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The Hearing Voices Movement in the United States: Findings from a national survey of group facilitators

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Empirical research on naturalistic hearing voices movement groups (HVG) has been limited to date. In an effort to better understand facilitator perspectives and variations in the structure of groups in the USA, we conducted a facilitator-led national survey of HVG facilitators. The survey included both close-ended and open-ended questions and was available online for 1 year. Participants were asked about the structure and composition of their groups, their perspectives on membership, clinician involvement, facilitator training and perceived impact of group participation on members. Thirty-two facilitators participated. The results underscore the diversity of HVG in the USA. The authors highlight three findings of interest: (1) participants’ disagreements or uncertainty regarding a narrower HVG focus on experiences that would traditionally be described as “sensory hallucinations” versus a broader subset of extreme or unusual experiences (including “beliefs”); (2) tensions regarding HVG collaboration with clinicians; and (3) insights into impact.

Keywords: Hearing Voices Movement; United States of America; peer support; psychosis; self-help

Introduction

The Hearing Voices Movement (HVM) is an international network that offers an alternative approach to understanding of the experience of what are commonly referred to as “auditory hallucinations.” The movement is primarily composed of three main elements: (1) Hearing Voices Groups (HVGs), which offer peer support self-help to voice-hearers; (2) techniques for practicing mental health clinicians (e.g., experience-focused counseling); and (3) a broader coalition of voice-hearers, researchers, family members, and clinicians engaged in research and advocacy. Internationally, HVGs associated with the HVM have steadily grown and expanded for the past two decades. While HVGs have been slower to take root in the USA, 57 groups in 16 states are currently listed in the US Hearing Voices Network’s group database, and these numbers have been increasing every year.

While there is little research available on naturalistic (unstructured) HVGs, a robust body of HVM-related research has emerged in recent years, including work focused on the phenomenology of voices (McCarthy-Jones, 2012; Woods, Jones,

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Alderson-Day, Callard, & Fernyhough, 2015; Woods et al., 2014), links between voice-hearing and trauma (Corstens & Longden, 2013; Longden et al., 2012) and the prevalence and characteristics of voices in non-clinical samples (Waters, Allen, Aleman, et al., 2012; Woods et al., 2015). In addition, there are several conceptual reviews of the HVM (e.g., Corstens, Longden, McCarthy-Jones, Waddingham, & Thomas, 2014; Sapey & Bullimore, 2013) as well as explorations of the cultural meaning of the HVM-inspired “voice-hearer” identity (Woods, 2013).

Research on clinician interventions associated with the HVM has also begun to emerge in recent years. For instance, Casstevens and colleagues (2006) conducted a randomized controlled trial (RCT) of a clinician-led therapy group using Coleman and Smith’s (2015) Victim to Victor workbook. The authors found no change in voice-related variables, but did report a significant decrease in depression. Research on the impact of participation in naturalistic peer-led HVGs has emerged much more slowly. Our group is aware of only two published qualitative studies on the experiences of naturalistic, peer-led HVG participants (Dos Santos & Beavan, 2015; Oakland & Berry, 2015). Both projects documented a range of positive impacts including increased hope, perceived improvements in voice-hearers’ relationships to their voices and increased social connectedness. These analyses also highlighted participants’ testimonials to the value of group ownership and horizontal relationships.

Unlike more structured self-help approaches such as Alcoholics Anonymous or Wellness Recovery Action Plan groups, HVGs typically do not follow a standardized format. Instead, local groups are encouraged to set their own rules, and regional networks have taken up different development strategies and placed more or less emphasis on particular facets of voice-hearing (InterVoice, n.d.). Different from strictly “peer-led” movements, the broader HVM includes many non-voice-hearing professional leaders and has developed clinical tools, including the Maastricht Interview, voice dialogue, and experience-focused counseling (Romme & Morris, 2013; Schnackenberg & Martin, 2014). While these diverse practices are amply documented on websites and in the gray literature, systematic research has yet to map out local or national differences in group organization and practices, facilitator training or facilitator values.

In order to address these issues within the context of the US, we developed a survey of hearing voices group (HVG) facilitators. The project was facilitator- and voice-hearer-led, and included the following primary aims:

- (1) To better understand the organizational structure and operations of US HVG, including membership, activities and facilitation protocol;
- (2) To survey facilitator’s opinions and perspectives on such issues as professional involvement, optimal facilitator training and US HVM priorities; and
- (3) To investigate facilitator’s perceptions of the impact of HVG participation and associated mechanisms of action.

Methods

The survey project reported here was facilitator-led (all members of the research team are facilitators; two identify as voice-hearers) and participatory. The initial draft survey was widely disseminated on US hearing voices and peer listservs and

feedback solicited. Multiple changes were made on the basis of the feedback received. The survey protocol then underwent an additional round of review by two peer researchers not affiliated with the HVM. The final survey was administered online following approval by the primary investigator's ethics board. The survey covered facilitator demographics, past treatment experiences, characteristics of the HVG, HVG activities and discussion content, and facilitators' perspectives on training, collaboration with professionals, and perceived impact. All major close-ended questions (except demographics) were followed up with an open-ended response option soliciting any additional information, context or explanation that participants might want to include. The survey was made available online for 12 months between May 2014 and May 2015. Links were posted in the Hearing Voices Network US (HVN-US) e-newsletter, and on multiple peer/service user and HVG facilitator listservs. In addition, all groups with contact information publicly listed in the HVN-US database were contacted directly in the spring of 2015.

Analysis plan

After the survey closed, we generated descriptive statistics for all survey questions. No questions were required, and participants were free to skip questions; for this reason, there was a moderate amount of missing data. Missing numbers are reported for all but a few questions (i.e. questions in which the responses were not necessarily applicable to all groups). Overall, responses to open-ended questions were significantly lower than responses to the close-ended questions. For some questions only a few participants volunteered additional information, and for others, responses concerned topics other than the target questions. For this reason, our group opted not to attempt systematic thematic analysis, but instead selected quotations by consensus among the three co-authors with the goal of providing additional depth and clarification. Wherever possible we selected quotations that captured the range of positions identified in the close-ended questions (for instead a pro-, a con-, and an in-between position).

Participants

Participant inclusion criteria were 18 years of age or older, and current or past facilitation of an HVG in the US. Thirty-two participants met entry criteria and agreed to participate. Table 1 lists the major demographic characteristics. Most participants were white (71.8%) and over half had a Master's degree or higher. Facilitators came from 13 different states. For context, 17 states were listed in the HVN-US HVG database at the time of analysis, encompassing 55 separate groups. At any given time, some of these groups may be active and some inactive. Our survey thus included facilitators from 76.5% (13/17) of US states with a listed HVG. While it is impossible to determinate the exact percentage of existing groups represented by our participants, if we estimate that each of our participants facilitated a single group, we would have representation from 58.2% (32/55) of listed groups. In practice, this estimate might over- or under-count groups because in some cases the same facilitator might facilitate multiple groups, or have moved from one state to another.

Table 1. Participant demographics.

Category	Percent (<i>n</i> = 32)
Age < 34	12.5% (4/32)
Age 34–54	37.5% (12/32)
Age >55	25% (8/32)
Age missing	25% (8/32)
Some college	12.5% (4/32)
BA	15.6% (5/32)
MA or above	50% (16/32)
Education missing	21.9% (7/32)
Male	15.6% (5/32)
Female	50% (16/32)
Trans	3% (1/32)
Gender missing	31.3% (10/32)
White	71.8% (23/32)
Asian American	6.2% (2/32)
Race/ethnicity missing	21.9% (7/32)

Results

Research question 1: Membership, activities and facilitation

Facilitator characteristics

Table 2 lists facilitator characteristics. Almost half of facilitators (43.7%) identified as voice-hearers. The majority (68.8%) had facilitated a group for one year or more, and over a third (37.6%) of participants facilitated (or had facilitated) more than one group.

Table 2. Facilitator characteristics.

Category	Percent (<i>n</i>)
<i>Facilitation experience</i>	
<1 year	25% (8/32)
1–4 years	50% (16/32)
>4 years	18.8% (6/32)
Missing	6.3% (2/32)
<i>Number of groups</i>	
1	53.1% (17/32)
2 or more	37.5% (12/32)
Missing	9.4% (3/32)
<i>Personal identification</i>	
Voice-hearer	31.3% (10/32)
Not voice-hearer	56.3% (18/32)
Missing	12.5% (4/32)
<i>Past treatment & mental health experiences</i>	
Inpatient hospitalization	65.6% (21/32)
Current or past SSI/SSDI	37.5% (12/32)
Prescribed antipsychotics	53.1% (17/32)
Currently experiences voices or unusual states	34.4% (11/32)
Past but not Current Voices or Unusual States	25% (8/32)

Group membership

Table 3 lists responses regarding the target membership of participants' current group(s). There was a broad spread of target members across different groups, with some including only members with voices and/or visions (21.9%); some any symptom that would typically be categorized as "psychosis" (18.8%); some any form of mental health challenge or distress (31.3%); and some any experience of altered states, including psychedelic or drug-induced states not otherwise related to mental health challenges (15.6%).

Discussion content and activities

Table 4 lists responses to close-ended questions regarding group activities, discussion content and external activities such as consultation. The majority of participants reported discussions of religious/spiritual connections (84.4%), paranormal phenomena (68.8%), conspiracy theories (68.8%), trauma (78.1%), and life stressors (84.3%). In addition to the group activities listed in Table 4, responses to the open-ended follow-up on group activities included group prayer, group meditation, arts-based activities, reading from collections of recovery stories and group outings such as a hiking trip. Additional activities for the general public included film screenings, talks, and informational materials.

Research question 2: Facilitator opinions and perspectives

Opinions on "ideal" group membership

In addition to asking about current target group members (Table 3), we also asked who participants felt HVGs ideally should target and include; 18.8% (6/32) advocated for groups focused "more narrowly on voices and visions" (i.e., sensory experiences), 53% (17/32) including "all types of experiences traditionally understood as "psychosis" (unusual beliefs, paranoia, "delusions," voices)", 34.4% (11/32) "types of experiences considered "extreme" including states of distress such as mania and suicidality"; 9% (3/32) "all mental health issues or symptoms and unusual experiences, including mild depression and anxiety;" and 31.3% (10/32) "anyone who wants to attend with an interest in exploring unusual experiences, possibly including psychedelic (drug) experiences, religious states, etc." Several participants checked

Table 3. Target group membership.

Category	Percent (n)
<i>Group membership</i>	
"Only persons who hear voices or see visions"	21.9% (7/32)
"Anyone with experiences that would conventionally be labeled 'psychotic'"	18.8% (6/32)
"Anyone with lived experience of mental health challenges, including depression or anxiety"	31.3% (10/32)
"Anyone who wants to attend regardless of treatment experiences & including those with unusual psychedelic and/or drug-induced experiences"	15.6% (5/32)
Missing or unreported	12.5% (4/32)

Table 4. Group activities and discussion content.

Category	Percent (<i>n</i>)
<i>Group activities</i>	
Voice profiling	34.3% (11)
Voice dialogue	28.1% (9)
Voices workbooks	43.8% (14)
Art-based activities	25% (8)
Mindfulness/meditation	31.3% (10)
<i>Discussion content: "Voices or other unusual experiences and ..."</i>	
Trauma or abuse	78.1% (25)
Religious or spiritual explanations	84.4% (27)
Paranormal phenomena	68.8% (22)
Precognition	43.8% (14)
Non-traumatic stressors/difficult events	84.3% (27)
Conspiracy theories	68.8% (22)
<i>External activities (in addition to peer groups)</i>	
Consultation to clinicians/agencies	37.5% (12)
Consultation to peer-run organizations	50% (16)
Refer community members to "HVN-friendly" therapists	28.1% (9)
Organize HVM trainings	78.1% (25)

multiple categories (allowed by the survey), a choice explained through open-ended comments such as:

I think it is important to continue to offer groups both for specific groups (voice hearers, people with "paranoia", depression etc.) and for people with multi level experiences. I see benefits to both and again the more choices we can offer people, the more empowered they will feel.

Others reflected on some of the tradeoffs between groups with a narrower focus versus broader groups:

I think Hearing Voices groups are particularly attractive to a voice hearer and effective with voice hearers because of limiting attendees to those who have similar unusual experiences with sensations; not [to] all service users/providers who can go to other support groups.

Several others explained that their groups used the term "hearing voices" as a broader umbrella category encompassing visions, extreme states and unusual beliefs. Asked specifically about the movement umbrella term (i.e., "hearing voices movement"), 31.3% (10/32) of participants felt that it was too specific to (or too centered on) voice-hearing, while 43.8% (14/32) disagreed. Contextualizing these responses, one participant explained in the open-ended follow up:

The semantics are challenging – I often explain "hearing voices" as an umbrella term, as several folks I know state their biggest challenges are with seeing visions, smelling smells, and belief systems they struggle to explain to others. At times, they express concern that they do not belong in the group, and we chat about this – [i.e.] whether an umbrella term is helpful or exclusive.

Perspectives on facilitator training

All participants felt that facilitators should undergo some form of facilitator training, although 34.4% (11/32) said that the need for HVG-specific training would depend

on the individual in question – i.e., in some cases an individual might have enough background to run an effective group without it. Those who responded to the survey question about preferences regarding the standardization of facilitator training across the US were evenly split: 34.4% (11/32) preferred standardization of facilitator training across the US, and another 34.4% (11/32) were opposed (data were missing for 10 participants).

Elaborating on what they felt high-quality facilitation training would involve in our open-ended follow-up question, many participants stressed the importance of distinguishing between a “meaning-centered” HVG approach and more mainstream clinical training (even if directed at peers). For example:

Consciousness raising, Consciousness raising, Consciousness raising! Voice hearers & others in our community are highly informed about medical model & have very little exposure to alternative ideas.

If individual comes from clinical perspective or is unfamiliar with recovery principles, it could be damaging to participants.

In response to an open-ended question on what training content should include, the majority of respondents stated HVM history and context, general group facilitation skills, and HVM-associated tools and techniques such as voice profiling and/or voice dialogue. A few participants also included content regarding extreme states and unusual beliefs, as well as cross-cultural variations and arts-based approaches. Two participants also mentioned specific clinical techniques (e.g., “behavioral therapy”).

Facilitator beliefs about collaboration and/or the inclusion of clinical professionals

Both open- and close-ended responses underscored differences of opinion across the sample regarding the inclusion of professional clinicians in groups as well as running HVGs in clinical settings. Of participants, 31.3% (10/32) felt that “facilitators should be voice-hearers” specifically; 43.8% (14/32), that “facilitators should be service users/survivors or have lived experience but not necessarily of voices”; and 37.5% (12/32) that “the experience of the facilitators does not matter if they truly understand hearing voices movement principles.” In HVGs with co-facilitators, 37.5% (12/32) agreed “only one needs to be a voice-hearer” and 28.1% (9/32) “only one needs to be a user/survivor or have lived experience.”

Responses to our close-ended questions about collaboration with clinicians were similarly mixed: 81.3% (26/32) of participants agreed that HVGs would “ideally operate outside clinical settings” (only 1 participant disagreed and the data were missing for the remaining participants). Nevertheless, 71.8% (23/32) agreed that HVGs should also be integrated into professional mental health agencies (only 2 participants disagreed and the remainder skipped the question). A further 68.8% (22/32) felt that HVG trainings should be available to clinicians in their area; 3 (9.3%) disagreed.

The open-ended responses provide additional depth and context. Some participants expressed wariness about professional involvement in HVG and the potential for co-optation, while others discussed the potential for the loss of boundaries between a true self-help group and a therapeutic group:

I believe strongly in different roles for voice hearers self-help/peer support and other professional services. I do not think it is empowering for non-voice hearers to facilitate, participate or observe except in trainings. I believe that we need practice in carrying out our own role in a quality, recovery-oriented manner and then collaborate and coordinate when useful. I believe self-help/peer support should not be provided, it should be experienced.

The hearing voices movement is doing well on its own without interference from traditional mental health professionals and the involvement of (God forbid) institutions. The whole idea is to minimize stigma and empower the voice hearer.

Holding the ethos of HVN as self-help (not clinical) is really important and often lost in our narrow minded paradigm of care.

Others instead emphasized the context or conditions of collaboration or integration. For example, if staff in traditional mental health settings were willing to honor the tenets of the HVM, the risks would be less marked:

It should be integrated *if* [the] mental health system gives space for it to retain its integrity, identity, & autonomy [but] not if it's co-opted in any way by mainstream programs.

Some participants expressed strong support for HVG in traditional mental health settings as well as integration or application of HVM approaches within clinical settings:

I think broadening the perspective and approaches to helping people in emotional distress across the full spectrum of mental health settings and within the general community is needed.

As treatment or assistance is pervasively obtained through MH or traditional systems, I believe it is essential to integrate as [a] means of fostering awareness and acceptance of the hearing voices movement.

I would like to see us promote this approach throughout the mental health system and particularly among psychiatry. Exposure, exposure, exposure!

Research question 3: Perceptions of impact and mechanism

Impact on group members

Participants were asked a series of questions regarding their perceptions of the impact of participation on group members. Of participants, 25% (8/32) reported that they had not personally witnessed a group member having stopped hearing distressing voices as a result of group participation, while 56.3% (18/32) reported having seen at least one member stop hearing voices altogether attributed to group involvement; 37.5% (12/32) reported having seen at least one “relapse” among a member of their groups that they attributed to group participation.

The survey also included a ranking question in which participants were asked to rank order eight areas of possible HVG impact from 1 to 8. Table 5 reports the percentage of participants who ranked each category as either a 1, 2 or 3 in importance. The three most highly ranked categories were (1) Connecting voices or other experiences to past trauma (40.6%); (2) Learning blocking techniques (34.3%); and (3) Exploring religious and spiritual meaning (31.3%). Notably, no category was ranked by the majority of participants as 1–3 in importance, suggested a range of views on what is most helpful.

Table 5. Percent of participants ranking each category as 1–3 in importance (out of 8).

Category	Percent (n)
Connecting voices or other experiences to past trauma	40.6% (13/32)
Blocking techniques	34.3% (11/32)
Exploring religious/spiritual meaning	31.3% (10/32)
Political consciousness raising	28.1% (9/32)
Understanding triggers	28.1% (9/32)
Self-stigma reduction and improved self-esteem	18.8% (6/32)
Normalization through contact with peers	18.8% (6/32)
Feeling understood through meeting others with similar experiences	9.4% (3/32)

Responses to our open-ended follow up on group impact augmented these results. Many participants focused on HVGs' impact on both a sense of belonging and mutual empowerment; several noted that HVGs provided a space in which members who initially felt uncomfortable speaking about their experiences could instead sit back and listen.

I noticed people in distress attend a group, often without engaging or speaking at all, but quite noticeably calm down and appear to feel safe and less distressed. I have also seen people struggling with a problem in their lives listen to feedback from peers that appeared to be helpful, fresh perspectives for them to try to utilize.

Participants are a vulnerable group that gain strength from sharing their experiences, normalizing their experiences, and being able to function successfully and with diminished fear (of the voices).

Some people haven't experienced knowing that they have choices. In group there is choice, equality, respect – these can impact people in relationship to service providers, voices, family members etc.

Perspectives on what helps distressing voices more broadly

In order to understand facilitators' broader beliefs about treatment and healing, we also included close-ended questions about the general role of traumatic experiences and regarding the relative importance of a range of available interventions. Asked about the links between trauma and voices, 34.3% (11/32) of facilitators felt that traumatic experiences were at least sometimes implicated in group member's voices, and over half (53.1%; 17/32) felt they were involved "most of the time" (4 responses were missing).

Asked to rate the importance of potential supports or interventions likely to be discussed in HVGs (including those provided outside of HVG), 34.3% (11/32) listed medications as important, very important or extremely important; 78.1% (25/32) said the same of "understanding triggers"; and another 78.1% of "addressing past trauma"; 65.6% (21/32) felt "religious or spiritual exploration" was important, very important, or extremely important; and 62.5% (20/32) said the same of "blocking techniques."

Discussion

To the best of our knowledge, the present study is the first investigation of naturalistic HVGs in the USA. We focus here on three important findings: (1) disagreements

or uncertainty regarding a narrower HVG focus on experiences that would traditionally be described as “hallucinations” versus a broader subset of extreme or unusual experiences (including non-sensory beliefs); (2) tensions regarding HVG collaboration with clinicians; and (3) insights into impact.

In the academic HVM literature, “hearing voices” is typically described in a narrower (sensory) way (Corstens, Escher, & Romme, 2008; Dillon & Longden, 2013). For example, Dillon and Longden (2013) explicitly describe the focus of the HVM as “rais[ing] awareness of voice hearing, visions, tactile sensations and other *sensory* experiences” (p. 130, emphasis added). In contrast, a large proportion of our US sample expressed a preference for including experiences beyond the sensory (such as unusual beliefs and states) and expanding the HVM to more explicitly include these experiences. The experiential parameters of HVGs is not an insignificant issue, and our findings raise interesting questions about possible cultural differences (interest in more narrow or focused groups in the UK versus broader groups in the US) as well as epistemological, sociological and phenomenological questions regarding the ways in which unusual experiences are categorized and divided as well as the implications of these divisions. If one goal of the HVM is to reclaim and redefine experience (Woods, 2013), the question of what experiences are included or excluded nevertheless remains salient.

Our findings regarding tensions over the role of clinicians within HVGS, as well as training of staff in traditional mental health settings are also of considerable interest. Notably, some participants expressed concerns not only about mental health clinician involvement in a direct sense, but also as regards the potential clinicalization of HVGs as a whole, even when facilitated strictly by voice-hearers. That is, facilitators might take on a traditionally clinical role, rather than free-ranging mutual exploration. Other participants described willingness to collaborate but experienced hostility from local clinicians. At a minimum, the prevalence and intensity of these concerns seem to merit greater discussion. Further dialogue regarding where and how to draw boundaries between the “clinical” and the “meaning or experience-focused” may be fruitful, and scholarship aimed at exploring both the political and clinical stakes of professional involvement might help carry such dialogues forward.

Some of our findings regarding impact – for instance, the centrality of trauma and the exploration of links between voices and trauma – were unsurprising and align with published HVM work (Dillon & Longden, 2013). Spiritual and religious explorations emerged as strong themes, however, and have been the subject of far less attention within HVM (cf Cook, 2015). Our findings regarding both relapse and the relatively high rate of facilitators who felt that HVG participation had led to the disappearance of voices were unexpected and merit further follow-up. Other areas of impact – increased belonging, availability of safe and open spaces – mirror past qualitative findings (Dos Santos & Beavan, 2015; Oakland & Berry, 2015). The use of techniques such as prayer and meditation within groups may also merit further study.

Clinical implications

While professional interest in HVGs is steadily increasing (Arenella, 2012; Dillon & Hornstein, 2013), there nevertheless remains a pronounced disconnect between the values of the HVM (as reiterated in participants’ comments and responses here) and mainstream clinical services. As noted above, several participants described marked

hostility from local providers and the absence of funding and/or support for group or network development. The authors hope that, in a modest way, this article will contribute to a small but growing body of literature in the USA that seeks the reevaluation of status quo clinical practices and greater awareness of unusual experiences as both personally and culturally meaning-laden among clinicians and administrators.

Limitations and future directions

There are several important limitations to our project. First, our participants were exclusively US-based facilitators and our findings should not be generalized outside the USA. In addition, because we surveyed facilitators only, HVG members may have substantively different perspectives on the issues included in this project. Finally, while we attempted to contact as many facilitators in the USA as possible, facilitators from several states did not participate and were consequently not represented. Therefore, our findings must be considered exploratory. We also underscore that the US HVM is also a constantly growing and evolving movement and the perspectives even of those facilitators included in the survey could very possibly shift over time.

Future research on HVGs is clearly merited. In keeping with the risks stressed by many participants with respect to “clinicalization,” such research would ideally move beyond traditional clinical outcomes and address impacts on identity, cultural positioning and broader conceptualizations of healing and health. In keeping with work in the medical humanities (McCarthy-Jones, 2012; Woods, 2013), we also see a cultural studies approach to understanding HVGs as vital: i.e., scholarship that approaches HVGs as cultural interventions located within a multi-faceted sociopolitical movement, not merely as a form of self-help. As this paper highlights, the stakes extend beyond conventional iterations of recovery, to the ways that society understands, categorizes and is or is not willing to engage with, voices and other unusual experiences.

Disclosure statement

No potential conflict of interest was reported by the authors.

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