

THE HEARING VOICES MOVEMENT: MENTAL HEALTH ADVOCACY AND RECOVERY

O Movimento dos Escutadores de Vozes: Militância em Saúde Mental e Recovery

Claire Bien¹

Graziela do Carmo Reis²

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ABSTRACT: The Hearing Voices Movement (HVM)³, a survivor-led movement that began in the late 1980s, has grown into a worldwide phenomenon through a network of Hearing Voices support groups (HVN)⁴ that challenges current belief that auditory verbal hallucinations are sign and symptom of schizophrenia and best treated with lifelong medication management. This article describes the origins and history of the HVM, the philosophy that informs HVN support group work, and the HVM's extraordinary growth, with a presence in 30 countries on six continents. The Connecticut, USA, experience is described and practical suggestions for forming HVN support groups are offered. The article concludes with a discussion of the future of the movement and a call for increased collaboration between the HVM and supportive mental health professionals to develop an evidence base for the efficacy of HVN support groups in treating those who experience auditory verbal hallucinations.

Keywords: Hearing Voices Movement. Recovery. Peer Support. Advocacy.

RESUMO: O Movimento dos Ouvidores de Vozes (HVM), é um movimento liderado por usuários que começou no final da década de oitenta e que cresceu através de uma rede de Grupos de Apoio aos Ouvidores de Vozes. Trata-se de um fenômeno mundial que desafia a crença atual de que as alucinações verbais e/ou auditivas são sinais e sintomas de esquizofrenia e que o melhor tratamento é feito através do gerenciamento de medicamentos

¹ Claire Bien, MEd, Counseling Psychology, is a writer, grant writer, mental health advocate/educator, researcher, and survivor who lives in Connecticut, USA. Her memoir, *Hearing Voices, Living Fully: Living with the Voices in My Head*, was published by Jessica Kingsley Publishers in June 2016.

² Graziela Reis, BA, Psychology, is a mental health advocate/educator and Public Health Administrator and Educator with specialized training and extensive experience in strategic health planning and management. Clinical work is focused primarily on children and adolescents.

³ HVM – Hearing Voices Movement

⁴ HVN – Hearing Voices Network

ao longo da vida. Este artigo descreve as origens e a história do Movimento dos Ouvidores de Vozes, apresenta a filosofia de trabalho adotada pelo grupo de apoio ao HVN e o extraordinário crescimento do movimento no mundo que atualmente está presente em mais de trinta países e em seis continentes. A experiência do Estado de Connecticut nos Estados Unidos foi descrita neste artigo que também oferece informações para a formação dos grupos de apoio ao HVN. O artigo conclui com uma discussão sobre o futuro do movimento e um convite para desenvolver parceria e colaboração entre os participantes do HVM e os profissionais da saúde mental com o objetivo de desenvolver evidências que sustente a eficácia dos grupos de apoio do HVN no tratamento daqueles que experimentam alucinações auditivas verbais.

Palavras-Chave: Movimento dos Escutadores de Vozes. Recovery. Suporte de Pares. Militância.

1 INTRODUCTION

The hearing voices movement, which began in the late 1980s, has grown into an international social movement through which individuals throughout the world who hear voices have found recovery. Today the movement has a presence in nearly 30 countries on six continents, including Europe, North America, Australia, Latin America, Africa, and Asia. More than 450 groups have been established throughout the world in such neutral settings as libraries, civic centers, and churches; as well as in hospitals, prisons, and mental health organizations. The extraordinary recovery achieved by large numbers of voice hearers, many of whom had languished for decades in psychiatric systems throughout the world, is a testament to the recovery model and the value of peer support. It also speaks eloquently to the fact that people who hear voices and have been diagnosed with schizophrenia are not irredeemably cognitively impaired. The methods used successfully to help voice hearers learn to cope with their voices, and if desired sometimes them drive away, have roots in person-centered therapy, cognitive behavioral therapy, and psychoanalysis. Because the HVM offers hope for real and substantial recovery from what has long been thought to be an intractable, incurable, biologically based disease of the mind, it has won the support of many non-voice hearing allies, including mental health professionals, family members, and patient rights advocates. This wide embrace speaks not only to the power of the recovery model and peer supports, but also to the humanitarian aspects of the principles and tenets of the HVM, which have demonstrated powerfully that with care, respect, support, and understanding, many people can find recovery and live full lives, even while hearing voices.

2 A BRIEF HISTORY OF THE HEARING VOICES MOVEMENT

The hearing voices movement was established in the Netherlands in 1987 by Dutch psychiatrist Marius Romme whose patient, Patsy Hage, wished to talk about her voices. Romme resisted initially because, like many other mental health professionals, he held to the belief that talking about the voices would cause them to proliferate. When he finally agreed, the two began to explore the content of the voices and discovered that the critical voices frequently reflected opinions and judgments Hage had grown up with—often stemming from her mother's own harshly critical voice. Over time, the two discovered that Hage's voices were strongly linked to her inability to acknowledge emotion and express aggression, and she began to get better. (ROMME, et al., 2009, p. 264).

Armed with this knowledge, Romme began exploring the utility of examining voice content in other voice-hearing patients. He discovered that there are certain basic truths about the origins of the voices people hear. Importantly, he discovered that those who experience distressing voices can learn to manage them—frequently succeeding in achieving a peaceful coexistence with their voices, or in persuading them to go away entirely. Romme and his wife, Dr. Sandra Escher, began collaborating and in 1993 published their first book, *Accepting Voices*. A second book, *Making Sense of Voices*, a manual for mental health professionals that provides a systematic approach for working with voice hearers and their voices soon followed. In these publications, Romme and Escher concluded that reducing voice-hearing to a pathological phenomenon was not always beneficial in helping people learn to cope with their voices. Instead, they recommended that effective practice for supporting distressed individuals should involve trying to understand the voice-hearer's frame of reference, supporting them in changing their relationship with their voices, and promoting the valuable role of peer support for decreasing social isolation and stigma. (CORSTENS et al., 2014, p. 209). The movement inspired by their work provides support to people who hear voices, have visions, and have other unusual experiences and beliefs.

Organizing peer support groups became an important focus of Hearing Voices Networks, and these initiatives were embraced by voice-hearers themselves as offering safe spaces to explore and understand their experiences. As a result, peer support began to be seen as a useful way to help people make sense of and cope with their voices. In 1988, a Hearing Voices support group was formed in Manchester, England, and by the mid-2000s,

nearly 30 countries around the world, including the United States, had established HVN support groups. There are now more than 80 groups in the United States.

The self-help and mutual support aspects of HVN support groups are the foundation of their utility. The British Psychological Association explored this in depth in their 2015 publication, *Understanding Psychosis and Schizophrenia: Why people sometimes hear voices, believe things other people find strange, or appear out of touch with reality and what can help*.

There are also many ways that people who are experiencing paranoia or distressing voices can help themselves and each other. Feeling isolated can be a major source of stress to people who are struggling with distressing experiences. Meeting other people with similar experiences in self-help groups and other settings can be a key to feeling less alone, and people are able to learn from each other about what can help. (COOK 2014, p. 68)

HVN support group participation has had a profound impact on the lives of voice hearers throughout the world. Case histories abound of people who have achieved substantial—and sometimes virtually complete—recovery (e.g., ROMME, et al., 2009 and BIEN 2016). Many former “revolving door” psychiatric patients are now international leaders in the Hearing Voices Movement. As a result, a growing number of clinicians are beginning to accept the idea that allowing voice hearers to talk openly about their voices and visions can foster the development of insight into the nature and origins of the voices.

In spite of the growth of the HVM and the work of such writers as Robert Whitaker, whose 2010 book, *Mad in America*, has dramatically changed the conversation about effective practice for people with serious mental health conditions, acquiring the necessary evidence base has been difficult due to resistance from both the psychiatric establishment and the HVM. One of the leading controversies is whether survivors should have a role in shaping the debate and accompanying research into the utility of HVN and other types of social support groups in fostering recovery.

Although the origins of the HVM were based in collaborative research led by Romme and Escher, the HVM primarily developed as survivor-led: Framing voice-hearers as a marginalized group, the HVM stands alongside other social movements that have prioritized personal experience and testimony as an important source of evidence, while having an uneasy relationship with the traditional research methods used within the medical and social sciences. As such, its history has diverged from the mainstream research agenda. However, recent years have seen a resurgence of empirical research both within the HVM and collaborations with academic and clinical allies. This has opened up a debate as to whether formal research has a place in the HVM, and, if it does, what type of research HVM members believe to be valuable. (CORSTENS et al., 2014).

If the HVM is to play a significant role in shaping the future of psychiatry, it is critically important that these conversations continue—and that they lead to productive collaborations that will expand the evidence base for the efficacy of HVN support group participation.

3 THE HEARING VOICES GROUP

As we have written, the Hearing Voices Movement has demonstrated in communities around the world that HVN support groups offer people who hear voices, see visions, and experience other unusual phenomena an opportunity to share their experiences in a safe, non-judgmental environment and to interact with and learn from individuals who have achieved substantial degrees of recovery.

Instead of urging voice hearers to ignore their voices, the HVM holds that effective practice for supporting distressed individuals should involve trying to understand the voice-hearer's frame of reference, providing support in changing their relationship with their voices, and promoting the valuable role of peer support for decreasing social isolation and stigma. The mutual support aspect of the group provides opportunities for voice hearers still fully in the thrall of their voices, or in the early stages of recovery, to interact with and learn from those who are farther along in their recoveries.

Research has found this form of peer support to reduce the rate and length of stay of costly readmissions, substance use, and depression while increasing hope, empowerment, well-being, quality of life, and engagement in self-care. (Davidson, 2016)

The groups offer a safe place for people to share their experiences of voices, visions, tactile sensations, and other unusual experiences and perceptions. Group conversations often focus on trying to understand what the voices are saying and offering advice on how to cope with the voices, or to formulate ways of respectfully challenging the voices' content. The opportunity to talk with other voice hearers results in increased self-awareness, a willingness to explore the nature and origins of the voices, and insight into the triggers for voices and measures that can be taken to mitigate distress. Equally useful is the role of peer support in decreasing social isolation and stigma. Encouraged and guided by their peers, many voice hearers can learn to shift the balance of power between themselves and their voices, resulting

in voice hearers feeling less at their voices' mercy, and creating opportunities for change and growth. (BIRCHWOOD et al., 2000; ROMME et al.; 2009, pp. 16-18).

Through the HVN I have learned that I am not unusual and that there are literally millions of people throughout the world who have had similar experiences and with whom my story will resonate. I also learned that many of the techniques I used to regain control over my mind and my life—argument, negotiation, acceptance when appropriate, and an unwavering determination to live as fully as I could in the real world—are tried and true methods of the Hearing Voices movement. This knowledge has set me free. (BIEN 2016, p. 20).

The safety and support offered by HVN support groups provides opportunities for voice hearers still fully in the thrall of their voices or in the early stages of recovery to interact with those who are farther along in their recoveries and to explore and come to understand the nature and origins of their voices. Group facilitators and other members offer wisdom, guidance, hope, inspiration, and practical solutions that can help those who still suffer find their own paths toward recovery. Allowing every individual to explore their experiences and develop their own unique narrative is enormously empowering, allowing them to take ownership of their experiences and create a life for themselves in which they are full citizens of the world. The reigning ethos in the support groups is individual choice—voice hearers do what they wish and need to do in order to live full lives.

4 INTRODUCING THE HEARING VOICES NETWORK TO THE COMMUNITY:

The connecticut experience

The State of Connecticut, USA, introduced the HVN to Connecticut citizens under the auspices of the Department of Mental Health and Addiction Services (DMHAS) in 2014 through a series of informational meetings and free trainings. A kickoff event was held at a community center administered by a peer-run nonprofit organization that provides mental health services throughout the state. Once trained, facilitators were encouraged to consider forming HVN support groups in their own communities and within a year, 10 groups had been established. By the end of 2016, Connecticut had 19 support groups in libraries, community centers, churches, and other neutral locations throughout the state. HVN resource groups have also been established in four Connecticut hospitals, including Yale-New Haven Psychiatric Hospital, Bridgeport Hospital, Bridgeport Community Mental Health Center, and Hartford Hospital. Group

growth is achieved through word-of-mouth, additional publicity, and provider referrals. In 2017, in response to considerable community interest, The Connection, Inc. offered an introductory HVN training.

Communities and institutions interested in forming HVN Support groups will wish to consider the following process: 1) Establish the framework in which the groups will be offered to the community. Because the HVM is not accepted as an evidence-based treatment for hearing voices, organizers must first determine how to introduce the movement's principles, tenets, and successes to the state or communities in which they wish to establish a presence. 2) Engage in a public and community relations campaign. Public and community relations and outreach is vitally important in raising public awareness of the movement. This is especially important in garnering support from the provider community. 3) HVN support groups are facilitated by individuals who have undergone a multi-day HVN training. These trainings are offered by Intervoice, the international organization, and by the Hearing Voices Network-USA. 4) Identify communities and institutions that would benefit from HVN support groups and identify/recruit prospective facilitators. The HVN suggests that a minimum of two and no more than three individuals be identified to facilitate each group. At least one of the facilitators should be a person with lived experience and ideally a voice hearer. Some institutions require that one of the facilitators be a member of the staff of the institution. If a staff member must be present, the staff member should also be a trained and certified HVN support group facilitator. 5) Identify community locations where groups will be offered, how people will learn about them, whether referrals will be necessary, and whether they will be open or closed groups. Community-based groups are typically open to all who have an interest in learning to cope with their voices and generally draw participants through publicity, word-of-mouth, and provider referrals. While support groups are usually held in community-based settings, an increasing number are held in institutional settings, including hospitals, mental health clinics, and prisons. Institutionally based groups are typically closed for reasons of privacy and safety, open only to individuals currently residing in the institution. Outpatient groups, held within institutional settings may be open if the institution determines that privacy and other concerns are met. However, because institutional settings often carry negative associations, the HVN advises organizers to choose neutral settings such as libraries, churches, community centers, or peer-run organizations for group meetings.

HVN support groups provide safe places for people to explore and come to understand the nature and origins of their voices. Group facilitators and other members offer wisdom,

guidance, hope, inspiration, and practical solutions that can help those who still suffer greatly find their own paths toward recovery. Allowing every individual to explore their experiences and develop their own unique narrative is enormously empowering—not only for those who are struggling, but also for the facilitators. The following narratives describe the experiences of four New Haven, Connecticut, HVN support group facilitators:

Experience1:

“I have taken more from our New Haven HVN support group than given. I have made several close friends/members that I keep in touch on a regular basis. As Walt Whitman once said, "I place everyone I meet above me in that I learn from them."

Experience2:

“Becoming involved with the HVN has been enormously freeing because I know now, for certain, that I am not alone, and that what I have achieved is not rare. It’s wonderful knowing that there are literally millions of people in the world who hear voices and who, like me, are able to live successful, independent lives.”

Experience 3:

“Being an HVN support group facilitator has helped me understand the thoughts and emotions that my son and others experience as voice hearers. It has enabled me to let go of my own pre-conceived reality and join others in theirs, as a way of acceptance—and without judgment.”

Experience 4:

“As the HVN has stated, ‘Hearing voices support groups are not rocket science.’ Sometimes I can get caught up in trying to learn new techniques or implement the latest evidenced-based treatment to assist people in coping with distressing voices. Ironically, I am learning that what might benefit people the most is being surrounded by other individuals with similar experiences, who provide validation, hope and support.”

Hearing Voices Network support group participation, where participants can freely share their experiences, provides a powerful way to open the doors to recovery and has been invaluable to many people who have suffered from traditional mental health care. The Hearing Voices Movement has restored the dignity of countless individuals who hear voices, see visions, and experience other unusual phenomena, with a resultant increase in hope,

empowerment, well-being, quality of life and engagement in self-care.

We understand 'voices' to be real and meaningful, something that is experienced by a significant minority of people, including many who have no problems living with their voices. Our research shows that to hear voices is not the consequence of a diseased brain, but more akin to a variation in human behavior, like being left-handed. It is not so much the voices that are the problem, but the difficulties that some people have in coping with them. (INTERNATIONAL HEARING VOICES NETWORK WEBSITE, 2016)

5 CONCLUSION

According to the HVM, five to ten percent of the general population hears voices at some time in their lives, with only about 30 percent entering the psychiatric system. Hearing Voices support groups depart in significant ways from traditional therapeutic groups in that their primary purpose is to normalize the voice hearing experience, raising awareness that hearing voices and having tactile sensations and other sensory experiences is a normal part of human experience. The understanding and support provided in these groups is invaluable and many participants have been able to wean themselves from medications, live independently, and have successful careers. Participation in HVN support groups offers the possibility of real and substantial recovery from psychosis.

The success of the HVM has fostered a growing number of research collaborations between HVM leaders and university researchers that seek to establish an evidence base for the utility of HVN support group participation. Participation in such research collaborations can be enormously empowering and can lead to greater and more lasting recoveries for voice hearers. Earning the right to serve as a co-researcher, study designer, and mentor by virtue of one's expertise by experience can mean the world to someone who, because of their diagnosis and treatment within the mental health system, has been largely excluded from life within the broader society.

Worldwide interest in and growth of the Hearing Voices Network may prove transformative for the future of mental health treatment for those who experience auditory verbal hallucinations and other symptoms associated with psychosis and schizophrenia. Wider availability of HVN support groups will provide more people with opportunities to engage with other voice hearers and to benefit from the hope, wisdom, guidance, and practical solutions offered by voice hearers farther along the path toward recovery. Their presence will also foster

greater interest in and opportunity for establishing meaningful research collaborations. Growing the Hearing Voices Network in communities throughout the world is an excellent and necessary step on the road toward fostering real change.

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