The voice-hearer

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Abstract

Background: For 25 years, the international Hearing Voices Movement and the UK Hearing Voices Network have campaigned to improve the lives of people who hear voices. In doing so, they have introduced a new term into the mental health lexicon: “the voice-hearer.”

Aims: This article offers a “thick description” of the figure of “the voice-hearer.”

Method: A selection of prominent texts (life narratives, research papers, videos and blogs), the majority produced by people active in the Hearing Voices or consumer/survivor/ex-patient movements, were analysed from an interdisciplinary medical humanities perspective.

Results: “The voice-hearer” (i) asserts voice-hearing as a meaningful experience, (ii) challenges psychiatric authority and (iii) builds identity through sharing life narrative. While technically accurate, the definition of “the voice-hearer” as simply “a person who has experienced voice-hearing or auditory verbal hallucinations” fails to acknowledge that this is a complex, politically resonant and value-laden identity.

Conclusions: The figure of “the voice-hearer” comes into being through a specific set of narrative practices as an “expert by experience” who challenges the authority and diagnostic categories of mainstream psychiatry, especially the category of “schizophrenia.”

Keywords: voice-hearing, voice-hearer, Hearing Voices Movement, schizophrenia, psychiatric survivor, mental health service user, identity

1. Introduction

Who, or what, is “the voice-hearer”? Minimally, the term refers to someone who hears a voice or utterance in the absence of any speaker; someone who, in psychiatric parlance, would be said to have experienced auditory verbal hallucinations (AVH). In the case of neuropsychological research, this definition is a clear and uncontroversial, albeit cumbersome, synonym for the scientific shorthand AVH⁺. But there are other contexts – interpersonal, political, clinical – in which the statement “I am a voice-hearer” has a deeper and more complex meaning.

The purpose of this paper is to offer what might loosely be called a “thick description” (Geertz, 1973) of the figure of “the voice-hearer.” I aim to show how, in high-income countries in the late twentieth century, “the voice-hearer” emerged as a culturally meaningful and politically charged identity enacted through a specific set of narrative practices.
Complementing texts such as Lisa Blackman’s powerful study of the “techniques of the hallucinatory self” (Blackman, 2001), and Ian Hacking’s genealogical exploration of multiple personality (Hacking, 1995), this paper seeks to understand “the voice-hearer” as a cultural resource that is used by people to articulate and share specific experiences, values and viewpoints. My use of quotation marks is intended to remind the reader that “the voice-hearer” refers not to any individual, but to a figure, symbol or category of identity. With this focus in mind, my analysis concentrates on a range of prominent texts (life narratives, research papers, videos and blogs) produced by leading figures in the Hearing Voices and broader c/s/x (consumer/survivor/ex-patient) movements.

2. In the beginning

Before 1987, there were no voice-hearers.

Of course, in one sense this statement is simply not true. Auditory verbal hallucinations have been listed as a symptom of schizophrenia ever since it entered the psychiatric textbooks and were a hallmark of madness long before that. Hearing the voice of gods, ancestors and spirits is also central to many if not all of the world’s religions, and, if Julian Jaynes’ *The Origin of Consciousness in the Breakdown of the Bicameral Mind* (1976) is to be believed, 5000 years ago we were all voice-hearers. Socrates, Moses, Margery Kempe, Joan of Arc, Virginia Woolf and Ghandi are among the most famous figures to have been identified as voice-hearers, and to remind us that these experiences were until recently at least as strongly associated with spiritual enlightenment, saintliness, creativity and philosophical insight as with madness and disease (Leudar & Thomas, 2000; McCarthy-Jones, 2012; Smith, 2007).

Nonetheless, it remains difficult to dispute that 1987 marked a turning-point in the history of voice-hearing, one which allows this long history of voice-hearing to be told in the first place. 1987 was the year that Patsy Hague finally persuaded her psychiatrist Marius Romme to accept, and help her make sense of, her voices (Romme & Escher, 2011). 1987 was also the year that they appeared together on Dutch television to publicise this new approach to voice-hearing and to seek responses from the general public. After the screening, hundreds of people phoned in to the programme, 450 of whom reported hearing voices (Romme et al., 1992). The world’s first hearing voices congress was held in Holland later that year, and from there an international voice-hearing movement spread first to the UK, which now has a network of over 180 hearing voices groups, and then to Europe, Australia, America and beyond.

Patsy’s story functions as a foundation myth, told and retold in multiple contexts and on multiple occasions. “Patsy was the first person in whom I accepted voices as reality,” Romme has observed, and she is thus “considered to be the figure-head of the ‘accepting voices movement’ by many voice-hearers” (Romme, 2009, p. 260). So what exactly does ‘the story of Patsy’ tell us about the figure of the “voice-hearer”?

3. Learning from Patsy Hague

At the heart of this narrative is the insistence that hearing voices is a meaning-ful experience; its first lesson is that voice-hearing is not a meaning-less symptom of an underlying illness or disease, but a key part of a person’s identity. Interestingly, Patsy’s story does not evoke the allied discourses of patients, mental health service users, consumers, psychiatric survivors or the mad pride movement (see Crossley & Crossley, 2001; Schrader et al., 2013; Speed, 2006) but develops a new vocabulary to talk specifically about one aspect of her experience. Hearing voices – here discussed in terms that emphasise intense feelings of distress and
confusion – is not one “symptom” among many but the central phenomenon with which Patsy must grapple.

The second salient feature of Patsy’s story is that it inverts the conventional relationship between patient and psychiatrist, clearly establishing the authority of the “voice-hearer.” From Freud and Dora to Laing and Mary Barnes, the history of the “psy disciplines” abounds with examples of the powerful pairing of female patient and her male psychiatrist (Appignanesi, 2008), and it is the contours of this particular pas de deux which signal a decisive shift in expertise. Although it is Marius who narrates this story in the anthology Living with Voices, the story he tells is one of his own passage from ignorance to enlightenment. Patsy refuses to accept that Marius cannot accept her voices, it is she who has educated him to accord her experiences meaning and respect. Marius, in turn, must “un-learn” his psychiatric training in order to collaborate in this process of discovery. As “experts by experience” voice-hearers have gone on to establish robust networks of self-help while also challenging the authority, ideology and practices of “experts by profession.” In this they have been “an essential force among the pioneers of the recovery movement” (Amering, 2009, p. i).

A third aspect of Patsy’s story to emphasise here is the extent to which “the voice-hearer” emerges from, and as a rejection of, a related but very different identity – that of “the schizophrenic.” Although voice-hearing is reported in a wide range of contexts (by no means all of them associated with psychiatric illness or distress), auditory verbal hallucinations are still considered a “first rank” symptom of schizophrenia and the experience is clinically, popularly and powerfully associated with psychosis. As is well known, schizophrenia is one of the most heavily contested psychiatric concepts (Woods, 2011c), and schizophrenia, or “the schizophrenic label,” is widely regarded as one of the most “spoiled,” or stigmatised, identities a person can be assigned through the process of psychiatric diagnosis (Estroff, 1989; The Schizophrenia Commission, 2012; Woods, 2011a). Adam James (2001, p. 4), observes that to be diagnosed as schizophrenic is “one of the most soul-destroying of human predicaments,” as Elyn Saks elaborates in her autobiography:

And now, here it was, in writing: The Diagnosis. [...] I’d always been optimistic that when and if the mystery of me was solved, it could be fixed; now I was being told that whatever had gone wrong inside my head was permanent and, from all indications, unfixable. Repeatedly, I ran up against words like ‘debilitating’, ‘baffling’, ‘chronic’, ‘catastrophic’, ‘devastating’ and ‘loss’. For the rest of my life. The rest of my life. It felt more like a death sentence than a medical diagnosis. (Saks, 2007, pp. 168–169)

The stories of Patsy Hague and Elyn Saks serve to highlight the fact that while “schizophrenic” is a label given to someone by psychiatry, “voice-hearer” is an identity more commonly articulated and authorised outside and in opposition to psychiatry. However, even when this is not emphasised or made explicit, “the voice-hearer” still speaks of psychiatry through this oppositional stance, or, rather, speaks of the experience of psychiatric treatment. While the so-called “healthy” or non-help-seeking voice-hearers are increasingly recruited into clinical, scientific and anthropological studies (Dein & Littlewood, 2007; Diederen et al., 2012; Laroi, 2012), and have long been invoked by the Hearing Voices Movement as proof that voice-hearing is a non-pathological part of ordinary human experience (Intervoice, 2012; Romme et al., 1992), it would seem that the people who derive most meaning from their identification as voice-hearers, and particularly those who participate in the movement, share not just a common experience of hearing voices but also a (frequently negative) experience of mental health services (Blackman, 2001, p. 189). Distress is not an intrinsic part of voice-hearing, nor indeed of psychiatric care, but the shared experience of mental health
services suggests that those who identify as voice-hearers know what it is like to hear voices which arouse feelings of fear, shame, anxiety, despair and self-loathing, and/or are accompanied by other profound and disorienting changes in the sense of self and world.

4. Voice-hearing and schizophrenia

The contrast and connection between voice-hearing and schizophrenia are rendered explicit in the story of Eleanor Longden. Currently completing her PhD in psychology, Eleanor is a leading figure in the Hearing Voices Movement and has published extensively on recovery, hearing voices groups and the relationship between voice-hearing, trauma and dissociation (Dillon et al., 2012; Longden et al., 2013; Longden et al., 2012). Eleanor has shared the story of her voice-hearing experience with voice-hearers, clinicians, academics and the general public through newspaper articles and online publications, at conferences, workshops and gatherings, and most recently via a TED talent search (Longden, 2012). Distinguishing the experience of hearing voices from the diagnosis of schizophrenia is central to her narrative: “I went in to the hospital a troubled, confused, unhappy 18-year-old,” she writes, “and I came out a schizophrenic … I came to embody what psychosis should look and feel like.” Eleanor describes her first meeting with post-psychiatrist Pat Bracken as a turning-point in her self-understanding. Bracken “didn’t use this terrible mechanistic, clinical language but just couched everything in normal language and normal experience,” inviting her “to see [her]self – not as this genetically determined schizophrenic who was biologically flawed and mentally deficient like a degenerate” (Longden, 2009, pp. 143–144). Eleanor’s recovery story is presented as a transition from “schizophrenic” to “voice-hearer,” from a clinical language of biological disease, deficit and dysfunction, to a “normal” language open to the discussion of emotions, personal history and experience. Voice-hearing is singled out as the first, the most salient, the most defining and meaningful of Eleanor’s experiences – speaking, as it does, of the suffering she endured as a child and at University, as well as of the emotional tensions and conflicts she currently faces. She concludes her story with the following message of hope:

I am proud to be a voice hearer. It is an incredibly special and unique experience. I am so glad that I have been given the opportunity to see it that way because recovery is a fundamental human right and I shouldn’t be the exception, I should be the rule. That is why I want to be a part of this movement to change the way we relate to human experience and diversity. (Longden, 2009, p. 146).

5. The importance of story-telling

I have argued so far that the figure of “the voice-hearer” has identified herself, and been recognised, as someone for whom the experience of voice-hearing takes on a significant if not central role in the constitution of identity; as an expert, capable of founding new traditions of empowerment and self-help while also challenging the expertise of those working in the mental health professions; and as someone who has explicitly rejected the label “schizophrenic.” “The voice-hearer” draws her interlocutor into a view of the world whose founding gesture is less the negative affirmation of psychiatry, and more the assertion of a new language (even if in practice the latter cannot happen without substantial efforts towards the former). Story-telling is central to this process, and, in turn, to the way in which voice-hearing is set apart from schizophrenia, being produced and performed as an identity in whose name meaning can be made, autonomy defended and flourishing envisaged.
The “exemplary cases” of Patsy Hague and Eleanor Longden already point towards the importance of the life narrative to the identity of “the voice-hearer.” Sharing stories is a ritual feature both of local hearing voices groups and larger international congresses; the exchange of narratives functioning variously as a form of testimony, healing, empowerment and the forging of individual and group identity (Cresswell, 2005; Mattingly & Garro, 2000). As well as establishing a sense of solidarity, storytelling also takes on an explicitly therapeutic function. In the Maastricht approach, developed by Marius Rome and Sandra Escher, narrative interviews have as their goal the development of a “construct.” Like the psychological “formulation” (Johnstone, 2012), the “construct” is a succinct written presentation of a person’s life story which, it is envisaged, will function as a person’s anchor amidst the turbulent process of accepting and making sense of voices that lies ahead (Romme & Escher, 2000). The “voice-hearer” has – has to have? – a life narrative that makes sense of their voices, so the question of how this narrative draws on and develops the wider genre of “recovery writing” and participates in the broader dynamics of activist and survivor storytelling (Costa et al., 2012) are important questions for future medical humanities inquiry.

If the centrality of life narrative to identity seems self-evident, it is worth remembering that within the dominant framing of psychiatry people diagnosed with schizophrenia have been, almost by definition, regarded as deficient or defective in narrative terms. The stories of people diagnosed with schizophrenia have been dismissed as essentially symptomatic—incoherent, disordered, expressive of an underlying brain disorder and so lacking in biographical meaning (as in Phillips, 2003). Highlighting the secrecy and stigma that have surrounded psychosis Elyn Saks argues that people with thought disorders do not keep a list of famous and successful people who share their problem. They can’t, because there is no such list. Comparatively few schizophrenics lead happy and productive lives; those who do aren’t in any hurry to tell the world about themselves. (Saks, 2007, p. 329)

If, dwelling within the psychiatric system, “the schizophrenic” was never entitled to a story, especially not a recovery story, “the voice-hearer,” by contrast, comes into being in the explicitly narrative environments of the local self-help group and the international Hearing Voices Movement, and through identification with the stories of key role models – and there are many – within these fields. Voice-hearing is thus a narrative mode of being, one that is performative, personally and socially meaningful, polysemic and open to change.

6. Conclusion

This paper has offered a brief account of the emergence of “the voice-hearer” and of some of the claims made in her name. Just as there are many different forms of voice-hearing, so people who hear voices all do not share the same experiences, values, beliefs and histories. If I have taken this heterogeneity and diversity for granted, it is with the intention not of trying to reify some kind of prototypical “voice-hearer,” but of highlighting the fact that in certain contexts identifying as a voice-hearer involves more than simply acknowledging an experience of auditory verbal hallucinations.

As with all identities, especially those which concern people’s most intimate experiences, “the voice-hearer” has not been universally embraced. For every Eleanor Longden, appalled by the dead-end and “degenerate” implications of her schizophrenia diagnosis, there is a
Sandy Jeffs, Australian poet and long-time mental health advocate, who asks “If this is a post-schizophrenia world, then who the hell am I?” She writes:

my narrative has been challenged by a rapidly changing and much more politically complex mental health world. I was attending conferences where the medical model was deconstructed brutally, consumers were rejecting the illness model and calling themselves voice-hearers, postmodern theory was melding with queer theory and morphing into mad theory. Schizophrenia has always ignited passionate defence or criticism as to its appropriateness for the condition it tries to describe and here I was in a whirlpool of theory and paradigm shifts around this enigmatic experience that has been my life for 35 years. The idea of ‘mental illness’ has an awful pessimistic determinism which for some people is an unacceptable burden. Perhaps by constructing my life around my schizophrenia I have accepted that burden too easily. But I am not just a voice-hearer. (Jeffs, 2012)

The importance of keeping open the possibility of multiple identities, and ensuring “the voice-hearer” does not derive her power and legitimacy through being distanced from the further-dehumanised “schizophrenic” is perhaps most succinctly encapsulated by Elisabeth Svanholmer, writing against the grain of Living with Voices:

Am I a recovered mental patient? Am I a schizophrenic? Am I a voice hearer? Yes and no. To me, these are all just words, labels. They describe something superficial. I am recovered and recovering. Being me and being human is a process of constantly experience, reacting and changing. 

The diagnosis ‘schizophrenia’ has opened doors within the social and psychiatric system in Denmark and it has helped me understand and respect my sensitivity. … For me to think of myself as a ‘voice hearer’ is just as much of a diagnostic approach; this label is just more specific and less influenced by years of taboo and stigma. As a voice hearer, I have been able to work with my problems in a way that makes sense to me. … I am gifted, sensitive, schizophrenic, a voice hearer, or a mentally disabled person, depending on who I am talking to and how they perceive the world. (Svanholmer, 2009, p. 152)

Twenty-five years after the Hearing Voices Movement first created the space for people to discuss voices, “the voice-hearer” has become established as an identity people can adopt, inhabit, and mobilise in order to lay claim to a view of voice-hearing as meaningful within the context of people’s lives. The challenge, perhaps, for the next quarter century is for the mental health professions fully to recognise this claim and its potentially radical implications. In this paper, I have argued that one way medical humanities research can help this endeavour is by exploring the origins, contours and dynamics of identities that have arisen in relation to the “psy” disciplines; offering “thick descriptions” which reveal the nuance and complexity of deceptively simple terms and so can potentially enhance communication in clinical and other settings.

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Notes

1. Although the term is being more widely used in certain clinical contexts such as early intervention in psychosis.

2. Note that for many in the Hearing Voices Movement this process of sense-making can only happen when the devastating effects of trauma and adversity are fully acknowledged.

3. Pointing to distinctions in the way schizophrenia and voice-hearing have been construed in narrative terms does not do justice to wider debates about the status of narrativity itself. For a review of these debates, see Woods (2011b); for a critical account of narrative “loss” in psychosis and its consequences for clinical practice, see Thomas (2008).

References


Jeffs, S. (2012). If this is a post-schizophrenia world then who the hell am I? Centre for Medical Humanities Blog. Retrieved from http://wp.me/p14fUh-zY


