

Listening to voices

Denno, Peter: Wallis, Stephanie: Caldwell, Kimberly: Ives, Jonathan: Wood, Stephen J.: Broome, Matthew R.; Mallikarjun, Pavan; Oyebode, Femi; Upthegrove, Rachel

10.1080/17522439.2021.1964583

License:

Creative Commons: Attribution-NonCommercial-NoDerivs (CC BY-NC-ND)

Document Version

Publisher's PDF, also known as Version of record

Citation for published version (Harvard): Denno, P, Wallis, S, Caldwell, K, Ives, J, Wood, SJ, Broome, MR, Mallikarjun, P, Oyebode, F & Upthegrove, R 2021, 'Listening to voices: understanding and self-management of auditory verbal hallucinations in young adults', *Psychosis*. https://doi.org/10.1080/17522439.2021.1964583

Link to publication on Research at Birmingham portal

General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes

- •Users may freely distribute the URL that is used to identify this publication.
- •Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
 •User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- •Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

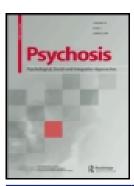
When citing, please reference the published version.

Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.

Download date: 20. Apr. 2024



Psychosis



Psychological, Social and Integrative Approaches

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/rpsy20

Listening to voices: understanding and selfmanagement of auditory verbal hallucinations in young adults

Peter Denno, Stephanie Wallis, Kimberly Caldwell, Jonathan Ives, Stephen J. Wood, Matthew R. Broome, Pavan Mallikarjun, Femi Oyebode & Rachel Upthegrove

To cite this article: Peter Denno, Stephanie Wallis, Kimberly Caldwell, Jonathan Ives, Stephen J. Wood, Matthew R. Broome, Pavan Mallikarjun, Femi Oyebode & Rachel Upthegrove (2021): Listening to voices: understanding and self-management of auditory verbal hallucinations in young adults, Psychosis, DOI: 10.1080/17522439.2021.1964583

To link to this article: https://doi.org/10.1080/17522439.2021.1964583

9	© 2021 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.
	Published online: 11 Aug 2021.
	Submit your article to this journal 🗷
ılıl	Article views: 84
Q ^N	View related articles 🗷
CrossMark	View Crossmark data ௴







Listening to voices: understanding and self-management of auditory verbal hallucinations in young adults

Peter Denno^a, Stephanie Wallis^a, Kimberly Caldwell^b, Jonathan Ives (pc, Stephen J. Wood^{b,d,e}, Matthew R. Broome^b, Pavan Mallikarjun^b, Femi Oyebode^b and Rachel Upthegrove (pb)

^aCollege of Medical and Dental Sciences, University Of Birmingham, Birmingham, UK; ^bInstitute For Mental Health, University Of Birmingham, Birmingham, UK; ^cBristol Population Health Science Institute, University Of Bristol, Bristol, UK; ^dOrygen, Melbourne, Australia; ^eCentre For Youth Mental Health, University Of Melbourne, Melbourne, Australia

ABSTRACT

Background: Auditory Verbal Hallucinations (AVH) are a hallmark of psychosis, but affect many other clinical populations. Patients' understanding and self-management of AVH may differ between diagnostic groups, change over time, and influence clinical outcomes. This study aimed to explore patients' understanding and self-management of AVH in a young adult clinical population.

Methods: 35 participants were purposively sampled from a youth mental health service. Participants completed diary and photo-elicitation tasks, and the resulting materials were discussed at in-depth interviews. Themes were derived using conventional content analysis.

Results: Three themes emerged. (1) Searching for answers, forming identities – voice-hearers sought to explain their experiences, resulting in the construction of identities for voices and themselves. Explanations were drawn from participants' life-stories and belief-systems. (2) Coping goals – patients' self-management strategies were diverse, reflecting the diverse negative experience of AVH, e.g. as distressing sounds, overwhelming emotions, or as threats to agency. (3) Outlook – participants formed an overall outlook on their life with AVH. Resignation and hopelessness in connection with disabling AVH are contrasted with "acceptance" or integration, described as positive, ideal, or mature.

Conclusions: Trans-diagnostic commonalities in understanding and self-management of AVH are highlighted. These offer targets for individual therapies and further research.

ARTICLE HISTORY

Received 29 January 2021 Accepted 2 August 2021

KEYWORDS

Hallucinations; Verbal Auditory; Psychosis; Personality Disorder; Qualitative Research; Self-Management

Introduction

Auditory Verbal Hallucinations (AVH), or "voices", encompass varied perceptions of speech, sounds, and words in the absence of external stimuli (David, 2004). Classically viewed as a hallmark of psychosis, it is now recognised that AVH have a broader prevalence, affecting those with personality disorder, post-traumatic stress disorder (PTSD) as well as Parkinson's Disease, Alzheimer's Disease and epilepsy, and up to 10% of the general population (Johns et al., 2014).

The presence of AVH in non-psychotic disorders and non-clinical groups has stimulated a vibrant debate in the literature, re-appraising AVH and their place in diagnosis. To investigate this, several studies have re-explored the phenomenology of AVH across diagnoses (Upthegrove et al., 2016; Wallis et al., 2020), finding more commonalities than differences (Schutte et al., 2020).

Other researchers have suggested that voice-hearers' understanding of and responses to AVH determine clinical outcomes more than AVH presence or phenomenology. Cognitive models of hallucinations explain AVH-related distress and need-for-care as a function of beliefs about voices, and individual cognitive factors, (Ward et al., 2013). They cite evidence that clinical and non-clinical voice-hearers can be distinguished by external, personalising, paranoid and delusional understanding of their experiences; and maladaptive responses such as preoccupation, avoidance and symptomatic coping methods (Johns et al., 2014); and that distress and need-for-care are predicted by beliefs about voices, independent of their phenomenological features (Peters et al., 2012).

In this context, there is a need for qualitative research into patient understanding and self-management of AVH, to inform and underpin cognitive (and similar) approaches, ensuring their constructs reflect voice-hearers' experience. Research into patient understanding and self-management of AVH will also inform the development of therapeutic approaches, self-help guidance, and clinical advice for patients and relatives.

Prior research includes the seminal model developed by Romme and Escher (1989), the foundational for the international hearing voices movement (HVM). However, the most recent reviews (Farhall et al., 2007; Knudson & Coyle, 1999) highlight the limited understanding of which coping strategies are effective, disagreement over what constitutes efficacy, and a tendency to list and sort strategies rather than understand them. Since this, numerous studies have explored these questions, including Boumans et al. (2017); (Chin et al., 2009); Clements et al. (2020), De Jager et al. (2015), Hayward et al. (2015), and Milligan et al. (2013). However, these have focussed on patients with psychosis, in whom patient understanding and self-management of AVH may differ. Several are explicitly informed by HVM theory. Furthermore, none has addressed this question in the context of early adulthood, a critical period during which many mental health disorders develop, and patients' understanding and self-management are established alongside treatments.

This study, therefore, aims to explore the first-hand experience of AVH in a cross-diagnostic group of young adults, focusing on their understanding and self-management of the symptom.

Methodology

A qualitative cross-sectional study was carried out. Diary and photo-elicitation tasks were used to enrich open, unstructured walking interviews.

Recruitment

Recruitment was carried out in an outpatient youth mental health service. Participants were identified from current caseloads, referral lists and MDT meetings, and assessed for eligibility in coordination with their clinical teams. Purposive sampling was employed to seek a range of experiences rather than a statistically representative sample.

Inclusion criteria were: (1) AVH occurring at least every other day; (2) capacity to consent; (3) age ≥16. Two cohorts were recruited. For the first cohort, "psychosis" was used as an inclusion criterion. For the second cohort, "psychosis" was used as an exclusion criterion.

All participants gave written informed consent, including the scientific publication of anonymised quotes and photographs. National Health Service ethical approval was obtained (NRES16/WM/0428).

Data generation

Qualitative data were generated using in-depth interviews, enriched by diary, photo elicitation and "walking interview" methods. Participants were given diaries and disposable cameras a week before the interview, and asked to make entries about episodes of AVH, describing the hallucination and their response, and to make photographs they felt represented, or evoked emotions relating to, their experiences. Diary is a well-established method to facilitate recall and reflection. Photo-elicitation

involves asking participants to take photographs, which are discussed during interviews. Images allow "emotional dialogue" about concepts that may be difficult to verbalise (Harper, 2002). In this context, they also promote reflection by challenging participants to translate a hallucinated auditory-verbal experience into a visual medium.

Walking interviews (King & Woodroffe, 2017) were carried out within the Birmingham Botanical Gardens. Walking through an open and leafy environment, we aimed to draw conversation away from the well-rehearsed medicalised discourse and uneven power dynamics of the clinical interview.

Interviews were conducted using an open and unstructured approach. Interviewers did not use a pre-prepared topic guide or questions. Instead, during the interview, participants' photographs and diary entries were used as a topic guide – interviewers and interviewees reviewed the materials together, and interviewers asked open-ended questions about these (e.g. "What does this photo represent?", "How were you feeling when you wrote this?"), and topics participants raised were explored using non-directive prompting. We chose this methodology to generate rich descriptions of AVH, reduce the influence of researcher preconceptions, and enable participants to describe their experiences in their own terms. Interview audio was recorded and transcribed.

Demographic data were recorded, and data on AVH frequency and quality were collected using the Voice Topography Rating Scale (Hustig & Hafner, 1990). Participants were offered £15 for travel expenses.

Data analysis

Interview transcripts were analysed using conventional content analysis (CCA) (Hsieh & Shannon, 2005). CCA produces an interpretation of the content of a qualitative dataset. Researchers first "immerse" themselves in the data through attentive reading and re-reading. They develop codes to label statements and ideas, then refine and group these codes into categories and themes. Results are derived directly from the data, without using preconceived codes or themes. We chose CCA to allow researchers to take ownership of data interpretation, whilst allowing participants' perspectives and narratives to shape the results.

Interviews were transcribed verbatim by the researchers (XX, XX and XX). Transcripts were coded by XX, who met with XX and XX to triangulate on codes and develop these into categories and themes. Analytic triangulation meetings, to discuss and agree on categories and themes, were held between XX, XX, XX and XX. A reflexive position was maintained by analysts throughout, paying attention to any preconceptions they may have had, with efforts made to "bracket" these out and work only with the data. The triangulation strategy outlined above helps lend credibility and trustworthiness to the analysis, ensuring that it was not overly influenced by a single perspective.

Results

35 participants completed the study. Participants had a range of psychosis and non-psychosis diagnoses, were predominately white and unemployed, ages ranged from 17 to 37, and most reported AVH occurring several times every day (Table 1). By the final interviews, no new themes or codes were emerging, suggesting that data saturation was reached.

Three themes emerged: (1) Searching for answers, detailing participants' understanding of AVH, their formation of identities for their AVH, changes in self-identity, and the voice-hearer relationship; (2) Coping: goals and strategies, exploring strategies participants reported using to cope with AVH, and the reasons they employed these; (3) Outlook: acceptance vs resignation, documenting changes participants reported in their outlook on their life with AVH. These are described below. Table 2 (supplement) gives code definitions, example quotes, and numbers contributing to each code.

Theme 1: searching for answers

15/35 participants described actively "searching for answers" – researching their voices' source, meaning or message, using the internet or other sources.

For a big part of time I was like looking on the internet for healers or spiritual healers or trying to understand etheric and trying to understand what's happened to me...so there's the part of this experience of what's going on leads you to try and investigate. (P100)

Almost all (32/35) participants reported an explanation for their AVH. Participants' explanations situated voices within their individual biographical and doxastic contexts (relating to their life-stories and belief-systems). Beliefs drawn on to explain AVH involved disembodied voices, the supernatural or paranormal, and mental illness.

It was as soon as I got this dreamcatcher that I started hearing voices ... I think it's the dreamcatcher that's sort of, made me possessed (NP002)

Biographical experiences cited to explain AVH included traumatic experiences and relationships. This was common in the non-psychosis group (6/10 c.f. 6/25 participants).

I was being bullied and obviously that's where it came from, because everything they were saying the voice was saying (NP007)

I think it's because my ex, before we split up she got pregnant and she had an abortion ... and ever since that I've been hearing a baby cry (P129)

Common in the psychosis group (12/25 c.f. 3/10) were descriptions of AVH as a punishment brought upon themselves by perceived wrongdoing or immorality.

"I been smoking too much weed, drinking too much, eating too much khat, no sleep, no food ... seeing too many girls, partying ... I was harming my body, harming my mind" (P126)

Defining identities for voices

AVH were almost unanimously (32/35 participants) described as communications from entities or agents. For this reason, we gathered codes relating to voice identity into the sub-theme "defining identities for voices". One participant in the non-psychosis group described a conscious role in constructing these identities.

I think at one point in my head I kind of assigned them as like . . . characters . . . like that's the angry one, that's the sad one, and then after that they became I guess more solidly separated into their own little character. (NP011)

Identities included specific characters (12/35 participants), specific groups (5/35 participants), and spiritual or religious entities (10/35 participants). Specific identities were drawn from participants' social network (e.g. friends, family), celebrities (e.g. sportspeople, TV personalities), or cultural/religious beliefs. 4/35 participants identified their voices as Jinn (spirits in pre-Islamic/Islamic mythology).

Particularly in the non-psychosis group (8/10, c.f. 7/25), participants identified AVH as "self" – their own thoughts, or (aspects of) their personality. Voices could be identified as self and as a specific character simultaneously.

She lives in the trees ... she got long black hair, she wears black ... I think she represents myself (NP003)

Unique to the psychosis group were voice identities involving technology employed by a secretive organisation or conspirator (5/25 participants). External identities ("Spiritual", "specific group") and descriptions of AVH as their "diseased brain", were more common in the psychosis group (see table 2).

They've got me under 24 hours surveillance. They control my thoughts using this ... Electronic Brain Link technology. (P137)



I'm aware that it's something gone wrong in my head to put it bluntly, whether it's a chemical imbalance or ... (P106)

Re-defining self-identity

Interviewees were particularly concerned to understand what their voices meant about them and their own lives.

I tried to understand why it had chosen me to talk to ... because there's, like, seven billion people out there! (NP005)

You think . . . they must be here for a reason, you know, because why me? I'm not being funny, but why not you? (P136)

Most participants (23/35) described how AVH had affected their own self-identity. We grouped these codes into a sub-theme, "re-defining self-identity". Self-identity and voice identity were often linked or reciprocal.

"I believe it's the MOD and the Americans working together to train me to be...a psychic detective or a psychic medium." (P131)

14 participants described adopting a "mentally ill" identity due to AVH, identifying AVH as symptoms of a disease.

When it first started, I thought that I might be, developing something really bad, so that's why I went to the doctors' ... I - I just thought something was really wrong with me (NP012)

Descriptions of a "personality shift" – describing AVH as changing or eroding their personality, were prominent in the non-psychosis group (5/10, c.f. 4/25 in the psychosis group). Some expressed concern, attempting to reconcile or rationalise negative or violent voices with their own character, delineating their voices' personality from their own, attributing character flaws to AVH, and attempting to disown them in densely navigated introspection.

I was worried like, oh, does it make me a bad person? especially 'cos sometimes they do say bad things (NP011)

It's so weird because I wanna blame it on the little girl but I blame it on myself ... maybe that's who I truly am, behind all the so-called kindness that people see in me (NP005)

Some described themselves as supported, protected or guided by voices which brought meaning or purpose to their lives.

It can help me see like, the bigger picture ... telling me that I am, um, on the right path to something great (NP005)

For others, voices became integral to their identity.

I see a lot of her in me... she just does things that I would do, she thinks the same way as I would think. It makes me who's me, it makes me myself... it makes me unique (NP003)

Relationship

Interviewees used social vocabulary to describe relationships with their voices. Relationships were often entailed in participants' voice- and self- identities. For example, complex, conflicting relationships – describing attachment to or emotional reliance on voices that were derogatory, aggressive and abusive – were prominent in the non-psychosis group (5/10 participants, c.f. 2/25).

Even though they were horrible it's like they were my friends, the only people I could rely on. I felt like I could talk to them If I needed to ... it's partly why I'm scared to get help ... I don't know what I'd do without them. (NP007)

Descriptions of a power struggle in the relationship with AVH, with voices attempting to coerce or influence participants, were common to both groups (22/25 and 7/10 participants). Most often,



participants described pressure to self-harm, particularly in the non-psychosis group (7/10 c.f. 8/25). Descriptions of AVH as having the power to influence their thoughts or actions were more specific to the psychosis group (13/25 c.f. 2/10).

Relationships coded "conspiring" were unique to the psychosis group, and involved AVH, mostly identified as groups, plotting against participants.

"They're going to set me up to make me look like I've gone insane and that I transfer all of my family's property into an account that gets liquidated." (P137)

Theme 2: coping – goals and strategies

Participants described using a wide range of strategies to cope with their AVH. These included cognitive techniques such as ignoring AVH, activities such as sports, exercise, music, TV, radio, socialising, eating, work, and prayer.

Participants also described why they used these strategies – we termed these motivations and justifications "coping goals". Four main goals emerged from the data: "distraction", "fighting for control", "reality-checking", and "emotional regulation". Strategies were usually generic – used to achieve several goals, often simultaneously.

Distraction

Most participants (21/35) reported "distraction" as a motivation for coping behaviours. Distraction was described as providing an alternate focus for attention (12/25 and 8/10); or as "drowning out" voices in competing auditory stimuli, as if AVH were a sound (3/25 and 6/10). Strategies cited as distracting were numerous, including music, radio, television, socialising, and work.

Just draw, play games, and listen to music ... It's a distraction and it's just, anything other than the voices (NP006)

When I listen to music, they kind of get a bit quieter or like in the background because like I get into it, and, yeah, they just kind of get quieter. (P123)

Fighting for control

Many participants (12/25 and 4/10) reported using coping strategies to resist commands or demands from AVH. Strategies employed in this "fight for control" included conversing or arguing with voices, challenging their statements and demands, aloud or in thought.

It'll say "Pick up that table"; I'll go "No", I won't say it out loud, but I'll think "No" (P106)

I just tell her to leave me alone. (NP002)

"Ignoring" or "blocking" AVH was reported by most participants (24/35). Both "ignoring AVH" and "conversing with AVH" were often used for other coping goals.

I can hurt it back, 'cus I can just about get my mind around it to blank it out, so I can beat it (P132)

Other strategies used to cope with commanding voices included deliberately complying with or appeasing AVH (8/25 and 6/10 participants), avoiding provoking AVH, and avoiding situations in which losing control could be dangerous. Most reported being able to negotiate with or overcome voices some of the time, dependant on situation, mood and intensity.

Sometimes I can tell them no I don't want to do that, but like it's hard to not follow them 'cause it feels like if I follow them they'll get quieter (P123)

It depends what mood I'm in. If I'm in a bad mood, they're in charge of me or sometimes I can, like, be in charge of them, like, tell them to go, or just get rid of them. (P124)



Reality-checking

19/35 participants described using strategies to establish whether a sound was hallucinated or real. We labelled this coping goal "reality-checking". Voices' quality and content, physical source and audibility to others were all integrated into judgements of whether a sound was hallucinatory.

I've gradually sort of started to differentiate between what's real and what's not real. (NP002)

12/35 interviewees described recognising voices as hallucinated as an ability which could be developed. Many referenced their first realisation that they were hallucinating. Later, recognising AVH as hallucinations and differentiating them from reality helped compartmentalise voices, disregard and dismiss them.

I guess because of the familiarity with the singular voice and the fact that I can distinguish it more as an independent thing as opposed to loads of them, I recognise that it's something going on in my own head, therefore, I can kind of continue (P106)

Voices were described as hardest to manage in situations where reality checks were difficult, such as crowds and public transport.

It's a lot worse when you walk your dog round the grove ... Cus you go looking around and you're thinking 'ahh these voices, where are they coming from' ... people walking past, you're thinking it could be them (P132)

Emotional regulation

Most participants described AVH as distressing, creating states of fear, distress and anger that could be overwhelming. The code "emotional regulation" grouped participants' statements that they used coping strategies to address emotional aspects or sequelae of AVH – calming and containing emotions (10/35 participants), or providing release/catharsis (8/35 participants).

Running ... It's just a form of release. Cause you've got no energy to think about anything else. (NP013)

Self-harm was described as a coping strategy by 8/35 participants (5/10 in the non-psychosis group). As well as "emotional regulation", this was described as a way of appearing voices, or of making them stop (fighting for control). 4/35 participants, all with psychosis diagnoses, reported suicide attempts as a response to overwhelming AVH.

I have felt like ... cutting myself and that to – just to make the pain go away ... It's release, it releases you. It's to release the stress. (P132)

External sources of support were another common coping strategy – speaking/interacting with family, friends and peers (15/35 participants); healthcare professionals; and pets (3/35 participants) were cited as valuable. This could provide emotional counterbalance – feelings of belonging, calm and "normality" – but sometimes involved harmful behaviours. External support was also used for "distraction" and "reality-checking" goals.

It makes you feel happy ... when you go and see your friends and you have a session where you get on it and you drink and you always do drugs with your friends, it makes you feel normal again, 'cause you go back to what made you feel normal before. (P137)

Outlook

20/35 participants made statements we coded as "biographical disruption" – describing the emergence of AVH as a significant change in their life-story or trajectory. Participants used the onset of AVH as a temporal landmark while speaking, and described AVH as having an impact on their lives that could be long-term and/or disabling.

If you said to me what would you like to do in five years I wouldn't know, I mean ten years ago I probably would've been able to answer that, no not now I don't know what I'm doing in the next minute (P135)

Interviewees returned to phrases and statements expressing a general outlook, attitude, or approach to this new chapter of their lives. They related their outlook to their understanding of AVH, and their experiences of managing the symptom. This theme gathers these statements, contrasting two attitudes: resignation and acceptance.

Resignation

Hopeless or resigned attitudes were expressed by 19/35 participants. Voices were viewed as fixed and indomitable. Unable to meaningfully cope with AVH, participants' self-management was reactionary and avoidant.

I don't really cope ... I just take every day as it comes. (NP003)

It has completely changed me. It's made me feel really crap. The voices don't leave me alone. I've lost a lot of things, you know. I ain't got a life any more really. I can't go out. (P136)

This was often associated with isolation and social withdrawal – sometimes due to broken relationships or unemployment; sometimes deliberately to avoid having to manage AVH in public or while socialising; and sometimes in obedience to commanding voices. 5/25 participants in the psychosis group described their life as being "on hold" due to AVH - subsisting, unable to self-actualise, progress or accomplish meaningful goals. Voices became a dominating presence in their lives, ending and precluding employment and relationships.

I've got no control over it anymore and I just feel, where's my life gonna go? . . . I've had to leave my job. The one thing that was like good that's going for me, so ... (P136)

Most participants expressed some dissatisfaction with coping strategies they used or had tried, with 13/ 35 reporting that "nothing helps". They described coping strategies as temporary, ineffective or counterproductive; using them only as they could not do anything else during AVH. Alternatively, they were concerned that they relied on coping strategies they recognised as damaging, e.g. self-harm or drugs.

I used to plug my ears so bad with a sharp object – it used to make my ears bleed. It wasn't right . . . I just thought it was a kind of an easy way out of it, to try and get rid of them. (NP001)

Mindfulness ... I would say it's unhelpful ... when you clear your head, you have nothing there and the voice kind of like, shows itself. (NP010)

Acceptance

16/35 participants discussed an attitude of "acceptance" toward AVH, aiming to live with/thrive despite their voices. Rather than withdraw, they attempted to adapt to hearing voices, and accommodate it within their lives, often engaging actively with treatment. They described this as a process of gradual adjustment – as they grew or matured, hearing voices became "normal", and was described as "everyday" or "a part of my life".

I can't think of like a particular turning point other than after like seven years of this shit like, I'm kind of used to it ... For something that's quite abnormal it's become very normal for me. (NP011)

That's what schizophrenia is, it's like hearing voices making out things that are not there un stuff, so I've learned to live with that, so everything's good now (P116)

Acceptance of AVH was described by these participants as their aim. Acceptance was described as an active choice.

it's worser than what it is until you accept it. If you don't accept it for what it is . . . it can send your mind worse (NP001)

There's no miracle cure to it, it's just you gotta get used to it and get on with it. (NP003)

Discussion

This study generated detailed first-hand accounts of patient understanding and self-management of AVH across diagnoses. The first theme explored how participants understood AVH, describing the formation of identities for, and relationships with, AVH. The second theme explores coping techniques through participants' reasons for using them. The third theme describes participants' outlook towards living with AVH. The themes were interlinked in participants' accounts – for example, some who identified AVH as a powerful group conspiring against them, reported coping via social withdrawal and compliance with AVH; and described these coping strategies as limiting their life, expressing a resigned outlook.

Within the first theme, participants described a search for answers as an integral part of their initial response to AVH. Romme and Escher (1989) discussed the "frame of reference" through which participants understood voices, and the benefit of certain schemata for coping. Interestingly, Boumans et al. (2017), interviewing non-clinical voice-hearers, found that all attributed their ability to thrive without seeking healthcare to "interpretive frameworks" through which they understood themselves and their voices. We captured descriptions of this explanation-finding process as active/volitional, and as influenced by participants' belief-systems – highlighting this process as a potential psychotherapeutic target.

Also within the first theme were the results of this search for answers. Participants described AVH as identities, and often described a relationship with these. Voices' identities could be intertwined with participants' own identities. Descriptions of "voice/self" confusion, and of dysfunctional relationships with AVH (revolving around self-harm, emotional abuse and dependence) were prominent in the non-psychosis group, and could represent specific features of AVH in personality disorder. However, the relationship between voice and hearer in psychosis has been explored by Chin et al. (2009), who described a similar "personification" process; as well as interaction, conflict and unity in these relationships. Descriptions of a negotiation of power/agency between voice and hearer were also common cross-diagnostically. In the psychosis group, some explanations were clearly delusional, and could form the border with positive symptoms.

This theme also highlighted the influence of participants' life-history on identity formation. Romme and Escher (1989) found that most voice-hearers linked AVH onset to specific traumatic events, and Scott et al. (2020), show that childhood trauma, self-schemas, and attachment styles predict negative content of AVH. The theory that AVH reflect and stem from trauma and social schemata is endorsed by participants in this study, who had considered, and spontaneously volunteered, narratives integrating voices into their own biography.

The second theme explores how participants managed AVH. Our findings align with research in psychosis, that natural coping strategies incorporate a heterogeneous array of activities, including behavioural (e.g. putting on music), cognitive (e.g. deliberately ignoring voices) and physiological techniques (Farhall et al., 2007; Knudson & Coyle, 1999). Techniques were used for diverse reasons. Many were not specific to AVH. There is direct clinical relevance here, as natural coping strategies can include maladaptive and potentially dangerous behaviours (e.g. substance abuse, self-harm), reminding clinicians to discuss coping strategies with patients.

Conflicting techniques were used – e.g. seeking vs. avoiding social contact, ignoring vs. engaging with voices, using earplugs vs. using headphones. The finding that some benefit from competing auditory stimuli while others find hallucinations difficult to manage in noisy environments could suggest distinct subtypes or mechanisms of AVH – e.g. spontaneous activity within auditory systems vs erroneous/overactive pattern-finding mechanisms. Alternatively, coping strategies may represent habitual responses to an intense, negative experience, with little underlying pattern. Quantitative research could target these questions – determining whether coping strategies fit consistent categories (e.g. noise vs. silence seekers) or are randomly distributed.

The third theme described the overall outlook that participants formed toward AVH, contrasting "resignation" and "acceptance". Participants linked their outlook to their beliefs about, ability to cope



with, AVH. Many participants sought to accept their experiences – this is consistent with previous qualitative findings (Hayward et al., 2015). Romme and Escher (1989) and Milligan et al. (2013) both situate acceptance or integration as the final stage in their normative models of voice-hearing. Quantitative research suggests acceptance of AVH is associated with general emotional well-being and resistance to voices, and inversely related to levels of depression, anxiety and stress (Morris et al., 2014).

Participants' clinical state could have influenced all 3 themes. Their TVRS scores, diagnsoses, and need-for-care indicated many experienced frequent or distressing AVH - reflecting our recruitment of psychiatric service-users, and potentially explaining the predominance of negative outlooks and symptomatic coping styles.

Throughout the themes, the similarities between the psychosis and non-psychosis groups were marked. This may reflect transdiagnostic similarities in AVH phenomenology, or commonalities in voice-hearers' response to AVH, despite distinct phenomenology. Further investigation is warranted here, particularly given the potential to develop therapeutic approaches with transdiagnostic benefits.

Limitations

This study has strengths in its broad focus, open design and novel methodologies. Limitations include the single-centre recruitment - all participants were in contact with the same outpatient psychiatry service, potentially shaping their discourse, and their understanding and management of AVH. Coupled with the demographic homogeneity of the sample, this produces results that reflect one specific cultural context and cannot be generalised. The influence of stigma on our findings, particularly given the semi-public interview setting, is uncertain. The influence of comorbidities, including autism and substance abuse, were not investigated, and experiences of AVH in neurodegenerative conditions or epilepsy were not captured.

Implications & future directions

Our results provide insight for researchers and clinicians. They highlight the complex and interactive process of identity-formation occurring between voice and hearer, and the influence of voicehearers' life-history and belief-system on this process. They support the extension of existing research and therapeutic approaches into non-psychosis groups, particularly non-pharmacological interventions. For example, Acceptance and Commitment Therapy (ACT) has been shown to improve symptom scores and reduce rehospitalisation and distress in psychosis (Bach et al., 2012). Our results suggest ACT is well-aligned with the coping goals of some voice-hearers.

In summary, this study reveals a diversity of understanding and self-management in young adults with AVH, expanding on previous work and taking a trans-diagnostic approach. Unique insights include answer-seeking, identity formation and influences on these, together with coping strategies including physical and cognitive tools. These can be seen as a framework for individual therapies. Outlooks toward voices, including acceptance for some young adults, highlight the need to agree therapeutic goals with individuals rather than unwavering pursuit of symptom reduction.

Acknowledgments

The authors thank the participants for their invaluable contribution to this work.

Disclosure statement

No potential conflict of interest was reported by the author(s).



Funding

The study was supported by the University of Birmingham Public Health and Population Sciences degree programme and Birmingham and Solihull Mental Health Foundation Trust Charitable Fund.

ORCID

Jonathan Ives http://orcid.org/0000-0002-5233-5000
Rachel Upthegrove http://orcid.org/0000-0001-8204-5103

References

- Bach, P., Hayes, S. C., & Gallop, R. (2012). Long-term effects of brief acceptance and commitment therapy for psychosis. *Behavior Modification*, 36(2), 165–181. https://doi.org/10.1177/0145445511427193
- Boumans, J., Baart, I., Widdershoven, G., & Kroon, H. (2017). Coping with psychotic-like experiences without receiving help from mental health care. *A Qualitative Study. Psychosis*, *9*(1), 1–11. https://doi.org/10.1080/17522439.2016. 1178798
- Chin, J. T., Hayward, M., & Drinnan, A. (2009). Relating to voices: Exploring the relevance of this concept to people who hear voices. *Psychology and Psychotherapy: Theory, Research and Practice, 82*(1), 1–17. https://doi.org/10.1348/147608308X320116
- Clements, S., Coniglio, F., & Mackenzie, L. (2020). "I'm Not Telling an Illness Story. I'm Telling a Story of Opportunity": Making Sense of Voice Hearing Experiences. *Community Mental Health Journal*, *56*(2), 196–205. https://doi.org/10.1007/s10597-019-00465-x
- David, A. S. (2004). The cognitive neuropsychiatry of auditory verbal hallucinations: An overview. *Cognitive Neuropsychiatry*, *9*(1–2), 107–123. https://doi.org/10.1080/13546800344000183
- de Jager, A., Rhodes, P., Beavan, V., Holmes, D., McCabe, K., Thomas, N., McCarthy-Jones, S., Lampshire, D., & Hayward, M. (2015). Investigating the Lived Experience of Recovery in People Who Hear Voices. *Qualitative Health Research*, 26(10), 1409–1423. https://doi.org/10.1177/1049732315581602
- Farhall, J., Greenwood, K. M., & Jackson, H. J. (2007). Coping with hallucinated voices in schizophrenia: A review of self-initiated strategies and therapeutic interventions. *Clinical Psychology Review*, *27*(4), 476–493. https://doi.org/10. 1016/j.cpr.2006.12.002
- Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual Studies*, 17(1), 13–26. https://doi.org/10. 1080/14725860220137345
- Hayward, M., Awenat, Y., McCarthy-Jones, S., Paulik, G., & Berry, K. (2015). Beyond beliefs: A qualitative study of people's opinions about their changing relations with their voices. *Psychosis*, 7(2), 97–107. https://doi.org/10.1080/17522439. 2014.926388
- Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288. https://doi.org/10.1177/1049732305276687
- Hustig, H. H., & Hafner, R. J. (1990). Persistent auditory hallucinations and their relationship to delusions and mood. *The Journal of Nervous and Mental Disease*, 178(4), 264–267. https://doi.org/10.1097/00005053-199004000-00009
- Johns, L. C., Kompus, K., Connell, M., Humpston, C., Lincoln, T. M., Longden, E.,Badcock, J. C., Cella, M., Fernyhough, C., McCarthy-Jones, S., Peters, E., Raballo, A., Scott, J., Siddi, S., Sommer, I. E., Larøi, F., & Preti, A. (2014). Auditory verbal hallucinations in persons with and without a need for care. Schizophrenia Bulletin, 40(Suppl_4), S255–S264. https://doi.org/10.1093/schbul/sbu005
- King, A. C., & Woodroffe, J. (2017). Walking Interviews. In P. Liamputtong (Ed.), *Handbook of Research Methods in Health Social Sciences* (pp. 1–22). Springer Singapore.
- Knudson, B., & Coyle, A. (1999). Coping strategies for auditory hallucinations: A review. *Counselling Psychology Quarterly*, 12(1), 25–38. https://doi.org/10.1080/09515079908254075
- Milligan, D., McCarthy-Jones, S., Winthrop, A., & Dudley, R. (2013). Time changes everything? A qualitative investigation of the experience of auditory verbal hallucinations over time. *Psychosis*, *5*(2), 107–118. https://doi.org/10.1080/17522439.2012.667438
- Morris, E. M., Garety, P., & Peters, E. (2014). Psychological flexibility and nonjudgemental acceptance in voice hearers: Relationships with omnipotence and distress. *Australian & New Zealand Journal of Psychiatry*, 48(12), 1150–1162. https://doi.org/10.1177/0004867414535671
- Peters, E. R., Williams, S. L., Cooke, M. A., & Kuipers, E. (2012). It's not what you hear, it's the way you think about it: Appraisals as determinants of affect and behaviour in voice hearers. *Psychological Medicine*, 42(7), 1507–1514. https://doi.org/10.1017/S0033291711002650
- Romme, M. A. J., & Escher, A. D. M. A. C. (1989). Hearing Voices. *Schizophrenia Bulletin*, 15(2), 209–216. https://doi.org/10. 1093/schbul/15.2.209



- Schutte, M. J. L., Linszen, M. M. J., Marschall, T. M., ffytche, D. H., Koops, S., Dellen, E. V., Heringa, M. S, Slooter, A. J. C, Teunisse, R., Odile A van den Heuvel, Afina W., Lemstra, Foncke, E. M. J, Slotema, W. C., Jong, J. D., Rossell, S, L., Sommer, E. C. I. (2020). Hallucinations and other psychotic experiences across diagnoses: A comparison of phenomenological features. Psychiatry Research, 292, 113314.
- Scott, M., Rossell, S. L., Meyer, D., Toh, W. L., & Thomas, N. (2020). Childhood trauma, attachment and negative schemas in relation to negative auditory verbal hallucination (AVH) content. Psychiatry Research, 290, 112997. https://doi.org/ 10.1016/j.psychres.2020.112997
- Upthegrove, R., Ives, J., Broome, M. R., Caldwell, K., Wood, S. J., & Oyebode, F. (2016). Auditory verbal hallucinations in first episode psychosis: A phenomenological investigation. BJPsych Open, 2(1), 88-95. https://doi.org/10.1192/bjpo. bp.115.002303
- Wallis, S., Denno, P., Broome, M. R., Wood, S., Ives, J., Mallikarjun, P., . . . Upthegrove, R. (2020). The Phenomenology of Auditory Verbal Hallucinations in Emotionally Unstable Personality Disorder and Post-Traumatic Stress Disorder. Irish Journal of Psychological Medicine, (1), 1–11. https://doi.org/10.1017/ipm.2020.77
- Ward, T. A., Gaynor, K. J., Hunter, M. D., Woodruff, P. W. R., Garety, P. A., & Peters, E. R. (2013). Appraisals and Responses to Experimental Symptom Analogues in Clinical and Nonclinical Individuals With Psychotic Experiences. Schizophrenia Bulletin, 40(4), 845-855. https://doi.org/10.1093/schbul/sbt094