

DO PROFOUNDLY PRELINGUALLY DEAF PATIENTS WITH PSYCHOSIS REALLY HEAR VOICES?

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HE PSYCHIATRIC LITERATURE has described profoundly prelingually deaf people with psychosis who report hearing voices. The present study proposes that such reports in fact reflect the beliefs of professionals in mental health and deafness and not the hallucinatory experience of psychotic deaf people. The study demonstrates that it is functionally meaningless to assert that a prelingually profoundly deaf psychotic patient "hears voices," and provides a theoretical structure from which to consider more appropriately the internal experiences of deaf people with psychosis, and to encourage the clinically relevant articulation of these experiences. The authors also suggest that the "true" phenomenological experience is of secondary clinical interest to the meaning imposed upon it by the client and the distress caused by it.

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The psychiatric literature has frequently made mention of the counter-intuitive finding that profoundly prelingually deaf people with psychosis report hearing voices. For instance, Critchley, Denmark, Warren, and Wilson (1981) studied 12 apparently prelingually profoundly deaf psychotic patients and reported that 10 patients reported visual hallucinations, and that 10 patients also described experiences "analogous to auditory hallucinations," although Critchley and colleagues concluded that "voices may not have been heard" (p. 30).

Schonauer, Achtergarde, Gotthardt, and Folkerts (1998) interviewed 67 prelingually deaf schizophrenic patients, in sign language, about their hallucinatory experiences over the entire

course of their illness and also reviewed clinical records of these patients' previous admissions. Deaf psychotic patients reported many more visual and tactile hallucinations compared to hearing psychotic patients. Although some deaf patients reported visual hallucinations of sign language messages, the hallucinatory reception of meaningful information appeared to be associated with the "auditory" modality. Schonauer and colleagues considered that deaf patients might be imagining in their own way what "hearing" might be, even though they had never experienced it.

Du Feu and McKenna (1999) concluded that auditory hallucinations may be a common phenomenon in profoundly prelingually deaf psychotic patients. They translated the structured

Present State Examination psychiatric interview (Wing, Cooper, & Sartorius, 1974) into sign language and interviewed 17 patients with schizophrenia and schizoaffective disorders, with onset of profound deafness prior to age 2 years (as far as could be ascertained), and attempted to evaluate whether these patients might in reality be describing other symptoms. Ten patients gave accounts of verbal auditory hallucinations with descriptions of content and spatial localization (although not voice quality). These did not appear to be attributable to other psychotic experiences and showed typical characteristics of schizophrenic hallucinations. The symptom was present in six patients who had been deaf from birth or early infancy. Interestingly, when asked how they could hear voices if they were deaf, patients typically were unable to give an explanation, or would (incorrectly) claim that they had acquired hearing. One patient believed that God had restored his hearing.

Although some phenomenological analysis has been attempted of these experiences, so far no clear explanation has been offered to account for them. In the present article, we attempt to dispute the assertions that profoundly prelingually deaf people, who have never heard a voice, know when they experience the hallucination of a voice. Research into the general fields of deafness and mental health is fraught with methodological problems; the exploration of voices and psychotic experience brings even greater problems, some of which may account for the disputable conclusion that profoundly deaf people do hear voices. In the present article, we outline the key features of these problems.

Degree and Onset of Deafness

Obtaining a sample of research participants who are truly profoundly prelin-

gually deaf is problematic. Deafness is not a uniform phenomenon but exists to varying degrees, ranging from profound prelingual deafness, in which the person has had no experience of hearing sound at all, to restricted hearing only in those frequencies required for verbal communication, to central auditory processing deficits in which a person has the full frequency range of hearing but cannot meaningfully process these sounds. Without thorough audiological testing, the actual residual hearing capability of a deaf patient is not always clear. Therefore, whether this patient does have some experience of hearing to form the basis for experiencing or making sense of auditory hallucinations remains unclear.

Similarly, even with early-onset profound deafness it is often difficult to establish at which point *exactly* a person became deaf. Traditionally, a baby is 7 to 8 months old before a "distraction test" is done. (This test requires the baby to sit on its parent's lap with a toy, while the health professional makes sounds out of sight to both the left and right of the child to see whether it will notice and turn to localize the sound.) This distraction method cannot be used with neonates and has poor sensitivity and specificity (Stevens, Hall, Davis, Davies, & Dixon, 1998), which means that many children with hearing problems are not identified until they start school. Conversely, however, unless a clear congenital cause can be identified in hindsight, it is impossible to say for certain whether a child was profoundly deaf before he or she started school or whether progressive hearing loss only reached the profound stage just prior to the time of diagnosis.

With modern advances in technology, more recently babies have been testable with the minute-long otoacoustic emission test, within 2 days of

birth. The test involves sending sound into the baby's ear and measuring the level of sound returned, which enables hearing function to be calculated. A similar test is the auditory brainstem response test, which registers neurological responses to auditory stimulation. Furthermore, reliable genetic screening of congenital deafness through a simple blood test is now becoming available (Preciado et al., 2004). Nowadays, therefore, the onset of deafness can be much more reliably determined. However, with older generations, time of diagnosis may have been as late as 4 to 5 years of age, at which point previous hearing experience may remain shrouded in mystery.

Onset of deafness is critical insofar as the first 4 to 5 years of a child's life appear to be the most vital in terms of acquiring spoken language. At the age of 6 to 8 months, the infant is already acquiring the first fundamentals of its native language, its brain dynamically "tuning" the cochlear to be sensitive to the phonemes and frequencies relevant to that language. (In illustration, the Chinese and Japanese languages do not discriminate between "L" and "R" sounds, and typically native Chinese and Japanese speakers cannot distinguish between these sounds either.) As such, the decoding of speech is an active central auditory process based on prior exposure and learning of what are meaningful sounds during the early life stages critical to language development (e.g., Kuhl, Williams, Lacerda, Stevens, & Lindblom, 1992). This means that a person's hearing experience in the first 4 to 5 years of life makes a considerable impact on the ability to decode speech. The existence of these critical early-language development stages may explain why, for instance, profoundly prelingually deaf children who receive a cochlear implant after age 7 years show little central auditory development even

years after implantation (Sharma, Dorman, & Spahr, 2002). It also suggests that someone who has been profoundly deaf from birth should not be able to decode (or perhaps even recognize as such) speech "heard" in auditory hallucinations. However, as we have already stated, in cases in which profound deafness is diagnosed quite late, it is very difficult to establish whether a person is indeed profoundly *prelingually* deaf and has no hearing experience whatsoever.

Issues of Communication Communicating With Mentally Distressed Patients

Bridging the communication gap between hearing researchers and deaf participants with psychosis is not merely a straightforward matter of translating spoken language into sign language, and vice versa. In asking people about their experiences, the implicit general assumptions are that they understood the question correctly and are able to reflect on their internal states and recall their recent experiences accurately, as well as express them in an understandable way. However, this is rarely the case with someone who is experiencing a mental health crisis. Problems in communication, reasoning, and suggestibility are a major issue with people who are distressed, confused, cognitively impaired, or, as in psychosis, experiencing combinations of these states. So when people suffering from psychosis are asked, "Do you hear voices?" (a question only meaningfully understood in the context of mental health culture anyway), and they say "yes," it cannot be taken for granted that they understood and considered the question in the correct context, and upon introspecting, recollecting, and carefully weighing up their experiences, decided that, in all likelihood yes, they probably do.

Interpreting Across Modalities

Communication and suggestibility take on deeper dimensions where deaf patients are concerned. Correct translation of assessment questions such as "Do you hear voices?" or "Do you have auditory hallucinations?" into sign language is extremely problematic. As Vernon and Miller (2001) point out, when interpreting occurs not just between two languages, but also between languages with different modalities (spoken and signed), the relationship between source and target texts can be even more complex. Sign language interpreters in mental health settings face extreme linguistic and cultural difficulties in interpreting the everyday language used in these settings. This is particularly true when deaf clients have limited English proficiency, which often requires interpreters to use expansion techniques in order to convey messages successfully.

Written discussions about interpreting issues, or any issue of an exchange of concepts between users of different languages, are notoriously difficult to present, being inevitably presented in at most one of those languages. Vernon and Miller (2001) admirably attempt to illustrate the difficulties, but they also demonstrate the real issue of presenting matters related to sign language or sign language users' *conceptual lives* in a different language (i.e., any written language). Just as "S'il vous plaît" translates literally to "If it pleases you" but is more accurately translated as simply "Please," so signs and words only loosely correspond. As a result, those two languages will not correspond in a comfortable word-for-word or word-for-sign relationship. Naive second-language learners nevertheless assume such a relationship in order to facilitate learning, although fluency can only naturally arise as the conceptual world of that learner adjusts to accommodate the new language. Sig-

nificantly, sign language interpreters also retreat to this emotionally safer, though linguistically risky, strategy when assisting with clinical interviews of psychotic deaf patients (Vernon and Miller, 2001). Thus,

1. when **A** (hearing) puts into words what is intended,
2. an interpreter then puts into sign what was said, and
3. **B** (deaf) extracts meaning and supposed intention from the presented translated statement, and **B** then
4. considers a response and puts it into sign, and
5. that response is translated into words/speech, and
6. **A** comes to some understanding of what was presented,

there are *six* points of potential misrepresentation and misunderstanding between A's original intention and what A understands to be the response.

Interpreting and Suggestibility

Some mentally healthy deaf people of normal ability may have difficulties with formal questions such as "How?" and "Why?" even in British Sign Language (BSL). Thacker (1991) suggests this may be because they are used to being *told* rather than *asked*. Also, questions may have to be phrased in multiple-choice form, with care taken not to lead or limit the deaf individual too much and by presenting concrete examples. Recent research in a forensic setting (O'Rourke & Beail, 2004) suggests that in conversations between deaf sign users and nonsigning hearing people, the use of BSL interpreters could make deaf sign users more prone to suggestibility. In this respect, we have observed that a sign often interpreted as "voice," involving a mouthlike handshape located near

the ear, often appears *after* contact with mental health services, whereas before then signs used to describe hallucinatory experiences differ considerably.

Concepts of "Hearing"

When profoundly prelingually deaf people with psychosis report hearing voices, it is unlikely that they are referring to the same experience that hearing people with psychosis have, simply because they do not have the same framework for "hearing" as hearing people. Indeed, in examining deaf psychotic patients' reports of auditory hallucinations, Critchley and colleagues (1981) found that "exact subjective experiences were difficult to determine." Some deaf people with psychosis describe "voices" more as "ideas coming into one's head" or as "the feeling of air brushing past the ears, like when someone speaks" (inevitably, such quotations represent interpretations of signed descriptions); Fraunhofer and Kitson (2000), by contrast, found that deaf people could describe their experience of auditory hallucinations in great detail. But whether this was akin to "hearing" in the conventional sense was impossible to say. One patient, who reported definitely hearing a voice through the ears, could identify that a person was "talking," but could not identify the speaker's gender. Fraunhofer and Kitson suggest that this may indicate that the experience was not truly auditory, in that properties such as voice pitch and sound could not be described. However, their conclusion may be too broad; what it appears to indicate is that deaf people cannot meaningfully or reliably describe their experience of "hearing voices" to hearing people.

However, it would be a mistake to think that deaf people have no framework for "hearing" at all. As we have already mentioned, many deaf people

may have some residual hearing, even if it is not sufficient for oral communication, and not every deaf person has been deaf from birth. Profoundly deaf people can still perceive the vibrations of sound. In this regard, Thacker (1994) reported on a patient who described how her sister was "talking" to her in her abdomen, which was where in reality she sensed the vibration of loud sounds.

Moreover, even profoundly prelingually deaf people naturally have their own ideas and imaginings of what "hearing" is like, just as hearing people have their own imaginary (and simplistic) construct of what it is like to be deaf. Research has shown that profoundly prelingually deaf children develop phonological representations of words while learning to read, through the experiences of speechreading, kinesthetic feedback from one's own throat during speech, cued speech, and fingerspelling. Each may provide information about the sound structure of words (Hanson, Goodell, & Perfetti, 1991; Sterne & Goswami, 2000), although phonological representations formed in this way are bound to be different from the hearing experience.

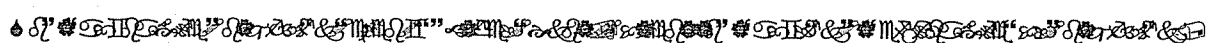
It seems then that, deaf or hearing, the human brain is predisposed to try to conceptualize "sound" in some way. This was alluded to by David Wright (1969) in his autobiography *Deafness*, when he described how he would find himself experiencing "sound-images" projected by his mind onto his visually perceived environment as a function of visual cues. Observing speechreading or the wind moving leaves on a tree prompted the imagining of accompanying sound, which he referred to as "phantasmal voices" or "eye-music." However, as Sachs (1989) points out, Wright was not deaf at birth and therefore had the experience of sound and speech as a basis for such mental associations, whereas a profoundly *prelin-*

gually deaf person of course would not. Freimuth (2002), however, points out that profoundly prelingually deaf people generally do not mention or complain about total silence in the same way that people blind from birth do not mention or complain about living in total darkness.

I cannot speak for all deaf people, but I do not live in a silent world. All movement registers as sound in my mind, that is how I lip-read. The movement of the lips makes a sound, which I "hear." Seeing the trees moving in the wind or the waves lapping the shore make sounds to me.

Fluorescent lights that are on the blink are very irritating to me and also several other deaf people I know, because it is like being in a noisy room. I also find someone tapping a table or constantly moving their hands irritating for the same reason. [Anonymous posting to a Deaf Web forum]

Profoundly prelingually deaf people sometimes report dreams in which they communicate with other people through speech. However, transfer of information is described as an almost "telepathic" process of "knowing" what was said, rather than having "heard" it (although what is meant by "not hearing" is as unknowable as what is meant by "hearing"). This description has a striking similarity to findings we have already mentioned, that psychotic deaf patients who reported hearing voices could not describe the voice quality—that is, pitch, tone, accent, volume, or even necessarily the exact words being spoken—even though they "knew" what the voices said. Kitson and Fry (1990) suggest that the reports of deaf mentally ill people hearing voices may not be so surprising when one considers that deaf people do possess the *concept* of oral communication. Although they have not been exposed to



the *sound* of voices, they do experience the accompanying *quality* (that is, behavior, gesture, facial expression, and posture), *function, meaning, and effect* of this vocal communication either in terms of responses in others or in themselves. Moreover, 9 out of 10 deaf people are born to hearing parents, many of whom do not learn to sign, and in the wider community only 1 person in 1,000 communicates in sign. As such, the most frequent socially meaningful (although perhaps not directly content-meaningful) communications are in an oral/auditory modality, however inadequate and incomplete it may be.

The Delusion of Hearing Voices

Psychosis is a heterogeneous phenomenon: Patients present with various affective symptoms and modalities of hallucination, paranoid or nonparanoid delusions, negative or positive symptom complexes, thought disorder, cognitive disturbance, and agitation or apathy. So if someone were psychotic and, with a confused and distressed mind and muddled frameworks, tried to make sense of his or her confusing experiences, that person could conclude that he or she was hearing something. Du Feu and McKenna (1999) have reported that some psychotic patients were said to have developed the delusion that they had acquired hearing. This raises the interesting question of where hallucination ends and delusion begins.

Whereas hallucinations reflect a direct experience of the aberrant salience of internal representations, delusions are a cognitive effort by the patient to make sense of these aberrantly salient experiences. The ABC analysis of auditory voice hallucinations (Chadwick, Birchwood, & Trower, 1996) comprises:

- A—an *activating* event (a voice experience)
- B—a *belief* regarding that experience
- C—*consequent* behaviors or affect

The model supposes that beliefs about the voice are secondary delusions, and this is an appropriate model for a cognitive approach to therapy for such experiences. However, for prelingually profoundly deaf psychotic patients reporting voices, it ought also to be considered that the delusional component may rather be as follows:

- A—a complex, inexplicable experience involving the apparent reception of meaningful information
- B—a belief that that the experience may be the hearing of a voice
- C—consequent behaviors and affect (including reporting the hearing of voices when asked)

As we have already suggested, even though they may never have experienced it, deaf psychotic patients may be able to imagine what "hearing" is like. A parallel can be drawn with hearing psychotic patients who report sensory "perceptions" that have no physical antecedents either, such as feeling that electric rays are penetrating the body or that they are possessed by an alien or spirit. This model provides a more useful framework for the experiences of many psychotic deaf people than one that simply asserts that they "hear" voices. It provides a potential strategy for therapy, which, incidentally, can apply equally to hearing psychotic patients: It invites the patient to reexamine and make sense of what seems at first a confusing and possibly frightening experience.

Secondary Gains

Sick roles and secondary gains are a necessary theme to explore within the mental health field. The experience of mental illness is generally private and not therefore available to direct objective examination. Rather, symptom reports and illness behavior are evaluated through a complex assessment of their impact and function in the patient's life. As human social contexts have become more complex through history, so have the accommodations and allowances made for sick and disabled members of society. As such, criteria for legitimate entry to the sick role have evolved, with modern society placing heavy emphasis on demonstrated tissue damage or organic malfunction, or severe mental distress as demonstrated through ratified psychiatric criteria. Because of the communication barrier, deaf people find it notoriously difficult to obtain access to services in times of distress, and feel easily isolated. The powerful reassurance of a professional taking notice of, and making apparent sense of, what seems a baffling and frightening experience is perhaps not to be underestimated.

Conclusion: Shifting the Frames of Reference

Church (1961) conceptualized the senses as "units of perception." They are a composition of the sensory stimulus input and the interpretation/identification of that stimulus input. Interaction and communication with other people plays an important role in the forming of these units of perception, as it establishes a consensus of concepts and frameworks within which stimuli are interpreted and identified. Therefore, perception units work in both directions: They form the basis for making sense of one's impressions of the world, but also offer a



shared framework by which one communicates these impressions to others in a meaningful way. Their sensory experiences being different, profoundly deaf people and hearing people are unable to establish shared concepts and frameworks around the experience of hearing and sound. In that case, a hearing person cannot ask a deaf person any meaningful question about an aural sensory experience, such as "Do you hear voices?" and a deaf person cannot reply in a way that is meaningful to a hearing person.

It is therefore illogical that mental health professionals regard everything that a deaf psychotic patient reports with extreme skepticism (for example, a claim to be possessed by the devil) except their counterintuitive reports of hearing voices. It seems that mental health professionals accept such patients' reports of voices because they know that some hearing psychotic patients report hearing voices and that this fits the hearing expectations despite its evidently paradoxical nature. Furthermore, the tendency to dismiss delusions as meaningless products of a confused mind (Aschebrock, Gavey, McCreanor, & Tippett, 2003; Berrios, 1991), rather than as experiences meaningful to the psychotic patient as attempts to make sense of their environment or of internal psychological conflict, is replicated in the failure to appreciate the unique *deaf* psychotic experience as meaningful *within deaf frames of reference*.

For instance, even in the research by du Feu and McKenna (1999), in which one of the researchers had an acquired hearing impairment herself and had some experience in using sign language, a structured psychiatric interview standardized on hearing patients and devised according to symptom presentation and clustering of hearing subjects was employed. In-

deed, researchers working with deaf people generally do use psychiatric diagnostic criteria developed with hearing patients. Evans and Elliott (1981), however, describe the misdiagnosis of psychotic thought disorder in deaf patients who have a fundamentally different way of communicating, and how the expression of emotions in gesture and action rather than spoken word or tone of voice can be misinterpreted as labile affect or impulsiveness.

This bias toward the hearing experience seems unavoidable. All scientific literature is *written*, and as such represents a philosophy of science, conjecture, hypothesis testing, categorization, deduction, and induction from a hearing perspective (BSL and American Sign Language, and possibly all other sign languages, have no written form). As a result, this literature may quite reasonably be seen to be culturally hearing. Models of wellness and illness, symptom clustering yielding diagnostic nosologies, treatment strategies, and *all aspects of mental health work* may also therefore be meaningfully understood as culturally hearing. In addition, this cultural bias remains almost entirely unnoticed (though not unimportant) when those working within these models and on the basis of this literature are themselves hearing. Just as people think it is *the other* who has the accent, so researchers and service providers working with people who are deaf are unable to perceive this hearing cultural bias. Just as one's native-language development in the early years tunes one's perceptions to the language in which one is embedded, and *away from* other languages' phonetic forms, so it becomes extremely difficult for inevitably culturally hearing mental health workers (whether themselves audiotologically hearing or deaf) to no-

tice the biases and distortions inevitable in the culturally hearing fields of psychology and psychiatry.

When a (culturally) hearing professional converses with a deaf psychotic patient about auditory phenomena that are grounded in this complex statistical analysis of symptom presentation in hearing people and a culture of academic psychiatry, it is easy to imagine the great extent to which weak links in the chain of communication can detrimentally influence the discussion.

When deaf psychotic patients report "hearing voices," they undoubtedly are experiencing something. Just what that is however, is not known. Moreover, hearing mental health professionals may have to come to terms with the fact that they most likely will never be able to know; that this experience is *unknowable*, because they do not share deaf phenomenological frames of reference. The only mental health professionals who may be able to make sense of these experiences are prelingually profoundly deaf mental health professionals—provided that they are able to extricate themselves from the cultural "hearingness" of the field.

Significantly, understanding the modality of the hallucination is not essential to helping the deaf psychotic patient manage these hallucinatory experiences. Indeed it may be more clinically adaptive to actively acknowledge that the modality is *not* known. Many relatively healthy and undisturbed hearing people hear voices (e.g., Romme & Escher, 1992) but do not necessarily feel bothered by them or impaired in their daily life functioning. In psychosis also, it is not the modality of the hallucinations that is a problem, or even the presence of hallucinations in itself; it is their perceived meaning and psychological impact that appear



to matter (Chadwick & Birchwood, 1994). The distress they generate and the delusional beliefs that are formed in an attempt to make sense of them may serve to maintain them (e.g., Beck & Rector, 2003). As such, effective interventions aimed at managing hallucinations tend to concentrate on changing their perceived meaning and reducing their distressing impact.

In deaf psychotic patients also, regardless of the question of modality, the *meaning* and *function* of their hallucinations appear to remain the same. The hallucinations still have content and meaning; they still generate thoughts and feelings in the patient, who may or may not be distressed by them, and who may or may not feel compelled to act on them. In terms of these dimensions, deaf and hearing people appear to share the same frames of reference. Therefore, it is possible that deaf psychotic patients can be helped to manage their hallucinations in terms of the meanings such patients assign to them, the level of control they experience over them, and the distress they experience as a result of them. Whether the same strategies that have been developed for hearing psychotic patients are effective in managing the deaf hallucinatory experience, however, like all aspects of deaf mental health, needs not to be assumed but to be explored.

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