HEARING VOICES - THE DUTCH EXPERIENCE: ROMME AND ESCHER

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"The world of voices is more real to me than the world that exists around it, the world we all together perceive, so I don't know what it is to live without voices"

Patsy (Interview with Sonja)

This quote was broadcast on 'Sonja on Monday', a popular evening chat show on Dutch TV. It heralded the start of a remarkable campaign spearheaded by Prof Marius Romme and Sandra Escher designed to radically change the way that we think about the phenomenon of hearing voices.

Professor Marius Romme is a Professor of Psychiatry at the University of Limburg in Maastricht, Holland, and **Sandra Escher** is a journalist who works closely with the department. Professor Romme has a long history of involvement in emancipatory politics. Romme and Escher have observed that for some people, hearing voices is a normal facet of those people's experience, as normal and as a deviant as being homosexual, a human variation that can, but does not have to be troublesome. The majority of the population do not hear voices in the clear and distinct way that a minority of people do. This does not mean that hearing voices is wrong and should be changed any more than we now believe that homosexual people should be forced to be heterosexual.

They argue that a great many of the problems caused to people who hear voices are due to the stigmatisation and prejudice that surround them, and that they, themselves, incorporate this negative view into their experience of hearing voices. The problems are amplified by explanations that the voices they hear have no meaning and that the voices are outside the control of the person who is experiencing them. If people who hear voices are consistently told that they are strange, that hearing voices is a bad thing and should be treated with drugs and hospitalisation, it is little wonder that these messages are internalised with major and extremely damaging consequences for the rest of those people's lives. On the other hand, if the person's family and social network accepts that voices are a special form of perception that can even become an inspiring part of a person's psyche, then it is far more likely that the person can live normally.

Romme and Escher argue that there are many similarities with the way homosexuality was and is perceived by society and particularly by psychiatry. Homosexuality has only relatively recently been taken off the index of psychiatric disorders (DSM III 1980); even now many people believe that homosexuality is a perversion which should be treated. Psychiatry attempted for many years various forms of treatment, none of which were successful. Homosexual people suffered vicious persecution from both their families and from society which resulted in great unhappiness. Homosexuality was associated with schizophrenia, alcoholism, crime, drug taking, suicide and almost every other deviance going.

"...the homosexual tends to be an unstable person and easily upset. Apart from the unhappiness which his abnormality gives him the homosexual tends to suffer from other forms of instability. He is often alcoholic...Homosexuality is common in schizophrenia...It may be that most of the psychoses which, with or without drugs, release abnormal behaviour are basically homosexual."

Quoted from 'Homosexuality: It's Nature, Causation and Treatment'
by Clifford Allen, Consultant Psychiatrist. 1956

Most people and even most psychiatrists would now concede that there is no causative link between homosexuality and pathology, and that the links with alcoholism, various forms of mental illness, and suicide were and still are due to the persecution and discrimination that homosexual people suffer from.

Romme and Escher argue that hearing voices is associated with a similar list of deviancy for the same reason that homosexuality was and that there is a similar solution. Like homosexuality, hearing voices cannot be cured. It can only be masked by drugs which have permanent and disabling side–effects. What can be cured is the discrimination and prejudice that people who hear voices suffer. What is needed is an emancipatory movement which allows people to freely acknowledge and rejoice in the fact that they hear voices, and encourages families and society as a whole to accept that hearing voices is an ordinary variation of normality.

Romme and Escher ask us to make a leap of the imagination to a future where it will be ordinary to see people openly conversing with their voices, where people will value their special ability and accept it, where parents will understand and accept that their children might hear voices without fearing that it is a sign of mental illness.

Romme and Escher's work, if it shows that 'schizophrenia' is one of the more severe reactions to life problems rather than of biological origin, will undermine the concept that schizophrenia exists as a distinct illness. At present, psychiatry considers hearing voices to be pathological and a first rank

symptom of schizophrenia. This means that if the person hears voices the chance of being diagnosed schizophrenic will be very high, rather than the psychiatrist using the sign of hearing voices to take interest in their life problems.

However, classical psychiatry has shown in the past that the diagnosis of schizophrenia is very adaptable. Though in the short term Romme's work will add force to the critics of the diagnosis of schizophrenia, in the longer-term psychiatry will take out 'auditory hallucinations' from the list of first rank symptoms and rely more heavily on the rest of the list. Indeed, Romme himself has already talked about a schizophrenic response to hearing voices i.e. hearing voices itself is not the problem, it is how you respond to hearing voices. This for Romme, could explain the central problem other psychiatrists have in his work, why so many people who hear voices are mad? These people are unable to integrate hearing voices into their day to day existence and suffer such a contradiction at the core of their being that it leads to madness. This psychological explanation could explain how oppression of people who hear voices leads to individual distress, it is however unlikely to help persuade the psychiatric establishment for whom it raises more questions than it answers. Psychiatrists at the best of times are reluctant to accept psychological explanations in favour of biochemical ones.

Romme and Escher's work is not an esoteric attempt to explain the causation of inner voices but a practical examination of people's experience of hearing voices and it's consequences. Many people who hear voices lead ordinary and happy lives but for those who are unable to live with the voices or are tormented by those around them, Romme and Escher's work is one the most important attempts to change their lives.

THE HISTORY

The following extract is from a report written by Romme and Escher which was then edited and published in the schizophrenia Bulletin (vol 15 no 2, 1989). The patient referred to below is Patsy Hage:

For some years, one of my patients, a 30 year old woman, has heard voices in her mind. These voices give her orders or forbid her to do things. They dominate her completely. She has been hospitalised several times and diagnosed as having schizophrenia. Neuroleptics do not have any effect on the voices although they reduce the anxiety provoked by them. But the medication also reduces her mental alertness. For that reason, in order to stay alert, my patient does not take medication over long periods and does not remain an inpatient long when she is hospitalised. Nevertheless, the voices have isolated her more and more by forbidding her to do things she has always loved to do.

Last year she started to talk increasingly about suicide. I felt she was taking a road with no turning point. The only positive topic in our communication then was the theory she developed about the phenomenon of the voices. The theory was based on a book written by the American psychologist Julian Jaynes (1976), The Origin of Consciousness in the Breakdown of the Bicameral Mind. It was reassuring for her that the author described hearing voices as having been a normal way of making decisions until about 1300 BC. According to Jaynes, hearing voices has disappeared and been replaced by what we now call 'consciousness'.

I began to wonder if she could communicate especially effectively with others who also heard voices, and whether her theory would be accepted by other people who had these experiences. This might have a positive effect on her isolation, her suicidal tendency, and her feeling dependant on the voices. She and I began to plan together how she might share some of her experiences and views.

From this point, things progressed rapidly. Speaking on a popular Dutch television programme, my patient and I invited people to contact us. After the television programme, 700 persons responded to our appeal; 450 of them heard voices. Of these 450, 300 reported not being able to handle them. Hearing from this last group was especially important in encouraging me to organise a congress for people who heard voices and who wanted to exchange ideas about their experiences.

We sent out a questionnaire to those who responded to the television programme in order to get more information from them. From those who returned the questionnaire, we selected a number of people who could cope with the voices and invited them for an interview about their way of coping. We selected 20 persons who we thought were able to explain their experiences in a clear way and who would like to tell their experiences in a clear way and who would like to tell their experiences to others who could not handle their voices. These 20 became the speakers at a congress attended by 300 people who heard voices, a congress that took place on October 13th, 1987.

This congress was held in a building unassociated with any psychiatry department or medical institution and organised in a manner very different from ordinary medical conferences where patients are invited to be examined and studied rather than to actually take part in the conference. I began with a plenary where people who hear voices talked about their experience and went on to small loosely facilitated workshops. The atmosphere created was one where people could freely exchange their experiences and the interpretations of those experiences.

"*The general atmosphere of the entire congress was of a meeting of a group of people with common interests and experiences. Although medical aspects of these experiences were discussed, there was no sense that this was a medical meeting or a meeting of medical patients. The participants freely shared their experiences, their many interpretations of these experiences including religious views or a range of other human reactions, and their approaches to coping. Some people were obviously troubled by their voices and saw them as part of a mental illness, but many had very different ways of understanding these experiences and appeared to be competent, not disabled, and depending on one's view of the nature of voices, not in any way ill."*

Foundation Response was founded following the first congress, with the assistance of Romme and Escher, as an organisation of people who hear voices. The first congress was followed by a second in November 1988 arranged jointly by the Dept of Social Psychiatry, University of Limburg and foundation Response.

This second congress was aimed at professionals as Foundation Response felt that professionals were not accepting that the voices they heard were real.

"This time a smaller number of people hearing voices, and a larger number of professionals were invited. By talking and explaining their experiences to the professionals, they hoped to help enlighten people to what was happening, as opposed to the professionals' theory of what was happening. They were trying to bridge the gap by enabling the professionals to meet normal, healthy people who heard voices without being psychotic."

Romme and Escher have since then continued to assist Foundation Response in its development and to write articles for journals and magazines across the world. They have had considerable difficulty in getting published outside Holland due to the singularity of their work and the resistance of the British and American press to 'foreign' work.

AN EMANCIPATORY APPROACH IN COMMUNITY PSYCHIATRY

Romme and Escher describe the way they work as emancipatory and contrast it to the more common 'treatment model' where deviation is seen as arising from the individual's illness, thus the individual alone needs treatment. They also contrast it with the 'parental model', typified by the National Schizophrenia Fellowship in Britain, which whilst on the whole accepting the explanations given by psychiatry, focus their efforts on attaining more resources for research and the care and treatment of sufferers/victims.

The emancipatory model aims to influence social dynamics which means altering attitudes, so that hearing voices is seen as a behavioural variation rather than a behavioural deviation. This has already happened for homosexuality which is no longer considered an illness. Romme and Escher are exploring this question for hearing voices and believe it may be a more appropriate way of dealing with other signs of mental illness which are equally intractable to the clinical treatment model, such as visual hallucinations.

Romme and Escher state that:

"The goal of the emancipatory approach in community psychiatry is to create a feedback force…that is strong enough to influence the social forces and may therefore change the social equilibrium. This is necessary because an individual who hears voices and has retreated from social integration as an insane person is not able to change or readjust society as an individual ……the individual has to unite with other people who also hear voices, and they must organise themselves as a support group to influence societal perception of this form of behaviour to overcome the taboo and be accepted as a variation in human experience…."

Romme and Escher believe that, in many cases, the illness model is a dead end for both psychiatry and for the people who are labelled by psychiatry, and not just for those who hear voices. Romme and Escher offer the emancipatory approach as a more effective long-term strategy with possibly dramatic effects in the short-term for a few of the people who hear voices.

Romme and Escher reason that if a particular behaviour is defined as pathological we must find out: whether it occurs in people who are not psychiatrically ill? Whether this behaviour necessarily leads to illness or whether there are other ways of coping? What is the relationship between how an individual is integrated into society and how they view the cause of hearing voices (i.e. people who hear voices in association with illness are generally less well integrated socially than people who hear voices and have never been ill)?

If psychiatry does not check each of these then it runs the risk, as it did in the case of homosexuality, of colluding in the persecution of people with deviant behaviour through inappropriate treatment.

THE RESEARCH

Romme and Escher through their work have tentatively identified three phases in coping with hearing voices: the startling phase; the organisational phase; the stabilisation phase. As with any attempt to categorise an experience it should be borne in mind that no one is likely to go through the phases exactly as described.

Of the 700 people who responded to the TV programme on Dutch TV, 450 actually heard voices. Of those, 186 completed questionnaires, 1224 women and 62 men. This is by no means a representative sample of the population of people who hear voices as they are not randomly selected, thus any statistics given below must be treated with caution. Where the percentages do not add up to 100% the respondent either did not reply to that question or the answer was unclear. 87 of the people who replied had heard voices for longer than 10 years, 50 for between 5 and 10 years and 56 for less than 5 years. Half of those who replied no longer heard voices.

Phase 1: The Startling Phase

Most people hearing voices said it began quite suddenly and could remember the moment that they first heard them. Three quarters of the people who replied to the questionnaire associated the start of the voices with a highly emotional event: 26 people with the divorce or death of an important person: 22 people receiving psychotherapy: 7 people with spiritualism: 74 people with other events (unrequited love, illness, pregnancy, accident). For some it was a terrifying experience and for most of the others it was a time of confusion, panic and fear, though less for those who first heard voices when they were children. 11 people first heard voices before the age of 10yrs, 19 people between the ages of 10yrs and 20yrs and 138 people after the age of 20yrs. This phase can last weeks, months or occasionally years. Most people heard more than one voice, one third of the respondents heard two voices and two thirds more than two. One in five of those who replied heard over eight voices. Half of the respondents reported that the number of voices changed over the years, usually declining.

Phase 2: The Organisational Phase

This is the period when people communicate with the voices and work out strategies of dealing with them. They may try different strategies.

Some people got angry with the voices but on the whole, this was an unsuccessful method of coping. Two thirds of the respondents had tried ignoring the voices which again, on the whole, didn't work. A third of the respondents had tried to impose limits on the voices e.g. setting aside times to listen to the voices. Two fifths of the respondents had tried some form of distraction e.g. singing, listening to a personal tape recorder. The most successful strategy seems to be selecting the positive voices (if there are any), listening and talking only to them and trying to understand them. A quarter of the respondents had tried this approach.

As Romme and Escher say:

"Acceptance of the voices seems to be related to a process of growth toward taking responsibility for one's own decisions. Always blaming others is non-productive. Or, as some described it, you have to learn to think positively."

The other strategy that is commonly used is that of structuring the contact with the voices for example assigning particular times to listening to voices or through rituals e.g. mentally casting away the evil spirits.

Phase 3: The Stabilisation Phase

This is the period when people have learned to live in balance with their voices, they are seen as part of the person. They can have a positive influence and people are not forced to do what the voices say but can choose to follow their advice if they wish to. In this phase people are content to hear voices.

People have various ideas as to the sources of the voices: 76 people considered the voices to be gods or spirits; 30 people interpreted the voices as a beneficent guide; 45 people considered the hearing of voices to be a special gift; 48 people recognised the voice as that of a person they knew in daily life.

Romme and Escher attempted to divide the people who replied to the questionnaire into two groups: those who were coping and those who were not. Those who were coping with the voices often experience the voices as positive and were able to keep the voices under control by talking to them selectively. On the whole, this group had learned to cope without help from others.

The group who were not coping were more likely to experience the voices as negative and attempt to control them by ignoring them. This group is more likely to seek help from a psychiatrist. Romme and Escher include in their work a large number of excerpts from interviews describing how particular individuals experience hearing voices. These make fascinating and absorbing reading but are impossible to summarise, as each person experiences hearing voices in a unique way. Below is a short excerpt from one such interview:

"If I look back I recall a very intense and gnawing homesickness. I tried to find something I could identify as the cause so I could work it out. That didn't help. At a certain moment- I was then about 39- I realised I had begun to have an intense inner life. I heard voices. In the first instance I thought I was having telepathic contact with someone in our village. I arranged with the voice to meet him at a local swimming pool. I entered and of course saw only the same familiar faces as always, started to sit down and heard a loud voice saying 'watch out, you're about to sit on me'. This was really strange. I was enormously embarrassed and didn't really know what to do."

The woman described how she searched for an explanation within spiritualism but found that unsatisfactory, then tried ignoring the voices without success and finally made peace with the voices and learned to live with them. Now she is able to say that she is glad to hear voices. At no time has she received any psychiatric care.

Romme and Escher tentatively conclude from their research that:

“Active coping with voices is a more effective strategy than trying to get rid of them by passive strategies such as taking medication, seeking distraction and other avoidance behaviour,”

A COMMENATRY ON THE DUTCH EXPERIENCE

Romme the Psychiatrist

Romme as a psychiatrist is in an awkward position. He is trying to use his power as a leading member of a powerful profession to assert the normality of a particular behaviour, whilst the rest of his profession continues to use this behaviour as a first rank symptom of schizophrenia. Through his role, he is associated inextricably in the public mind with the treatment of the mad. Thus, when he appears on television with a person who hears voices, his very presence indicates that this woman has something abnormal about her, even though he might say with his words that to hear voices is not a symptom or sign of madness.

However, if he had not been a psychiatrist with the prestige that goes with that profession, he would have found it immeasurably more difficult to arrange an interview on a popular television show. His presence gives the topic of hearing voices legitimacy and credibility where most other people would be written off as mystics of the ‘lunatic fringe’.

With the concept of emancipatory psychiatry Romme and Escher recognise their power and the powerlessness of oppressed groups and the need for psychiatry to use its force to help people who hear voices be accepted. However, Romme’s presence as a psychiatrist could undermine the struggle of Foundation Response even as Romme and Escher have helped to begin the group and help to support it through its growth. Romme’s role and profession reinforce the link with psychiatry, and consistently move the discourse back to the language of helping professions, ‘coping and caring’, rather than the language of emancipatory politics, ‘fighting and anger’.

It is not that the two approaches cannot complement each other, they are two sides of the same coin. However, if the language of ‘coping and caring’ becomes dominant it undermines and weakens those who want political change. Foundation Response must move out of the kingdom of psychiatry and into a separate existence in the ‘normal’ political sphere. It will attract supporters from the world of psychiatry but also from many other parts of mainstream politics. In the long term, it will be these supporters who will bring about lasting change.

The great danger is that Romme and Escher’s work will be absorbed into mainstream psychiatry without affecting society at large. Their work might ruffle a few feathers and psychiatry will have to adjust a little. People who work in psychiatry and the general public will understand the experience of hearing voices a little better. Treatment for people who hear voices will be more varied and appropriate but there will be no great long term changes. The temptation is to concentrate on the short-term benefits of developing self-help groups, coping strategies and on exploring the experience, at the expense of creating a political movement of people who can change, for good, the position in society of people who hear voices. Romme’s job as a psychiatrist is already beginning to take him in this direction as he struggles to maintain professional credibility. His job is to research, sending out questionnaires, interviewing people, collecting data; it is not primarily about supporting a vestigial political movement.

Undermining Psychiatry

The medical model, used by the majority of western psychiatrists, rests on diagnosis to determine which treatment is appropriate for the individual patient. Romme and Escher’s work suggests that this individual treatment is often harmful and at best can only mask the voices that people hear. Psychiatrists, by advocating such treatments, may be colluding in the oppression of people who hear

voices in the same way that psychiatry treated homosexuality for so many years, and helped to maintain the idea that homosexuality was a disease that needed to be cured. If it is true that hearing voices is no more deviant than homosexuality than how many more ordinary human variations have been transformed by psychiatry into 'symptoms' of mental illness?

If hearing voices can no longer be considered a symptom of schizophrenia then this puts the diagnosis under further strain. Schizophrenia has already been attacked for being a hotch-potch, a catch all diagnosis with no scientific credibility, and Romme and Escher's work will not help.

The emphasis in their work is not to dismiss hearing voices as merely a symptom of schizophrenia but to recognise that everyone has their own particular experience of hearing voices. The task they have set themselves is to explore this experience in all its richness but more importantly to help people who hear voices to explore the experience for themselves and to compare their experience with other people's. This in many ways reduces the role of the psychiatrist to that of an enabler, someone who brings people together to explore their experience. This contrasts with the present role of psychiatrists, where the psychiatrist is the expert who knows and understands the illness, and the patients are told what to do, and on the whole discouraged from exploring their experience either by themselves or with others who have similar experiences.

Thus, Romme is in an awkward position vis-à-vis his colleagues. Consciously and deliberately Romme and Escher are trying to destroy the bedrock of psychiatry from within. So far Romme has not had a significant impact on western psychiatry. If Romme and Escher's work becomes better known and better understood outside Holland and especially if it gets into populist media, Romme's colleagues will turn on him. The first stratagem will be to ignore the work, Romme and Escher have had considerable difficulty getting published outside Holland. The next stratagem will be dismissal of the work. This has begun to happen; a recent article in the British Medical Journal was entitled 'Hearing voices may be normal but happens most commonly in schizophrenia and alcoholic hallucinosis'. This article does not even mention Romme and Escher's work but implicitly denies it any importance. It begins by stating that hearing voices may be normal but then goes on to detail methods of reducing voices if drugs don't work including resting and wearing earplugs.

The next stratagem used by Romme's colleagues will be vilification of him personally and professionally. This is when the testing time really begins and Romme and Escher are already aware of the dangers. Romme must walk a tightrope of maintaining his professional credibility as a psychiatrist and staying firm in his allegiance to Foundation Response and emancipatory psychiatry. It is questionable whether this is in fact possible as Romme and Escher's work is in direct conflict with many of the base tenets of clinical psychiatry, and the only way that Romme can remain credible to mainstream psychiatrists is by proving himself on their terms.

Romme and Escher will be vilified through association. Psychiatrists will judge them by the company they keep. Many people who hear voices are involved with religious, paranormal and mystical groups as these offer alternative explanations for hearing voices. These groups are considered unsuitable company for respectable members for the establishment. People will use this association as an indication of the untrustworthiness and unreliability of Romme and Escher's work.

It is only fair to say that both Romme and Escher have great experience in the politics of mental health and are well aware of the kind of pressures they are under and a constant theme in with Romme is his insistence on remaining within the acceptable limits of psychiatry. Romme wishes to continue to use the power of psychiatry to aid the cause of people who hear voices, which he cannot do if he is ostracised from the establishment. However, he openly acknowledges the contradiction and that he cannot escape from it but only work with it.

Romme and Escher: The scientists

Romme and Escher work for the Department of Social Psychiatry at the University of Limburg as research scientists. Exploring the phenomenon of hearing voices is only part of the work they do. Most of their work is concerned with what they call 'social psychiatry', which in this context seems to mean researching the actual day to day lives of people with mental health problems.

Other papers they have published with each other or with other authors include: Group differentiation of chronically mentally ill in the community, an instrument for adequate treatment planning: Social vulnerability and prolonged psychiatric illness: and Do chronic mental patients get the appropriate ambulatory treatment?

These illustrate their concern with the actual experience with patients rather than only their presenting symptomatology. They question the appropriateness of much of the standard psychiatric care that is offered both by ambulatory centres (i.e. places that people can walk into like day care centres, out-patient clinics) and by in-patient facilities. They are seeking more effective ways of planning treatment.

Their research, however, is only at the beginning stages and they have been recently been allocated a further four years of funding to continue it. This four years funding will be used to organise a further four conferences at the rate of one per year. One of these will probably be on the experience of children who hear voices but it has yet to be agreed.

As has been pointed out previously their findings are, at present, only speculative. They have shown that there are people who hear voices and are happy to, but this fact was already known by mainstream psychiatry even though it was largely ignored. Particularly, this knowledge has never informed in any way the treatment that psychiatrists prescribe their patients, which is invariably about disguising the voices and never considering them in a positive light.

The statistics that they have compiled from the 186 questionnaires are at best indicative as the sample used was in no way random. The hope is that are far more people who are happy hearing voices than was shown by the questionnaires but until a much larger study is carried out which takes a truly random sample of the population of [people who hear voices there is no way of being certain. This leaves the avenue open for other psychiatrists to state that although some people who hear voices are coping with them, the vast majority are not.

The most illuminating and rich material that Romme and Escher have is from the interviews and conferences. It shows in graphic detail how people experience hearing voices, and the different ways they learn to live with them. This information would be dismissed by most scientists as being anecdotal and therefore interesting but proving nothing. Case histories are used by psychiatrist a great deal but usually to illustrate established facts (e.g. the career of a ‘schizophrenic’) not to demonstrate new theories unless backed up solid statistical evidence.

Conclusion

The study of hearing voices as judged by mainstream science is still in very early stages. It is doubtful anyway that science can prove what Romme and Escher wish to prove, which is that hearing voices should be accepted as a normal part of life. Psychiatry can simply shift its position slightly, acknowledging that normal people can hear voices too, but together with other signs or symptoms it is still indicative of severe mental illness. Similarly, thought disorder is a first rank symptom of schizophrenia, though insufficient on its own to diagnose schizophrenia. What may happen is that through Romme’s work, hearing voices becomes less significant in the diagnosis of schizophrenia. Psychiatrists will use it in combination with other symptomatology instead of using it on its own to diagnose schizophrenia.

Romme and Escher’s position is a moral one, not a scientific one. That they are saying is that hearing voices should be considered a normal variation in human behaviour, as is homosexuality. Romme and Escher, amongst others, are working on new therapies that may be able to help people get rid of their voices, though this seems a little unlikely. Romme and Escher are going further than this treatment model where the primary objective is to cure the patient of the problem of hearing voices. They are saying that hearing voices is not a bad thing that must be got rid of. It is not indicative of mental illness, and as such should be removed from psychiatric textbooks as being associated with schizophrenia. In the end, as with the struggle to remove homosexuality from the realm of psychiatry, this is a moral and political battle, not a scientific one.