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Auditory Verbal Hallucinations in Schizophrenia Mode of Onset and Disclosure

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Abstract: Recent reviews on auditory verbal hallucinations (AVHs) advocate a qualitative and interdisciplinary research that not only is limited to single descriptive features, but also involves contextual issues and co-occurring psychopathology. In this study of mainly readmitted patients with the International Classification of Diseases, Tenth Revision, diagnosis of paranoid schizophrenia and experiencing AVH, we performed a qualitative, phenomenologically oriented interview study. The focus was on the beginning of hallucinatory experiences, time to disclosure of the symptom, and the context surrounding the disclosure. We found that on average the patients experiencing AVH for 6.5 years before disclosing the symptom to a psychiatrist. Moreover, the term "voices" was typically appropriated by the patient during his contact with a psychiatric treatment facility. None of the patients considered themselves as being psychotic or severely mentally ill. The AVH in the majority of the patients was associated with other pathological subjective experiences. The significance of these findings is briefly discussed in relation to the concept of insight, diagnosis of psychosis, and early detection.

Key Words: Auditory verbal hallucinations, schizophrenia, disclosure, insight

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uditory verbal hallucinations (AVHs) form a central symptom in A unitory verbal nanuemations (17.116), learning the Diagnostic and the current diagnosis of schizophrenia in the Diagnostic and (DSM 5) Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association, 2013) and in the International Classification of Diseases, Tenth Revision (ICD-10) (World Health Organization, 1990). In ICD-10, the presence of hallucinatory voices discussing the patient or commenting on the patient's thoughts or actions is sufficient to diagnose schizophrenia (if the duration criterion is fulfilled and the exclusion criteria are not met). In both DSM-5 and ICD-10, a hallucination is considered an erroneous perception (e.g., in DSM-5, "a perception-like experience with the clarity and impact of a true perception but without the external stimulation of the relevant sensory organ"). More generally, AVH is typically viewed as a well-defined entity in itself with certain quasi objective properties that can be unproblematically quantified, addressed without a need of considering more encompassing structures of subjectivity (consciousness) (Henriksen et al., 2015; Leudar and Thomas, 2000; Parnas and Urfer-Parnas, 2017).

Three comprehensive reviews (Larøi et al., 2012; McCarthy-Jones et al., 2013; Woods et al., 2014) have concluded that the field needs phenomenologically oriented qualitative and interdisciplinary

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ISSN: 0022-3018/20/20809-0689 DOI: 10.1097/NMD.0000000000001179 research on the nature and diagnostic value of AVH. Since these publications, a substantial literature has emerged. Conceptual issues have been addressed by different groups (Henriksen et al., 2015; Pienkos et al., 2019; Ratcliffe, 2017; Upthegrove et al., 2016; Woods, 2017). Moreover, several phenomenologically oriented studies of AVH focusing on descriptive issues in diagnostically mixed samples have been performed (Daalman et al., 2011; Johns et al., 2014; Stanghellini et al., 2012; Woods et al., 2015). Jointly, the conceptual and empirical studies point to the complex nature of AVH. A review of Englishlanguage literature by Waters and Fernyhough (2017) of 43 empirical studies comparing auditory and visual hallucinations between nonclinical samples, medical and neurological conditions, drug- or alcoholrelated disorders, and major psychiatric disorders concluded that simple descriptive features discriminated poorly schizophrenia spectrum patients from other groups. Consequently, the authors advocated future investigations to focus on broader contextual issues and cooccurring psychopathology.

We therefore decided to undertake an empirical qualitative and phenomenologically oriented investigation of experiential, existential, and developmental aspects of AVH in patients with schizophrenia. In this particular report, we are interested in the following issues:

- 1. The age of onset and duration of hallucinations before their disclosure and the naming of pathological experiences as being "voices."
- 2. The patients' reaction to and their comprehension of these phenomena.
- 3. Reasons and circumstances for disclosure.
- 4. Associated experiences and the overall sense of subjectivity.
- 5. Insight in the pathological status of AVH.

METHODS

The study was conducted in 2018 at the Psychiatric Center Glostrup, a university-affiliated department of psychiatry with a catchment area of 300,000 inhabitants. This center is one of the five centers that jointly provide general psychiatric services to the greater Copenhagen area. There are no private inpatient psychiatric facilities in Denmark; therefore, our sample is socioeconomically unselected. Given the qualitative and time-consuming nature of the study, we strived to obtain interviews from 20 patients.

Sample

Twenty patients with AVH and fulfilling the ICD-10 criteria of schizophrenia were included in the study. The participants had to be considered capable of tolerating lengthy interviews because the study's goals were to catch the qualitative aspects of the experience of hearing voices. The exclusion criteria comprised aggressive-agitated behavior, forensic status, involuntary admission, organic brain disorder, and clinically significant drug or alcohol abuse. The patients were recruited randomly when they did not meet the exclusion criteria and reported AVHs. All patients had received the diagnosis of paranoid schizophrenia. Twenty-four patients were invited to participate, mainly from the wards for inpatients, but also from outpatient clinics. Four declined because of having planned other activities at the scheduled time of the interview. The final sample consisted of 8 men and 12 women (mean age, 32 years; range, 18-53 years). Three patients were recruited during their

first admission, whereas the remainder was recruited from hospitalized patients. The patients from outpatient clinics (n = 2) were also earlier rehospitalized patients. The socio-demographic characteristics are shown in Table 1. The ethical committee approved the study, and the patients participated on the condition of informed consent.

The Interview

Specifically, for this study, we have prepared a semistructured questionnaire consisting of several domains of interest. The questionnaire was constructed in the process of pilot clinical interviews, discussions within the research group, and studies of the literature. The structured element during the interview consisted of the obligation to cover all interview domains. The interview domains reported in this study consisted of the following items: the age of onset, duration, disclosure and its circumstances, reactions to the voices, and accompanying subjective experiences and insight.

Apart from the obligation to cover all domains, the interview was conversational and involved encouraging the patients to reflect and express themselves freely according to standard phenomenological principles (Nordgaard et al., 2013; Parnas et al., 2005). In addition, we also inquired using 26 items from domain 1 (stream of consciousness) and 2 (basic self) from the Examination of Anomalous Self-Experience (EASE) interview (Parnas et al., 2005). The interviewer (J. E. Y.) is an experienced clinical psychiatrist in the position of a consultant and is trained in the use of the EASE interview by the senior author (J. P.). The purpose of employing EASE items was not to arrive at a quantitative score but to obtain a description of the accompanying subjective experiences. The co-investigators (J. P. A. and A. U. P.) are both senior consultants and researchers. All interviews were audiotaped and transcribed verbatim for the use of consensus discussions between the investigators to divide the transcripts into the target domains of the study.

RESULTS

The Age of Onset and Duration of Hallucinations before Their Disclosure and the Naming of Pathological Experiences as Being "Voices"

There was a considerable variation in the age of onset and disclosure of AVH (Table 2). The average age of onset of AVH was 16 years. The duration of AVH from onset to disclosure ranged from the same day to 40 years after onset, with an average of 6.5 years. Ten patients experienced AVH for 5 years or more before disclosing. Immediate report of voices at the day of onset occurred in two children and two adults, the latter already receiving psychiatric treatment.

Ten patients began to experience voices in childhood or early adolescence (younger than 14 years). They had an average duration of AVH from onset to disclosure of 11 years. The rest (n = 10), who were 14 years or older when they started hearing voices, had an average time

TABLE 1. Sociodemographic Data

Gender (n)	Male	8		
	Female	12		
Age (years)	Mean (SD)	32 (10.4)		
	Median (range)	28 (18-53)		
Education	n Primary school			
	Completed a higher degree of education	3		
	In process of completing education	4		
Occupational status	Disability pension	3		
	Unemployed	12		
	Actively studying or on a sick leave	5		

from onset to disclosure of 2.5 years. Looking only at patients who were older than 25 years at the start of AVH (n = 5), their average time from onset of AVH to disclosure was 1 year.

All patients, who reported AVH to a professional, were immediately referred to treatment. There was a substantial time lag between first treatment contact to the health care system and disclosure to a clinician, an average of 7 years. For most patients, their first treatment contact to the health care system was before the development of AVH. Reasons for contact to the health care system could be, for example, a feeling of depression, anxiety, or altered self-experience.

At the onset of AVH, the majority of patients felt that there was something "wrong." It was not in the sense of feeling sick but more as a different kind of personal experience. The term "voices" was first typically acquired in the psychiatric setting.

Case 3: The psychiatrist explained to me that it was "voices." "What did you call them before?" Thoughts. "So, you did not think upon them as "voices"? No, I thought upon them as thoughts. Thoughts I am forced to think. By my brain or something.

Case 8: I just thought it was something I experienced, that it was normal and the way I experienced the world. When I got these questions: "do you hear voices," I said, "but I do not know if I do" and they explained by saying "do you hear something you feel others cannot hear?" And yes, I did, and I thought, "well, it must be "voices" that I can hear.

The Patients' Reaction to and Their Comprehension of These Phenomena

The patients' reaction to AVH varied, in part depending on the mode of onset (insidious, sudden, etc.). The patients typically experienced surprise, curiosity, anxiety, or embarrassment.

Case 6: I got surprised, and I tried to ignore them. And a little afraid. "Did you think there was something wrong?" Yes, I think so. "What did you do then?" Nothing.

Case 11: I kept it to myself. "Why?" I thought to myself that it was something strange that I really did not want to share with anyone. It was kind of embarrassing.

Most of the patients perceived AVH as their own inner private experience, not shared with other people, although being real in the sense of being a personal intimate experience.

Case 17: I didn't think there was anything wrong (...) "Did you tell someone?" Who would help me? Where would I go, and who would believe me? (...) I knew it was something in my head.

Reasons for and Circumstances of Disclosure

Disclosure of AVH primarily took place when the patients were reaching desperation. At that time, most of the patients were suicidal and could no longer work or function in life, needing help or care.

Case 10: I could feel that I could no longer handle my life, and I was afraid I would do something when my big sister was home alone with me. I was afraid I would do something that would hurt her. That I would kill myself and she would be sad. So, I chose to admit myself to a psychiatric hospital.

The disclosure happened most frequently in a clinical setting.

Case 15: The senior consultant came, and I can remember it took him a while to get an eye contact with me, to calm me down. I can remember he said my name several times before we had an eye-contact, and then I ... then I ... I told him.

TABLE 2. Age at Onset of First AVH, Age at First Contact With a Treatment Facility, Age at Disclosure, Time Between Onset of AVH and Disclosure, Time Between 1. Contact With a Treatment Facility and Disclosure

Age at Onset of First AVH (Years)		Age at First Contact With Treatment Facility (Years)		Age at Disclosure (Years)		Time Between Onset of AVH and Disclosure (Years)		Time Between 1. Contact With Treatment Facility and Disclosure (Years)	
Mean (SD)	Median (Range)	Mean (SD)	Median (Range)	Mean (SD)	Median (Range)	Mean (SD)	Median (Range)	Mean (SD)	Median (Range)
16 (10.6)	16 (3–37)	20.8 (9.3)	17 (4–45)	23 (10.5)	23 (4-45)	6.5 (10.0)	3.5 (0-40)	7.2 (6.1)	5 (0–20)

Case 5: It is a cocktail of my childhood and my education that I have not seeked help before now. It is only because I have hit the bottom of my life so hard as I have now, that I opened up to this doctor, which was so lovely. It is wrong to say that she was sweet and kind. But she just hit the right tone. There was something I thought that it had to be done now. That if I did not talk about this I would go back on the street, become homeless again and end up as a dead man.

Only five patients, all of them children at the time of onset of AVH, did not disclose directly to a professional but to friends or family.

Case 18: I asked my friends "can you hear something, can you hear someone talking to me or you" and they said "no, there is nobody talking." I quickly understood... That there was something wrong with me. They looked upon me differently and I did not want that. So, I thought "ok, there is something wrong with me, it is probably best to keep it to myself. I won't tell again." And I did not until I was 18 (to a psychiatrist).

Associated Experiences and the Overall Sense of Subjectivity

We rated the EASE items on a lifetime basis. In all cases, the patients reported one or more altered self-experiences. The most common altered self-experiences described was loss of thought ipseity, thought pressure, perceptualization of inner speech or thought, ambivalence, hyperreflectivity, ruminations, diminished sense of basic self, distorted first-person perspective, and anxiety. The following vignette describes a typical patient:

Case 9: Emma, 27, has always felt different from other people. She hears her own thoughts aloud, and she can localize her thoughts in front of her head. She is often in doubt about her choices. She cannot describe when these phenomena started. In recent years she has been experiencing thought interference, thought block, and thought pressure. She anticipates future conversations. She feels as if other people are staring at her.

Right before she started hearing voices for the first time, aged 21, she was stressed, had sleep problems, had a lot of thoughts in her head, was hypersensitive to sounds, and had a lot of anxiety. She started having an inner dialog, asking herself questions and trying to answer them. Then she began hearing a voice talking to her.

Now she only hears voices in stressed periods. Up until the voices are coming, she can feel that her thinking pattern changes. She hears ringing in her ears, and she has too many thoughts at the same time. She begins to ruminate. She loses control over her thoughts and is unable to stop them. Then she feels as if the thoughts are not her own—as if they are at a distance from her. They are thoughts she has had before, but they no longer feel as belonging to her. She starts listening to her thoughts because she is curious about what they say. In this moment, the voices become further separated from her.

Insight in the Pathological Status of AVH

The majority of the patients did not consider themselves as being psychotic. Their reaction to hearing voices was for most of them to keep them to themselves and try to ignore them, until the hallucinations and/or the patients' lives became unbearable and led to help seeking.

Case 7: I tried to convince myself that it was not real, that I cannot be mentally ill, because that is not me. And only sick people experience these things.

Case 18: "Do you feel sick, or that there is something wrong?" Other people would say that I am sick, but I don't feel sick. I feel that it is a part of me. And that this is just how I am.

Case 14: I tried to find a way out of this life, because I could not really handle what was going on in my mind. I spent time on the sofa watching movies. It was a way of trying not to think so much about it. But it did not really help. "Did you ask for help?" No. Because I thought this was something strange. I did not think there was anyone I could come to with this. Who would I go to ...? I was alone with this one.

None of the participants felt sick or ill in the sense analogous to experiencing a somatic illness such as influenza or arthritis. However, they felt that there was something wrong with them or that they were different. The patients seemed to manage to separate their ordinary daily life and their experiences.

Case 1: "Do you feel sick?" No, I would not say that I feel sick. I would say I feel different. There is something different about me. Case 4: "Do you feel sick?" No, not at all.

Some patients explained that they, on a "theoretical level," very well could see that their experiences were abnormal, were pathological, and would equal madness or schizophrenia. However, "in the real world," they were not sick, and that world of their own reality had nothing to do with theoretical notions of schizophrenia, hallucinations, or "being sick."

Case 9: "Do you think you are sick?" No, not really. Or, pure theoretically, I understand that not everybody hears voices and stuff like that, but I don't think that I am sick.

Some participants explained living in two different worlds, both feeling equally real, for the most part, not conflicting with each other.

Case 17: I have always known that this was my place; this was my reality. Away from other people's reality. I live in this world just like all humans. And then I also have my own reality. Of course, I know that there is not a man standing there talking to me It all takes place in my head. I know that. And I am completely aware of that. But to me, it is my reality. I have lived like that for years. I really feel that I live in two worlds. "Is one of the worlds more real than the other world?" No, there is no difference in the level of reality.

Other participants felt some kind of division inside of themselves: as if a small part of themselves knows that they are mentally ill and that their experiences are pathological. However, the main part of the self does not feel sick or that there is something wrong. The two parts may be in conflict about the issue: sick or not sick; the "not sick" part will dominate and be the true reality.

Case 8: "Do you feel as if you experience two worlds at the same time?" I feel I am separated from this world that I experience. That I... that this is a universe, and then there is another universe inside of my head. As if they are not connected. It is as if I am a simulation or something in a created world.

Case 10: My world is the most real. What's going on in my head feels more real.

DISCUSSION

We will first address some methodological issues. This study attempts to respond to the call for detailed qualitative research in AVH, including broader contextual issues and co-occurring psychopathology as suggested in recent systematic reviews (Larøi et al., 2012; McCarthy-Jones et al., 2013; Upthegrove et al., 2016; Waters and Fernyhough, 2017). The sample size is small, but it must be evaluated upon the context of time-consuming interviews and evaluation procedures involving several senior clinicians and researchers. A related issue is to what extend our patient sample is representative of schizophrenia in general. As long-term follow-up studies (Bleuler et al., 1976; Ciompi, 1980; Huber, 1997) indicate, a vast majority of patients with schizophrenia become readmitted several times throughout their lifetime, and our sample fits into this pattern. We therefore believe that our sample (mainly readmitted patients) represents typical schizophrenia patients experiencing AVH. Consequently, although we cannot propose epidemiologically valid generalizations, we believe that we can describe certain qualitative characteristic features of AVH in schizophrenia.

The most striking result was a long duration of AVH before disclosure. Moreover, for several patients there was also a substantial time lag between first contact to the psychiatric service and disclosure. A study by Bogen-Johnston et al. (2019) concluded that the delay to disclosure was linked to the feelings of embarrassment and shame. We also found that feelings of embarrassment and fear of rejection or shame were contributing to nondisclosure. However, we can point to several other interdependent factors. First, the vast majority of patients did not conceive of themselves as experiencing an illness akin to a somatic disease. The disclosure typically happened when the patient arrived at a situation of profound subjective suffering or dysfunction in life. Similarly, to the findings of Bogen-Johnston et al. (2019), the disclosure was facilitated by appropriate context and the presence of an empathic clinician. We also found that the patients did not consider the AVH as a symptom of disease but rather as a strange or habitual private experience. Moreover, it is clear from several reports that the terminological status of the AVH as "voices" was typically acquired in the psychiatric setting. In other words, the naming (nomination) of their experiences as "voices" was nearly always proposed by the clinician. It is as if the event of naming was what made the experience into a symptom. Originally, the patients lived these phenomena as immanent or internal experiences in which certain moments of their flow of consciousness acquired a more demarcated, salient, alienated, and often linguistic meaning. In other words, the patients did not consider their private experiences as being analogous to a perception of an external or acoustic object. Taken together, these findings undermine a purely medical notion of the symptom and a well-defined phenotype with a referential function (i.e., pointing to underlying pathology) (Parnas and Urfer-Parnas, 2017). We are inclined to believe that the immanent phenomenal status of these experiences is one of the reasons that the patients did not consider themselves to be ill in a way analogous to

experiencing a somatic illness. This disanalogy from a medical symptom appears to be an important factor involved in the long duration of AVH before disclosure.

If we follow the definition of insight according to DSM-5, awareness of illness and its symptoms, then as already indicated, none of the patients viewed their condition in this way. The following quote from Professor Elyn Saks (Saks, 2009, pp. 972–973) illustrates this point:

I completely recognized that the things I was saying and doing and feeling would be thought to amount to a diagnosis of schizophrenia; but I thought that it was not true—I didn't really have the illness (...). So, my thinking went, I looked like I had schizophrenia (...) but if we knew enough, we would see that I really did not.

E. Saks had an indubitable experience reflective of other forms of reality not yet accessible to our scientific methods.

Our findings are concordant with previous in-depth descriptions of AVH (Baillarger, 1846; Bleuler, 1911/1950; De Clérambault, 1925/ 1992; Klosterkotter, 1988), which indicate that AVHs in schizophrenia do not possess an intrinsic perceptual character. These findings are therefore at odds with the DSM-5 definition of hallucinations (Parnas and Urfer-Parnas, 2017). Moreover, the patients' uniform lack of insight and the patients' conviction about an access to an alternative ontological domain suggest that the common view of psychosis as a condition of erroneous interpretation of empirical reality cannot be maintained (Parnas, 2015; Sass, 1994).

In all cases, the AVHs were not an isolated phenomenon but were embedded in a range of anomalous subjective experiences such as hyperreflectivity, thought pressure, experiential distance between thoughts, and the sense of subjecthood. The majority of the patients reported feelings of being different ("Anderssein") beginning already in childhood or adolescence. This is a sense of difference that precedes finding out what is different. It is a feeling of having another kind of internal world and a sense of not being connected to the shared social reality (Henriksen and Parnas, 2014). As we have suggested in previous studies (Parnas and Henriksen, 2016; Parnas and Urfer-Parnas, 2017), most of the patients regarded their AVH as being expressive of an access to another dimension of reality inaccessible to other people (see the quotation of E. Saks above). This other dimension of reality originates in the midst of the patients' subjective life, and for this reason, it presents the patients with an indubitable character of being real and relevant (Charbonneau, 2001).

The clinical implications of this study point to the need of a refinement of psychopathological knowledge and the quality of interviewing because AVHs present phenomenal variability and are usually not considered as symptoms by the patients. For these reasons, they tend to evade detection, diagnosis, and consequently adequate intervention. This point is especially important in view of the contemporary efforts of early detection and intervention in psychosis.

DISCLOSURE

The authors declare no conflict of interest.

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