

What It's Like to Hear Voices and How an Alternative Approach Can Help. Introduction and Background

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Ben Gray is an academic and researcher in the field of mental health and was also diagnosed with schizophrenia in 2003, when he spent a total of 12 months in a mental health hospital. In this article, he relates his personal experience and story to make a polemical and admittedly one-sided case against traditional psychiatry and compulsory medical treatment. He ties his experience to espouse a modern anti-psychiatry based on the works of [1-3]. He concludes that there needs to be more attention paid to voice hearers' stories and accounts of mental illness, which he links to the rise of democratic psychiatry and the growth of the hearing voices movement, headed by organisations such as Intervoice, Asylum Magazine, MindFreedom, Working to Recovery and the Hearing Voices Network.

This personal account is also written partly in response to The Power of Psychiatry [4], that suggests a growth in subtle and gentle 'techniques of self' (such as talking therapies, counselling, psychotherapy and cognitive behavioural therapy) to regulate 'problem populations' such as those with mild mental illness. This personal account suggests the opposite, arguing that psychiatry is paternalistic, forced, coercive, disempowering and punitive against people with severe mental illness under Section.

HEARING VOICES: A PERSONAL STORY

Certainly, my negative conception of traditional psychiatry and compulsory treatment is coloured by the 12 months that I spent in a psychiatric acute unit. Kept under Section 3 of the Mental Health Act of the United Kingdom (which allows mental health services to detain people with mental health problems for up to six months), I was both obliged to stay in hospital and forced to take antipsychotic medication against my wishes, though physical force was never used against me.

My strange religious beliefs were perhaps quite rightly classified as delusions and discounted by my psychiatrist,

nurses, and also my family, but this left me with the impression that my experiences, however negative and painful, were also being discounted and that I was not being listened to in order to be more deeply and humanely understood. The famous line of [2] often came to my mind:

"If you talk to God, you are praying; If God talks to you, you have schizophrenia."

Among the people I met during my time in hospital was Rosemary. She was an unassuming, quietly spoken woman, unremarkable apart from an air of sadness. Rosemary had told me and many of the nurses that she would be better off dead than hearing any more of the terrible voices that kept her from sleeping. Better up there with her mother in heaven, she told me, than down in the hell of the psychiatric ward with her voices. Within a few days of being discharged, Rosemary was with her mother again. The nurses called a meeting in the communal lounge. There had been an accident. Rosemary had thrown herself in front of a train. The girl next to me at the meeting broke into tears.

Night after sleepless night and through the long, seemingly endless days in the ward, where smoking and television stood in place of any attempt of therapy, I and my fellow patients experienced similar feelings to those of Rosemary: feelings of loss, isolation, pain, sorrow, self-pity, confusion, and helplessness.

"You're alone," an insidious voice whispered to me. "You're going to get what's coming to you." "You're going down there!" it shouted. "You wait until you see what I'm going to do to you!"

When I heard my voices, which would often shout at me, no one around me moved or looked startled. It was just me hearing the voices. I tried not to answer them. Better to ignore the voices, repress them, and soldier on, I thought. I had seen others screaming back at their voices, and it had

left me with mixed feelings of consternation, pity, and fear. I did not want to look mad, like them. Any symptoms of hearing voices would go on medical case notes, be raised as proof of insanity at my case reviews by my psychiatrist and the nursing team, and keep me locked up in the hell of the ward away from family, friends, and what seemed like a long-distant normal life.

I learned several important lessons too: never admit that you hear voices; certainly never answer them; do exactly as you are told by staff or concerned family or you will be seen as ill; never question your diagnosis or disagree with your psychiatrist; and be compliant and admit your mental illness or you will never be discharged and your medication will be increased. If you refuse medication, as I did initially, you will most likely be given a depot injection of an antipsychotic drug. In my opinion, depot injections are used punitively to coerce compliance with oral medication (or making people take their tablets), despite these depot injections having very bad, humiliating and painful side effects (such as muscle stiffness and the inability to sit still), in my personal experience. The side effects of depot injections are so severe, that you soon learn to comply with oral medication and take your prescribed antipsychotic tablets.

All the time, the voices got worse. “Hot fire in your eyes!” shouted a voice to me in the hell of the ward. “That’s where you’re going. In the fire of the sun!”

Many of the people, and there have been hundreds, with mental illness who I have talked with both as a patient and as a researcher and academic, tell me that they have had to suppress and hide their voices in order to be considered well, stable, and healthy. Not only is this a suppression of symptoms, but it is also a suppression of people’s personhood. Traditional psychiatry, in this gloomy and pessimistic view, could be argued to be little more than an instrument of social control and of oppression and a system of scientific belief that perhaps unintentionally crushes people’s subjectivity, choices, human rights, and free will. The majority of individuals with schizophrenia and mental illness that I have spoken with, and from my own personal experience in a psychiatric acute unit I have to agree, find meeting with their consultant psychiatrist threatening because any unusual thoughts or behaviour can be taken out of context and construed as psychotic. Many people with mental health problems are genuinely afraid of meeting with their psychiatrist or other members of the mental health team. I remember a teenage boy in the ward literally shaking and wringing his hands with fear before his weekly case review with his psychiatrist, much to the concern of nurses, the boy’s mother, myself, and the boy’s mental health advocate.

Many people with mental health problems hide their symptoms, their aberrant beliefs, and their voices to stay out of hospital, but this means that they are ostracised and that there is a lack of dialogue between mental health professionals and people with mental health problems. This also means that there may be a lack of disclosure and of what is really going on in people’s lives and what voices they may be hearing. Because people with mental health problems fear the psychiatric encounter and are afraid of punitive intervention or compulsory treatment, psychiatrists and mental health professionals are not getting the full picture so as to agree a consensus on care plans and treatment. This is also true of family carers, who are increasingly being called upon to provide around the clock support for people with mental health problems in the community. Family carers are often little more than the unpaid workhorses of community care, who lack the skill and information necessary to provide adequate support to their family members with schizophrenia and mental health problems who may hear voices.

More worryingly, when in hospital, violence is sometimes used as a tool for getting noncompliant patients to take their medication, usually via depot injection. This violence is often conceived of as right, as just, and in the patient’s best interest. Certainly, many nurses I have spoken to have not only said that they do not like administering forcible injections but also say that they have a duty of care. Violence as care is an oxymoron and hides the institutionalised abuse of people with schizophrenia and mental health problems. I myself have witnessed 8 occasions where patients have had to be very violently restrained by staff and only 2 assaults by mental health patients on nurses. This is in line with evidence that people with mental health problems are more likely to experience violence on their person rather than attacking other people.

Psychiatry has taken a biomedical approach, with the prescription of powerful antipsychotic medication, including drugs such as olanzapine, risperidone, and clozapine, all of which I have been prescribed. These powerful antipsychotics have serious and debilitating side effects, are toxic, and have also been suggested to be harmful to those taking them in the long term. These antipsychotic medications have often been described as a “chemical cosh,” leaving people like me who take them passive, debilitated, and zombie like. This could be suggested to lead to the tranquilisation of people’s personal beliefs, however irrational, and their thoughts, subjectivity, and feelings. Such an approach could certainly be argued to crush diversity and discount the diversity of people’s experience of life and the world, in the name of normalisation and keeping a stable social and medical order.

Put very crudely, popping a pill is far less of a burden on a health service that has limited resources, a lack of money, severe pressures on beds, and a lack of inpatient provision, which often depends on family carers who lack the knowledge and expertise of dealing with people with mental health problems who may be in distress and where care in the community is limited in scope and often means no care in the community, leaving people with mental health problems with the feeling that they are alone, forgotten, invisible, and ostracised.

All this means that there is little study of what schizophrenics' voices say to them, which would make people's experiences more valid and meaningful and also lend itself to a more human account of mental illness. People's experiences of hearing voices are silenced, which can only augment ignorance and fear, both in society and in the mental health-care system. Little attention has been given to what people with mental health problems think and feel and what treatments they would prefer. Psychiatry over-relies on powerful antipsychotic medications, and there are long waiting lists for less invasive treatments such as counselling and cognitive behavioural therapy.

To complicate and make matters worse, it is almost impossible to talk with other people and relate the pain that voices inflict when they are raging inside you and shouting you down. It is even harder to face the voices and achieve what psychiatrists and mental health professionals call "insight." My voices, in particular, often sounded telepathic, as though people were speaking to me through their minds. My voices would often be racist or abusive about mental health staff and other patients. It is perhaps not surprising that voices like these, if dismissed as bizarre delusions and not discussed as at least phenomenologically or subjectively "real," may sometimes lead to violent behaviour toward staff and other patients or—as I have witnessed—the smashing of hospital furniture, equipment, and the television from which the voices emanated.

The main point to reiterate is that these voices are silenced and dismissed as delusions and that they are managed mostly by medical treatment and thus not addressed in human, compassionate, alternative and sympathetic terms that might begin to tackle the root cause of the problem, which in turn might help people cope more profoundly and insightfully with their voices.

Certainly, the overreliance on medication is perhaps not surprising, given that people who hear voices can be perceived as aggressive, irrational, and violent. My voices often took on a demonic or hellish quality: "You think you've been exploited and abused?" a demonic voice often shouted at me. "You wait until you see what I'm going to do to you! You wait until you see what I look like!"

But this is partly the point: other people cannot hear the schizophrenic's voice. There needs to be a dialogue so as to treat the voice hearer's experience as valid and meaningful [3]. A more democratic psychiatrist listens to people with mental health problems and is open to their experiences and voices, so not stigmatising the voice hearer, which in turn may lead to more holistic, alternative, complementary, democratic, and sensitive packages of mental health care.

The final straw of my negative experience of traditional psychiatry was my appeal to be set free from Section 3 and released from hospital against my psychiatrist's advice by a Mental Health Tribunal. I thought this Tribunal would listen to me, but I found the whole process of the Tribunal a kangaroo court, biased against me. There are three members on the Tribunal's panel, two of whom are professionals (one legal, usually a solicitor or barrister and one medical, usually a psychiatrist) and only one lay member, a person who is not medically or legally trained but with some mental health experience. I thought that the odds were against me and that the whole process was biased by elites and those on the upper echelons of society. More controversially, I thought that these elites (including my psychiatrist and mental health nurses) took a perverse pleasure of wielding power and keeping me under Section, taking away my freedom and my voice.

DISCUSSION

The Rise of Democratic Psychiatry and the Hearing Voices Movement

What I have learnt as an academic and researcher, as well as a mental health patient labelled with schizophrenia, is that what people with mental health problems want is to be treated as equal citizens with equal human and medical rights. People with mental health problems who hear voices or hallucinate want to be valued, as we all do, not feared and ostracised. They want their views and opinions taken into account, especially as regards what sorts of treatment they have and in their care plans. They want a right to accept or refuse medication and not have it forced upon them supposedly for their own good. At the very least, people with mental health problems want their stories, narratives, and voices to be valued and taken into consideration. Such an approach would take people's diversity, and their diverse experiences and beliefs, into consideration and not label people as mad or bad but value them as human beings, with all the faults and strengths that being a human being entails. Such an approach would give rise to a more democratic and person-centred psychiatry, which would also view mental health patients' experiences as a form of expertise to be shared with professionals rather than discounted as delusions.

What is required is a balance of perspectives between traditional psychiatry and the diverse experiences of people with mental health problems, with the aim of achieving a consensus on pathways of treatment and new, innovative, and alternative methods of mental health practice [5]. Hearing voices groups and voice hearers' internet discussion forums are just two contemporary examples as is the use of advance agreements and directives. Advance agreements and directives allow people with mental health problems to stipulate their preferred treatment when they are stable and well, in advance, so that their preference is known if they become unstable and unwell in the future.

Central to this process is the rise of democratic psychiatry and the hearing voices movement, headed by the eminent psychiatrist Marius Romme and organizations such as Intervoice (<http://www.intervoiceonline.org/>), Asylum Magazine (<http://asylummagazine.org/>), MindFreedom (<http://www.mindfreedom.org/>), Working to Recovery (<http://www.workingto-recovery.co.uk/>) and the Hearing Voices Network (<http://www.hearing-voices.org/>).

Democratic psychiatry and the hearing voices movement do not ostracise and silence people who hear voices but create space for their voices, narratives, stories, personal thoughts, and experiences, which will lead to more humane and holistic approaches of understanding and treating schizophrenia and mental illness in the future. This means that psychiatry rather than doing things "to" or "for" people must begin to work "with" them.

According to [6]:

The term 'schizophrenia' is not just stigmatising, but also fundamentally flawed. It is a label without scientific validity. Diagnosis ignores connections between life experiences and core illness experiences. We urge mental health professionals to listen to what their patients are telling them and help them understand their experiences.

There needs to be more lived experience research, developed, run and led by people with mental health problems. This research also needs to be transcultural, addressing the voices and experiences of black, Asian and minority ethnic groups. My experience of psychiatry was negative, but one person I met on the ward said she felt "safe" in hospital. Other more radical and strident voices suggest that recovery is only possible outside the confines of psychiatry and the mental health system. These diverse voices, perspectives and experiences need at last to be listened to, valued and heard. If not, as one individual put it during a research interview: "We are the forgotten ones".

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