

## Feature

### Hearing Voices: tracing the borders of normality



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In the 1980s, a collaboration developed between psychiatrist Dr Marius Romme, his patient Patsy Hage (who heard voices), and journalist Dr Sandra Escher. They sent out a television appeal to other voice hearers, asking them to get in touch, and share their stories. Hundreds of voice hearers responded to their plea: some were able to cope with their unusual experiences, but others struggled to do so.

In their subsequent research, Romme and Escher examined why some people could cope independently with hearing voices, whereas others found such experiences distressing and tended to come to the attention of mental health services. They suggested that the degree of distress related to voices was associated with how an individual appraises them. For example, the degree of perceived intrusiveness of voices might be associated with greater distress and a need for mental health care.

Such research sowed the seeds for the Hearing Voices Movement, which advocates an alternative attitude to the experience of hearing voices than is usually found within mainstream psychiatric services. Rather than viewing voices as a fundamental sign of mental illness, proponents of the movement suggest they are unusual, but ultimately understandable experiences that often relate to traumatic or problematic life events. As such, they can be experienced by anyone, whether or not they have other symptoms that require a psychiatric diagnosis. Importantly, they believe that a person can develop coping strategies to deal with their voices, primarily by confronting the life events that lie at their core.

In psychiatry, hearing voices is often taken to be a cardinal sign of psychosis and has traditionally been thought of as an entirely abnormal experience, indicating the need for treatment. However, rather than being bizarre and distinctly out of the realm of normal experiences, some research suggests that hearing voices could actually be more common than initially thought, even among otherwise healthy people. Furthermore, some groups, such as the Hearing Voices Network, argue that they are a sane response to an insane world. How do we reconcile these different approaches and decide where to draw the border separating normal experiences from abnormal experiences that indicate illness?

Voice hearing has been reported among otherwise so-called healthy individuals. However, it is unclear whether epidemiological methods that use psychosis screening questionnaires to reveal these so-called healthy voice hearers are simply identifying those at increased risk of psychosis or whether hallucinations can exist as a discrete experience in an otherwise healthy person. What these data do suggest is that a simple dichotomy between the healthy and those with psychosis is unlikely. Several alternative models are suggested, including the idea of a continuum, with hallucinatory

experiences spread throughout the population but skewed towards those with a diagnosis of psychosis.

What then determines when a voice requires treatment? Although some people have isolated experiences, rare hallucinations, or find their voices comforting or in some way beneficial, others find the experience of hallucinations distressing. Some people, described as having an at-risk mental state, do not reach the criteria for a psychotic disorder, but nonetheless experience distress and functional impairment within the context of attenuated psychotic symptoms, such as voices. Dr Paolo Fusar-Poli, consultant psychiatrist at OASIS (Outreach and Support in South London) in Lambeth, London, UK, suggests that “the problems start when hearing a voice accumulates with other mental health issues, such as anxiety and depression, plus functional impairment, drug abuse, traumatic events...which all brings you to the point of being help-seeking. At that point, you may need services, such as OASIS.” It seems therefore that the important factor is the degree of distress and functional impairment associated with the experience of hearing a voice.

The service offered by OASIS caters for young people at risk of psychosis who are experiencing subclinical psychotic symptoms, but do not meet the criteria for a diagnosis. OASIS works with schools, colleges, and primary care to increase awareness of attenuated psychotic symptoms and to offer support to those who find that these symptoms are distressing and interfere with their psychosocial function. Their patients are help-seeking, distressed not only by voices, visions, or other hallucinatory experiences, but also, and often to the greatest extent, by the associated psychosocial problems. On referral, patients are assessed with the Comprehensive Assessment of At-Risk Mental States (CAARMS), an extensive and in-depth assessment that identifies prodromal symptoms of mental illness.

Among those meeting the criteria for prodromal psychosis with the CAARMS, the transition rate to psychosis is 30% within 2 years. Therefore, there is a danger that rather than working preventatively to avoid transition, such services apply psychiatric labels to the other burdens of young people who are already experiencing distressing subthreshold psychotic symptoms, but who might never actually develop a full-blown psychotic illness.

One concern is that of unneeded treatment for those who will never develop frank psychosis, and this particularly relates to antipsychotic medications. However, this concern is likely misplaced. The first-line treatment for an at-risk mental state is psychotherapy, most often cognitive behavioural therapy. NICE recommendations, supported by evidence from several randomised controlled trials, suggest it can halve the risk of

psychosis onset. Dr Fusar-Poli says, “nowadays, prodromal clinics worldwide tend not to use antipsychotics, and they prefer psychological therapies”, reserving antipsychotic medication for those whose symptoms worsen to the point of making a transition.

Unwarranted antipsychotic treatment might actually occur more often in primary care and non-specialist settings. When a patient mentions hearing voices, non-specialists might immediately jump to conclusions and apply the label of schizophrenia. For general practitioners without specialist psychiatric training and struggling with large caseloads, this jumping to conclusions might lead to antipsychotic treatment more often than is necessary. Although in some cases the symptom might truly be a sign of psychosis that necessitates antipsychotic or psychological treatment, in many cases this might not be true at all. Allen Francis, author of *Saving Normal* and former chair of the Diagnostic and Statistical Manual-IV committee says, “There is not any one cause of hallucinations—they can occur as a feature of many psychiatric, substance, and neurological disorders and also as part of normal experience in people who aren’t sick at all.” Therefore, before a voice is attributed to schizophrenia, these other causes must of course be ruled out, and the possibility that a person is not psychiatrically ill at all must be considered. Furthermore, Francis has observed the potential for abuse that over-inclusive diagnostic classifications can have, particularly from self-interested drug companies. After all, increasing the pool of potential patients can be a profitable business.

Even if patients are treated with psychotherapy within a specialised service possessing the knowledge and skills to provide appropriate care and support, there is still the risk of stigma attached to receiving psychiatric care. Few studies have directly addressed this issue by asking patients about their experiences. Furthermore, stigma might be experienced as a result of several factors. Patients at services such as OASIS are mostly help-seeking, distressed by their symptoms, and experiencing a range of related psychosocial and mental health problems. This constellation of problems might actually be as stigmatising as a mental health label itself. For many young people, struggling with school and interpersonal relationships is likely to cause an incredible amount of distress. Furthermore, although only 30% of people make the transition to psychosis, this does not mean that the other 70% recover fully from their problems. Evidence is emerging that those who do not transition to psychosis continue to present with psychosocial problems or other mental health disorders.

Although services for at-risk individuals aim to support those with distressing experiences, the way that they do so differs conceptually from the approach of the Hearing Voices Network. Essentially, to psychiatric services, voice-hearers are patients or potential patients. By contrast, the Hearing Voices Network consider hearing voices as meaning-laden

experiences that might be unusual but are not abnormal. Dr Annis Cohen, a Clinical Psychologist who has set up and facilitated a Hearing Voices Network group within the South London and the Maudsley National Health Service Trust, told me, “I think it really is about the difference between whether you see psychosis as an illness or not.” Even though mainstream psychiatry might consider the influence of psychosocial factors on mental health, the dominant model tends to be biomedical. Importantly, the groups differ from mainstream psychiatry by not actually offering an explanation at all. Rather than a rejection of biomedical explanations, “it’s about having a space where services users or people who hear voices can support each other, and where all explanations are tolerated”, whether they are biomedical, psychological, spiritual, or paranormal.

Within this approach, what is important is that the experiences are deemed meaningful. Romme and Escher found that for many people suppressing or avoiding voices sometimes helped in the short term, but were related to distress over a longer period. Rather, acceptance and attempts to understand the voices are encouraged. As psychologist and voice-hearer Eleanor Longden described in her recent TED talk, she believes that the voices were trying to give her a meaningful message about the experiences she had, and it was only as she began to listen to this that she was able to cope with them. For Dr Cohen, the testimonials of voice hearers such as Eleanor Longden, Ron Coleman, and others about the potential of the Hearing Voices Network approach “is very powerful.”

Does this mean that those who hear voices are never in need of psychiatric support or treatment? Dr Cohen suggests that it is not necessarily about the point at which hearing voices becomes a disorder worthy of a psychiatric label, but rather the point at which people are so distressed that they need support. She added, “equally though medication is not always the wrong answer.” In some cases, medication can help people to cope with extreme experiences in a helpful way, whatever the assumed cause. Of course, as both a mental health professional and part of the Hearing Voices Network, Dr Cohen might differ from other members of the network, some of whom would reject medication as a solution altogether.

Finding a balance between these competing views to define the borders of normality is not easy and delineating this border remains a continued discussion within psychiatry. However, despite their conceptual differences, it seems that the Hearing Voices Network and psychiatrists working within the biomedical model are nonetheless working towards the same goal. They all recognise the distress that can accompany unusual experiences, such as hearing voices. As such, they are all attempting to find how best to support people to cope with their voices and the associated distress, and to prevent these voices from adversely affecting their lives.

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