stay in hospital I felt that containment and pharmacological intervention were the only means of 'therapy' in the first few weeks. Later on there was the prospect of occupational therapy. Janner (2007) stated that containment and pharmacological intervention shouldn't characterize acute ward stays.

Not having your status explained to you doesn't help; i.e. what it means to be a voluntary patient. It is best to be clear and explain about rights and the capacity of the patient.

I tried to walk out of the hospital. But, I had nowhere to go, I just didn't want to be in hospital being observed constantly, I felt like I was a rat in a lab being experimented on and having my blood pressure checked at regular intervals, never being told if it was high or low, and being given medication that I had to take; not being told what exactly the tablets were was incredibly disempowering. Whilst in the beginning of the first episode I needed to be in hospital, being there wasn't a positive experience (Kelly et al, 2010). I experienced days of emotional numbness and when I could feel some emotions again I was tearful. The prospect of staying in a locked ward was threatened by staff when they saw how tearful I was. Luckily I was never frightened of other patients, I was merely curious as to their stories and concerned for their welfare.

When I went to bed at night I was so medicated that as soon as my head hit the pillow I was in a deep sleep. There was no time for reflection on the day's events, no processing of thoughts or emotions, no dreams and then a new day began all over again. It felt like a terrible nightmare existence. Part of what makes me who I am and human is my ability to reflect upon my experiences and interactions and I felt robbed of this ability to get in touch with what was going on in life.

Therapeutic relationships did not develop with staff in the hospital; the team to which I was allotted, changed every time I was summoned to be questioned by them. As an outpatient I rarely saw the same nurse or doctor twice. The most effective therapy that occurred in hospital was talking to other patients. As previously mentioned one of the goals of recovery (Smith, 2000) is to have control over one's life and I found this ability to be very much reduced once in hospital.

I felt at ease in the second hospital. It was a confined space, but that didn't seem to matter. During this episode and period in hospital I suffered severely with delusions. I had lost a lot of weight and grew very thin. I had stopped eating and became catatonic. I lived in a different reality before and between the ECT sessions, my

existence was full of delusions and I needed intensive nursing care. My memories are very vague of this period. I remember hearing friends' voices when they came of visit, but not really seeing their faces. I have no recollection of other friends' visits. Like Janner (2007) I found the staff to be non-judgemental, patient, kind and supportive.

I remember one nurse taking me aside and saying I would have to make some changes in my life when I got out. Then I knew that my life would have to be different in the future. The episode of illness gave me a chance to rethink my life and to change tack with my career. As in the study by Ridge & Ziebland (2006), my depression gave me the chance to stop and rethink my life and to identify what was most important to me. I worked one day a week almost immediately following that admission and I made thoughtful decisions about my work and social life.

I remember the 'assessment' type questions that I was asked during the first admission: Are you hearing voices? Do you feel you have any special powers? Do you have suicidal thoughts? These questions freaked me out, 'what was a suicidal thought?' I wondered for the first time in my life. The questions spurred me on to think about self-harming. The questions also made me question my own sanity. I don't remember being asked open questions besides maybe a direct question such as, 'how would you describe yourself?'. I felt lost in the hospital the first time. Even when I was asked late one night by a member of staff if I felt lost, I was too scared to admit it, such was the fear I felt. I feared a future of being contained within a hospital forever for none of the professionals could give me any kind of timeframe for my recovery, which also made me feel even more hopeless. Of being confined, I felt like my whole life's future was on the line. It wasn't until I became friends with another patient that my recovery truly began.

The worst thing about being paranoid is that you're afraid of situations and people that you should not normally be afraid of. It's like your mind has run away with itself, fear and threats

can come from any source. I had an overwhelming feeling that if my depression continued I would be in hospital indefinitely and if the paranoia returned I might never get out.

Being driven back to Ireland by a good friend before my hospital admission in 2000 I was aware that my mind was not right. I was afraid that there would be men in white coats waiting for me at home. They never wore the white coats when I went to the hospital and thankfully they were not waiting for me at my front door as I'd feared. When one starts to lose touch with reality it is the scariest time for the patient, for I can slip into psychosis and may have the potential to become catatonic again. I guess that's why my own wellbeing is so important to me now. These days it is ten years since the first admission to hospital, I feel like I am far down the recovery route. I feel more at ease with myself since Ridge & Ziebland (2006) and comfortable in my own skin. I have developed a newfound belief in my own worth as a human being and that is far more profound to me that the reoccurrence of symptoms of psychosis.

## USEFUL ADVICE TO MENTAL HEALTH PROFESSIONALS

- Do not assume that you have a more superior picture or perspective of the patient's health than their own perspective. Patients are often experts on their own health and experiences.
- Talk to a patient in the way you would to friend, not from a standpoint of I am well and the patient is ill, but from a mutual understanding that you are now just being with someone who could be distressed that you could support.
- Make allowances for a slowed understanding when appropriate, explain things like the effects of medication very thoroughly and give the patient some element of choice over their recovery pathway and medication.
- Get to know the patient. What is their usual role in society when they are not unwell? Get to know their values and interests and what makes them tick.

- Being observed on a ward can be an unnerving experience for patients; the more staff engage with patients the better, within reason.
- An appropriate amount of privacy should be given to the patients for visits from friends and family.
- An explanation of how a ward operates and the roles that different staff members have would be helpful for patients, especially if it is their first admission to hospital.
- Continuity in care is very important to the patient, so that good therapeutic relationships with staff can be developed, whilst in hospital and later in the community setting.
- A full explanation should be given to patients upon discharge with a plan for how to manage early warning symptoms – should they reoccur in the future.
- When assessing patients ask them open questions which allow the patients to tell their own story.

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