

ACCEPTING AND MAKING SENSE OF VOICES

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What means “hearing voices

I don't know if you are familiar with the concept of hearing voices. We studied hearing voice being the experience of hearing one or more voices who are not heard by anybody else, but are experienced as coming from someone or something else. They are experienced as “not me”. In psychiatry such experiences are called auditory verbal hallucinations.

The title accepting and making sense of voices indicates what are the main strategies when relating to people who hear voices.

Accepting voices means that we all accept that the voices heard are really heard by the voice hearer. It does however not indicate that what the voices say is literally true.

Making sense of voices means that the voices are telling things that are related to what has happened in the life of the voice hearer. We therefore should be interested in their background, should try to understand them, stop trying to repress them, but respect them.

In this lecture I will tell you about The main result of our research. With patients hearing voic

- The outline of its beginning and development
- The main results of our research : Voices are signals of the hearers problems

- The consequences for working with voice hearers.

The outline of the beginning and development of this new approach

Our interest started when a patient made it clear to me (Marius) that for her the psychiatric approach was not very helpful. Because as a traditional trained clinician I was only interested in her experience as a “hallucination” and with that and some other symptoms, I then created a diagnosis. But she was interested in the voices and the power they exerted over her; in the hinder they gave her; in what they told to her etc. She did not like my reductionist approach. Because she was hindered by the voices and medication did not work with her. She became more and more isolated because the voices forbid her all kind of social activities.

In order to break through this isolation we organised a meeting with another patient hearing voices and they got very enthusiastic in talking about their voices. They recognised each other experience. But still they did not know how to cope with their voices. To solve this problem we asked, with the help of Sandra Escher, for support from a TV talk show, because that was a way to contact people.

Our aim was to meet in this way somebody who not only heard voices, but also was able to cope with them. In this talk show Patsy, the patient, told her story and I asked if there was somebody who knew how to cope with the voices to contact us. To our astonishment 700 people reacted. To organise the information we constructed together with Patsy Hage, a questionnaire. From those who returned the questionnaire we selected people who could explain rather clearly what they did in coping with their voices. They became the speakers on a congress we organised.

It was then that we met quite a number of people who heard voices and had never been a psychiatric patient. They were functioning socially quite well. This was a shocking experience for me as a psychiatrist who had always identified hearing voices with psychopathology. This experience however made the following research questions of interest:

- Is hearing voices in itself a sign of psychiatric illness? -
Is the presence of hearing voices related to a particular psychiatric illness
- Are there differences between the characteristics of the voices heard by patient voice hearers and by voice hearers who never became a patient
- Are certain feature or characteristics of hearing voices related to the presence of problems in the life of the voice hearer?

Is hearing voices in itself a sign of mental illness ?

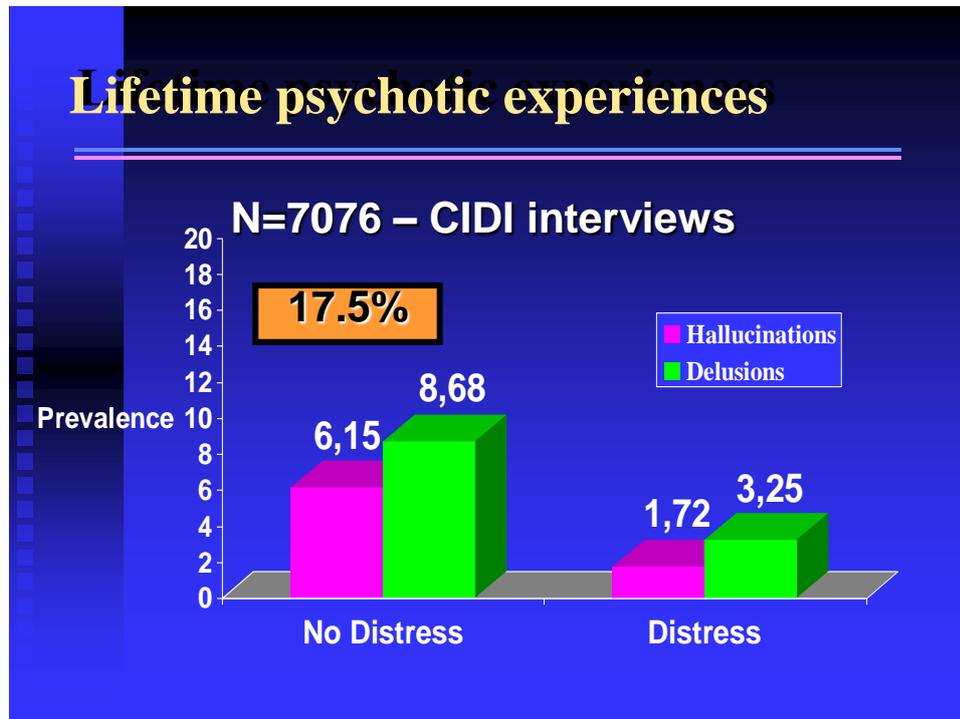
When we looked in the epidemiological literature we found several studies showing that hearing voices was apparent in normal functioning people.

The first studies we met, using a psychiatric diagnostic instrument, were the studies of Tien (1991) and Eaton (1991)

These two studies are general population studies done in a population of 15000 persons. Tien found 2-4% auditory hallucination of which 2/3 had no problems with their voices and one third looked for help because of having trouble with the voices. Eaton repeated this study with a psychiatrist doing the interview, he found 45% with criteria for a psychiatric diagnosis and only 16% with the diagnosis of schizophrenia, but 55% without an illness.

Also in Holland an epidemiological population study was done with 7000 people. (This study was called the Nemesis study done by the Trimbos Institute in Utrecht) This follow up study over three years showed many more people

experiencing hallucinations and delusions then patients with these experiences.(the data were worked out by Prof dr. Jim van Os in Maastricht)



17,5% of the population showed any psychotic experience, while only 4.2 % experienced distress of these experiences and only 1.5 % could be diagnosed according to the DSM IV with a psychotic illness. This study also showed that Of the 6.15%with hallucinatory experiences (visual as well as auditory) only 1.72 were giving distress to the person.

From these studies and our own meeting with people, who hear voices and never became psychiatric patients, we concluded that hearing voices in itself is not a sign of mental illness.

We then asked ourselves:

Is the presence of hearing voices, giving distress only related to a particular psychiatric illness, like in the Psychiatric diagnostic system only with schizophrenia We found in the literature quite some studies indicating that auditory hallucinations are apparent in many different conditions.

We also did an inventory in our social psychiatric care service in Maastricht with 288 subscribers patients of which 81 (28%) told us to experience hearing voices.

Diagnosis	Yes	Percentage	total subscribers
Schizophrenia	N=33	53%	N=62
Dissociative disorder.	N=4	80%	N=5
Depression`	N=25	28%	N=90
Psychotic disorder.	N=7	41%	N=17
Personality disorder.	N=6	13%	N=48
Otherwise (anxiety)	N=6	9%	N=66

Their main diagnosis was quite diverse as you can see at this power point. Not only schizophrenia but also dissociative disorders, depression and personality disorders. The sample was not representative for dissociative disorder. They are underrepresented because an instrument to establish the diagnosis was not used at the service.

Our next research question was: do certain features differ between patients and healthy people hearing voices

We therefore started a systematic comparison of three groups of voice hearers. One group of patients diagnosed with Schizophrenia; one with a dissociative disorder and the voice hearer group who never became patient or healthy group.

The first remarkable result was the lack of difference between the patient groups and the healthy group as far as the experience itself was concerned. **All groups**

heard voices, that where not mine, not their own thoughts, but voices from someone else.

This made us even more interested in what the differences might be between the patient voice hearers and the healthy voice hearers. From this comparison we observed that the differences especially concerned the person's reaction to the voices

	Schizophrenia		Dissociative disorder		Healthy V.H.	
Positive voices	N=15	83%	N=10	67%	N=14	93%
Negative voices	N=18	100%	N=14	95%	N=8	53%
Predom. Pos.	N=2	12%	N=2	13%	N=11	79%
Neutral	N=4	22%	N=3	20%	N=1	7%
Predom. Neg.	N=12	67%	N=10	67%	N=0	0%
Afraid for voices	N=14	78%	N=11	84%	N=0	0%

Both groups, patients and non-patients, hear negative **and** positive voices, therefore that is not the difference.

1) But it is very clear that patients experience their voices as predominantly negative while healthy voice hearers experience their voices as predominantly positive.

*2) Furthermore patients are afraid of the voices they hear and non-patients are **not**.*

3) Patients are also more often disturbed by the voices in their daily functioning.

These differences make it clear also why the healthy voice hearers have no reason to go to a psychiatrist and why the patients do go look for help.

To observe that difference a diagnosis is not necessary, but possibly even harmful.

Relation with life history

There are healthy people hearing voices, but only in 2-4% of the population. While in patient groups – like in schizophrenia and dissociative disorder and affective disorder – the percentage of people hearing voices is much higher: 30-50%.

This arose our interest in the life history of voice hearers. Because we could imagine -- coming from a social psychiatric background -- that patients might have experienced more problems in their life histories than non-patients and that they might not be able to solve their problems. Therefore we held quite extensive interviews with the voice hearers in all three research groups and found the following relationships between hearing voices and the life history, see next Power point slide

Relationships with life history

The general population surveys show only a small number of people who experience hearing voices: 2-4%, while the frequency with the patient groups is much higher: about 50% with schizophrenia and 40% with dissociative disorders

It is this difference between the general population and the patient population that lead us to think that patients might have more problems in life than the general population. Therefore we became interested in analyzing the life histories of patient voice hearers and relate them to the characteristics of their voices.

In all our 7 studies with around 350 voice hearers we observed that they laid a relationship between their voices and the trauma's they had experienced.

In our last study, published in the book living with voices, 50 voice hearers report their recovery story. In that study we were told about the following kind of traumatic experiences.

- 1) sexual abuse in 18 stories (3 combined with physical abuse)
- 2) Emotional neglect in 11 stories (3 combined with sexual abuse)
- 3) Adolescent problems in 6 stories
- 4) Intense multiple stress in 4 stories
- 5) Long time bullied in 2 stories
- 6) Physical abuse in 2 stories (3 combined with sexual abuse)
- 7) No clear traumatic experience in 7 stories.

In all our studies we found three kinds of relationships between the voices and the life history of the voice hearer

- 1) Traumatic experiences or heavy stress related to the onset of the voice hearing experience
- 2) Hearing voices working as a defence mechanism for overwhelming emotions
- 3) The characteristics of the voices having links with what has happened to the person

Ad 1) The most useful relationship is what has happened at onset of the voices. There has been an intense difficulty or traumatic experience in 70% of the people hearing voices. In the interview we spend quite some time and questions on exploring this relationship because that is an important step in exploring what problems the patient should be helped with.

Ad 2) The function of the voices as defence mechanism can make us aware of the emotion(s) the person has special trouble with to express. For example if the voice makes the person angry the person has always a serious difficulty in expressing anger and therefore to express anger has to be learned.

Ad 3) **The Links**

The Links between the characteristics of the voices and what has happened to the person are rather useful. We will give only two examples of the characteristics of the voices after sexual abuse. We observed many of these links in the group of people who recovered from their distress with their voices which we published in the book "Living with voices" - PCCS Ross on Wye in Engeland

Sexual abuse

- Flore: *With me, there was never any confusion about the voice. I recognized it; it was the abuser's.*
- Jolanda: *My voices have a name. Nina is about 7 years of age. She is still a child. Nina originates from a long time ago and she is connected to the sexual abuse, which started when I was 7. I think Eva is 18 or 20 years old ... Eva came when I was 18 and my family withdrew the formal complaint to the police about the person who had sexually abused me. Eva wanted me to act sturdier, so I fight for my own interests.*

With sexual abused people tell about their voices as being reproachful. Like being a bad person and other things that are told to them by the abuser. Or they feel themselves guilty because the abuse did stimulate sexual feelings as a automatic bodily reaction and then afterwards is interpreted as being guilty of the abuse. Quite often the voices express certain emotions like with Jolanda in case of her voice Eva who was reproachful because she did not sufficiently defend her own interests.

There are many more examples to be given about the links between the characteristics of the voices and what has happened to the voice hearer. Like for example with being bullied over long term periods the voice hearer often carries the voices of the bullies with them.

We therefore developed an Interview schedule to systematic inform us about the separate voices, heard by the voice hearer. From that interview we make a report and discuss this with the voice hearer to be sure we have covered all aspects. We then make a construct about the relationship between the characteristics of the voices and what are unsolved problems of the voice hearer. Also therefore

we developed an instrument, which is too difficult to explain in this short lecture. In the meantime Dirk Corstens has tested this instrument in 90 voice hearers.

Consequences for Psychiatric approach

When hearing voices in itself is not a sign of mental illness but the difficulty to cope with these voices seems to be the problem, then the person should be helped to cope with the voices. And when the voices are a signal that there are serious problems the person has not solved, or learned to cope with, those problems should be worked through. The consequence in psychiatric care is to accept and make sense of this experience and to support the person with solving his/her problems. Medication only never solve these problems. Analysing the relationship between the voices and what has happened to the person is necessary to help a person to solve the emotional consequences of what has happened.

This is hard work especially for the voice hearers themselves and therefore they need a lot of stimulation and support. It is also hard work for the professional, However this work is more interesting than circling around the problems and prescribing drugs and seeing a person becoming a chronic patient.