

# **On the Right to Be Crazy, the Right to Treatment and the Responsibilities as a Patient**

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The problem I want to address concerns those persons who do not want to be our patients and to get treatment even if they are easily identified as mentally ill and suffering from being socially isolated, losing their jobs and often in conflict with their own family and people around. How should we deal with these persons – is there a right to be psychotic and what about the right to treatment and to a healthy life?

I will give a few examples;

1. A woman, now 54 years old, had a rather long career in health administration, got a PhD in public health and soon after that had a serious psychotic breakdown with initial feelings of a milieu catastrophe coming and also being paranoically in love with a person in another part of Sweden, who communicated with her daily through television, radio and newspapers. She refused any investigations and to try any drugs and ended up in a rather miserable state compared to her early life, socially isolated, not working and in serious conflicts with her former colleagues going to court to defend what she perceives as her rights.
2. A 50 year old man has had a schizophrenic disorder for many years, he has taken medications periodically, but the last few years he has refused. He is continuously hallucinating, living quite on his own, very socially isolated, mostly spending his days on his bicycle going around the town. When trying to approach him and offer him treatment he says that “it is like living in a movie” and he wants to stay in that state.
3. A 30 year old woman has been in a psychotic state more or less for the last 10 years. She lives with the idea that she is coming from another planet visiting this earth and when offered medication she says that “I am schizophrenic and I want to stay like that”.

Every psychiatrist can tell similar stories. Now, what is the problem? The problem is that there are quite a big number of people living out there in the community who suffer from apparent and severe mental disorders by any definition, who often live a miserable life. In the welfare state they have some kind of housing, get a small pension and they survive. In poor countries their situation is often very bad, being vagrants and beggars and outskirts. These people often risk being driven out of their apartments by their landlords because of complaints from neighbours or because not paying the rent or neglecting of even destroying the flat, not tidying up etc. Everybody knowledgeable about their situation would like them to be able to live a different and more decent life. How should this be accomplished?

The first and basic question must be; why are these persons behaving like this, especially in countries where there is treatment available and where there is a support system that is prepared to support and help.

One common way of explaining this low-compliance to treatment is the negative effects of the drugs we offer. There is a vast research in the field of side-effects and non-compliance. The experienced side-effects, often quite special when using high doses of neuroleptics, are very disturbing, but I do not think this is the basic problem. Over the years I have got the idea that for some persons being psychotic or living in a delusional world is much more satisfying than a life with less exceptional experiences, but still suffering from the limitations that a severe mental disorder mean in spite of other treatment efforts. One patient told me that "I have fun when I am manic". Being in daily contact with the pope, the president of America or Russia or other important persons, being the son of Haile Selassie or even more being Jesus Christ or even God himself, will give life a very special meaning. I think it is utmost importance that we study the existential meaning of being psychotic much more intensely to be able to understand why so many of our patients stop taking their medications or want to reduce the medication to levels that we know are not good enough to reduce what we see as symptoms and signs of serious mental disorders.

Another issue is the stigma connected with mental illness. The fear and shame of being a psychiatric patient or having a mentally ill family member is creating a lot of problems. Here is also the problem of self-stigmatization of patients and families, which is probably as important as the stigmatization and discrimination from others at least in our western culture.

So, what to do? I think most people with some experience of living with, working with and/or treating the persons I have in mind, would agree that medication can contribute to a better life even if not cure. So, how can we overcome this problem where the right to treatment and the right to health are in conflict with the right to freedom of choice and autonomic decisions.

Before I go into this conflict between two basic ethical principles I want to say a few words about competing stigma. In my view the best and most effective way is to improve the treatment options. The drugs must be more efficient and the psychotherapeutic approaches and family interventions much more developed. Epilepsy is a good example of a disorder in which effective treatment has changed the situation radically in most countries where this is available. From being a very stigmatizing disorder, epilepsy is now considered as any other disorder in at least western countries. Mental retardation is another example of the situation where we do not have an effective treatment or cure, but where needs adapted support in housing, daily activities, jobs, persons with mental retardation now live a much better life than before and less stigmatized. So, improved treatment and improved social care and support, combined with information about the nature of the disorders and the treatment opportunities will gradually reduce stigma and discrimination and in the long run also certainly make it easier for persons suffering from severe mental disorder to accept and attend the services.

But the question about the conflict between the right to health and treatment and the right to self determination is more difficult.

One crucial issue is the nature of the mental disorder. What is the freedom of thought and action of a patient having a serious delusional disorder? Has he any reasonable degree of freedom of choice when being obsessed by delusional ideas of grandiosity, love or persecution? I think the evidence that schizophrenia, for example, is basically a neuro developmental disorder, maybe complicated further with neurodegenerative processes and psychological defences – make it reasonable to say that this person is not acting out of a free will in refusing medication and support? Personally I think that the more we find that severe psychotic disorders are disorders of the brain, the more we will consider possibilities to at least make a treatment trial in the early stage of the disorder and if necessary force the patient to do this. So, I will question the autonomy of a severely psychotic person. But this is a controversial stand point.

The possibility to force a patient to take treatment is accepted in almost all countries world wide and the compulsory treatment and care is usually regulated by law. The legislation is usually more geared towards protecting the right to autonomy and self determination then to safeguard the right to health and treatment. Also compulsory treatment is now in most legislations world wide decided by court procedures.

When the court is involved in decisions about compulsory treatment there will be an inevitable conflict between two different ways of looking at the problem. Courts react on things that have happened, whilst the medical system wants to prevent things to happen. For example if we want to prevent suicide or violent behaviour or the deviant social behaviour, but also a life in misery because of what we believe is basically a medical problem – a mental disorder we would like to intervene before persons get into more severe problems whilst the court system is reacting after people have already got into problems, for example, being violent against others or behaving self destructive or living in open misery. So, it is often difficult to persuade the court to make decisions on compulsory treatment before something serious has happened.

Traditional human right makes a difference between a person who is considered competent and incompetent and this thinking is influencing most of the legislation world-wide. A person is considered in-competent to stand a trial if he is seriously mentally ill, which means that he is not even accused for doing a criminal act because he is considered not aware of what he was doing and the consequences and he had no intention to do harm. I also think it is time to question this kind of reasoning. How do we know that somebody does not really know what he is doing and that he has no intentions? The present Swedish legislation is good in this respect because it does not care whether a person is competent to stand a trial or not. A person is always taken to court if it is clear that he has committed a crime and the court decides whether he is guilty or not. After that comes the question what kind of punishment or consequence should be the result? If he is considered seriously mentally ill he can not be put into prison, but should be sent to a mental institution for forensic

psychiatric care. I think it is to deprive a person of his human status if we consider him not competent. However, there are situations when the court for good reasons can decide not to make a case, so this will always be an area open for discussion.

So, is there a right to be psychotic and stay psychotic? When discussing this with Sir David Goldberg, a prominent British psychiatrist, recently he clearly stated that there is a right to be psychotic. I am not so convinced that this is a right we should defend rigorously. I think we should discuss much more than we do the freedom of choice of severely mentally ill persons, the right to a decent life as healthy as possible and the right to treatment. These persons are usually heavily dependent of society for their living, for their housing and other kinds of support including medication because they are not earning their living themselves anymore. So their condition is a cost for society and of course especially for the psychiatric care. We should have to use a lot of resources to restore at least a minimum of mental stability in these persons when they in the end become our patients. To me it would be reasonable to say that this kind of a patient should be obliged to take their medication over a longer period of time. For this purpose some kind of possibility to treat involuntarily also when the patient is not staying in a psychiatric institution would be reasonable. It must be a human right to be as healthy as possible and as mentally stabled as possible. It can not be in the persons interest to be violent towards his family or neighbours or to unknown people in the street or to live in misery.

But, if we treat persons compulsory it is also an ethical demand on us to provide him/her with the best available treatment. Unfortunately it is often not so. In many places compulsory admitted persons do not get the best the institution can offer and this is a shame.