

Voices are much more than a symptom

As vozes são muito mais que um sintoma (resumo: p. 14)

Las voces son mucho más que un síntoma (resumen: p. 14)

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Abstract

The international Hearing Voices Movement, which emerged in the 1980s, understands the phenomenon of hearing voices not just as a symptom, but helps in the development of strategies to deal with these voices. The objective of this study was to understand how people who participated in groups of voice hearers in the Brazilian health system dealt with such experiences. This was a qualitative research study, carried out in 2020, with data collection from in-depth interviews and field diary, analyzed using content analysis. Adult participants (4) attended the group for more than a month. It was possible to explore the individual coping strategies developed from the experiences of each one with their voices. The group was also an instrument of socialization and, from the normalization of the experience, of greater self-acceptance and reduction of stigma.

Keywords: Self-help groups. Mental health assistance. Mental health recovery.



Introduction

Hearing voices that other people do not hear is a permanent phenomenon in humanity. In the last century, however, this experience has been constantly associated with diagnoses of mental disorders^{1,2}. Contradicting this comprehensive paradigm, the International Hearing Voices Movement (IHVM) arose in the 1980s, from the collaboration between people who hear voices and Dutch health professionals and researchers. Since then, the movement has gained strength and seeks autonomy, respect, and quality of life for people who experience this phenomenon. The movement also believes in the need to combat the prejudices that involve the phenomenon of hearing voices and encourages support for people who need it^{1,3,4}.

One important form of action of the movement is the creation of groups of voice-hearers, where people who go through such situations can meet and share experiences. These groups are spaces to validate feelings and act in favor of the individuals' belonging^{5,6}. By investing in the subject and fighting against silencing and isolation, IHVM can be seen as a deinstitutionalization strategy, with a strong aspect of fighting against stigma and prejudice⁵.

Studies have already pointed out that the voice-listening groups are a resource to facilitate the recovery process, with improvement in the hearing of voices, as well as in social, emotional, and clinical aspects. Such results are evidenced both in groups that take place in the community, within mental health services, as well as virtually. Those who participated in these strategies began to better understand their own dynamics with the voices, as well as present a sense of belonging, identification of reasons for certain behaviors and exchanged information on how to deal with this experience with other participants⁷⁻⁹.

In the latest World Health Organization¹⁰ (WHO) Guide on Mental Health, actions that encourage *recovery* and community participation are indicated and valued, as well as the creation of person-centered strategies that respect human rights. Among them, hearers' groups are cited as models to be followed¹⁰. Therefore, it is of interest to the field of Collective Health and the Brazilian Psychiatric Reform to put in place strategies based on this paradigm¹¹, because they see the individuals, their histories, and their contexts in their integrality.

Recovery is a concept that emerged in the 1970s and was established as a movement and model to be followed, from experiences and exchanges among users of mental health services. It is related to a change in paradigm, in which the notion of cure and remission of symptoms is overcome, and the individual starts to be seen with more hope and search for quality of life¹¹. This paradigm asserts that the individual who suffers psychically can recover by remaining a citizen, seeking life in the community - regardless of whether or not the symptom has been removed. It also encompasses the fields of education, work, and leisure¹².

The IHVM, in line with the *Recovery* Movement, also advocates that people can develop skills to deal with voices, in order to maintain autonomy. These skills can be developed throughout life, and are also techniques that can be shared among people who attend the groups¹³.



Additionally, understanding the subjective meaning of the voices may be important to guide coping strategies, because an approach that proposes to better understand the subject will have greater meaning and acceptability, increasing the chances of these tools being used in everyday life¹⁴. Some research in Brazil, based on voice-listening groups, have already listed several coping strategies for this experience when it becomes a suffering. Attitudes such as ignoring the voices, talking to them, questioning what they say, being distracted by other activities, or talking to family members about them have proven effective^{15,16}. They end up composing an important repertoire to foster a clinic centered on the citizens' experience and not only on their diagnoses.

Therefore, in this paper, we will also investigate the coping strategies of voice-hearers. The present work is a section of a larger research, and aims to understand how people who participated in voice-hearing groups in the Brazilian National Health System (SUS) dealt with the experience of hearing voices.

Material and methods

This is a qualitative research carried out in the municipality of Curitiba-PR that used in-depth interviews and field diary preparation via participant observation as the main methodological tools. This type of research takes into account the singularities of each individual and seeks to know the experiences and representations^{14,17} about the lived experience. This methodology presupposes greater proximity between researcher and field, adapting well to the health context when there is a need to understand the processes that surround it¹⁷.

The research was carried out in a Psychosocial Care Center (CAPS) in Curitiba - where the first author was also a worker. This specific CAPS is a service that assists people in emotional distress, with or without substance abuse¹⁸. This healthcare center operated at the time of the research, providing care to a population of 142,577 inhabitants, divided into 12 neighborhoods¹⁹. It was a CAPS that did not have the capacity to receive people at night, operating from 7 AM to 7 PM and offering multidisciplinary clinical care¹⁸.

Angrosino²⁰ says that it is in the interest of the qualitative researcher to have access to the experiences as they occur in their natural context, also performing participant observation. As a form of data collection, the author also indicates the field diary, which was kept by the researchers. These data were collected throughout 10 meetings of a voice-listening group, in which the researchers participated in the aforementioned CAPS, between January and March 2020. The group was happening previously and independently of the research. The researchers' initial planning was a longer participation in the group, however, due to the COVID-19 pandemic, the participation was limited to the period previously mentioned. The field diary entries were made the day after the group meetings. The general characteristics of the participants were recorded, as well as their speeches and their behaviors, in chronological order, as oriented by Angrosino²⁰.

In addition, in-depth interviews were carried out between September and October 2020 with the group participants. Recruitment privileged participants over 18 years



old who were in treatment at CAPS and who regularly attended the aforementioned Voice Hearers group for at least 1 month.

The Voice Hearers group had 10 fixed participants, who were in the group weekly and met to discuss the subject of voice hearing. The group took place once a week, lasting 1 hour. The participants had the leading role of the group, that is, its functioning privileged horizontality, according to which all those who participated had their history and voice respected. The group occurs as an exchange of experiences, in which one participant helps the other based on his or her own experience.

Before any recruitment, the research was presented to the CAPS team and the users. Those who accepted received the Consent Form (CF), which was read, and their doubts were clarified. Afterwards, interviews were scheduled with each participant who accepted and signed the CF. All interviews were audio-recorded and transcribed in full. In the transcription, all names were replaced, and information that could lead to identification was suppressed or changed to preserve confidentiality.

The guiding questions used in the interview aimed to understand the following aspects: the history of the subject in relation to the voices, including his/her interpretation and beliefs regarding the phenomenon; the ways he/she uses to deal with the voices, and what can help and hinder this process; and, finally, the participation in the group of voices hearers and how has been this experience was explored. More questions were asked in the course of the interview, in order to deepen and better understand what the interviewees reported, bringing information from different angles and directly involved with the lived experience²¹.

This specific group of voice hearers was chosen for the research because it followed the recommendations of IHVM regarding the principles of the experience approach: (1) hearing voices is a human experience that can be understood as natural, explained differently and understood in the context of life; (2) hearers are encouraged to take ownership of their experience, seeking acceptance and understanding; and finally, that (3) the support of people going through similar experiences can help in the process of recovery²².

The data obtained from the interviews and the field diary were analyzed using content analysis. This methodology adapts well to the style of research carried out, because it understands the need to understand that the subject's speech is inserted in a context, and that this subject is also active in the construction of knowledge²³.

We followed the analysis procedures recommended by Franco²³ and Campos²⁴. It began with pre-analysis, the first contact with the transcripts, followed by multiple readings of the material, understanding key points of the text. After an exhaustive reading, the units of analysis were selected according to relevant themes, also taking into account previous knowledge in the area and the research objectives. This was followed by categorization and subcategorization, listing meanings closer to each other, to create analysis categories. And, finally, there is the inference and interpretation phase, in which assumptions and the search for meaning in the results were made, related to the world literature.

This study is part of a larger research project, approved by the Research Ethics Committee under opinions numbers 2.362.016 and 2.405.461, CAEE: 78785517.3.0000.0102

Results and discussion

Interviews were conducted with 4 participants, and one of them was re-interviewed, because in his first interview some data were scarce due to his more introverted profile. This totaled 5 interviews (Frame 1).

Frame 1. Characteristics of the participants

NAME	AGE	GENDER	TIME TO TREATMENT (CAPS)	TIME THAT HEAR VOICES	TIME IN GROUP (MONTHS)	DURATION OF INTERVIEW	TIME OF REINTERVIEW
Bispo	53 years old	Male	5 years	> 2 years	3	15 min	Yes/ 12 min
Salvador	49 years old	Male	6 years	> 20 years	18	40 min	No
Frida	55 years old	Female	6 years	Since childhood	6	45 min	No
Virginia	50 years old	Female	1 year and half	~ 2 years	2	15 min	No

Source: The Authors

The interviews, allowed to notice that the voices have an impact on the subjects' lives, and that they needed to establish ways to deal with them to be able to go on with their daily activities. The descriptions of how they deal with these situations, frequent in their daily lives, were varied. The actions that these people use to deal with the situations, from their experience and experimentation, can be called coping mechanisms. A study that carried out a review on the state of knowledge of research focused on the diagnosis of schizophrenia and hallucinatory symptoms identified that the coping mechanisms used can be aimed at reducing the voices, or they can aim at improving the feelings associated with them²⁵.

Moreover, the interviewees said that their reactions varied according to the experience: some voices aroused one type of reaction, while others triggered other responses. When they saw or heard people with whom they had or have an affectionate relationship, they tended to react more receptively and engage more easily and interact with them. On the other hand, when the voices were experiences with unknown people, perceived as invasive and intense, the reactions were more defensive, less interactive, aiming at self-protection. As Frida quotes, in this excerpt

That it is a constant learning too, yes. It depends on the person that it is and what that person represents, what that vision represents, you will deal differently. It's my brother, for example, I'll talk about my mother, you know? (Frida)

Marius Romme and Sandra Escher¹ surveyed data on people's relationship with voices, demonstrating the complexity and importance of life histories. The authors started several conversations, including at a congress, with people who hear voices,



to better understand this phenomenon, its relationship with life history and how people outside the psychiatric circuit deal with this issue, giving for the first time a voice to those who hear voices, putting them at the center of the debate - overcoming the notion of “symptom”. From this, then, IHVM says a lot about the importance of investigating the tools for coping with voices, because they tend to be articulated with the subjectivity of the subject, as well as with his or her beliefs about life¹.

For these reasons, a strategy that works for one may not work for another: strategies are unique^{16,26-28}. The techniques used can be behavioral or cognitive actions. These strategies can be one-time, for short-term use, or more ingrained, for the long term. Some are for practical benefit, such as lowering voices, and others are for emotional benefit, such as minimizing negative emotions²⁹. Knudson, Coyle¹⁶ also described the existence of social and sensory strategies. In the research findings, it was possible to find all these examples of strategies.

It is also valid to understand that the strategies employed in practice based on the personal experience of the situation have great relevance because they place the subjects in a leading role, valuing their own way of building resources to alleviate suffering¹⁶.

In this research, for example, Virginia said she could deal with the voices based on the understanding that she didn't need to respond to their demands, understanding that she could make judgments and choices. According to her, the voices told her to do bad things, which she interpreted as demonic:

I thought: I'm not going to do that, because it's the voices that are telling me to do it. It's a bad thing, so I didn't do it. (Virginia)

Similarly, another participant in the group reported that in order to get out of the persecutory state, he used logical reasoning. He was able to think that if he didn't do anything to be persecuted, then it must not really be happening, and these thoughts allowed him to reassure himself.

These strategies are consistent with what has been described in other research, according to which regaining control over the situation, with the person putting himself in the center, can help in the recovery process²⁷. With this, the individual leaves a passive posture and becomes active in his life. This discussion about rationality and decision making also appeared in the research results of other authors²⁵. The author observed that in voice-listening groups there is a lot of discussion about the fact that, although the voices guide commands, it is the hearers who could actually carry them out - thus placing the possibility of the person issuing a value on the action and making the decision to carry it out or not. It is also worth noting that within this strategy there is the understanding that the subject and the voices are separate, valuing once again individuality¹⁵. This process, however, is not simple, and must be tied to individual beliefs, once more respecting the subject's understanding of themselves and their voices - because some subjects may perceive these voices as different from themselves, just as others may have the impression that they are part of themselves. Other participants said that talking or being close to someone can help. For Frida, being close to her mother was a source of relief.



So, I would stay, I would run into my mother's room, get on my knees, hold the blanket, put it under my head and stay until dawn. So, there were these things like that, you know? I don't know how to explain it. There it was like a comfort, there near my mother, it seemed that nothing happened near my mother. (Frida)

Likewise, other participants also cited that talking to someone, thus changing the focus of attention, was something beneficial. Such strategies were also found in other research on the same phenomenon, which indicate that individuals who hear voices seek other people to talk, feel safe or distract themselves^{13,15,30}. Chun, Tsun²⁸ says that this strategy is related to shifting the focus from voices to social interaction, which is shown to be protective with respect to other negative feelings.

Another strategy cited by Frida, when she is having unpleasant bodily sensations (bugs running under the skin), is to make use of the prescribed medications, which, she says, help her in her daily life. It is worth remembering that, to be in accordance with the paradigm of *recovery*, it is important that we increasingly value the subject's unique experience with medication, creating conditions for the user to have a voice and a place as a citizen³¹. The conscious use of medication can also be combined with other strategies, because one does not necessarily exclude the other³². Within the voice-hearing groups, there is even room to talk about medication, its therapeutic and adverse effects, as well as tips on how to deal with such effects³².

Medication as a support possibility is also pointed out in the research of Kantorski *et al.*²⁵ and Corradi-Webster, Leão, Rufato³⁰, who tell that the use of these medications may not eliminate the voices, but help keep calm to deal with the situation.

Frida also mentioned that something that helped her was trusting the professionals' guidelines and putting them into practice. It can be affirmed that a good bond with the professionals tends to predispose to an improvement in relation to the feelings, and, within this perspective, it is important that the professionals value the experience of the living, perform the person-centered care, and share the decision making¹⁶.

The interviewees also mentioned pleasurable activities that required concentration or creativity, such as manual or body practices. The performance of activities can help because the person who is listening to voices can divert their focus from them, and may feel less invaded^{13,25,30}.

We painted things, we painted dishcloths, we made vases, everything with the therapist down there. It helped me more, I didn't keep hearing voices, coming home more motivated, right? (Virgínia)

I have to breathe, I learned that now, breathe in, breathe out, hold on, count to six and slowly let go. I learned this and it helped me a lot" (Frida)

Knudson, Coyle¹³ also found the use of relaxation and meditation as a coping strategy. In specific research on mindfulness as a support for those who hear voices, the participants had a reduction in negative sensations as a result of the voices³³.

Bispo said that he always goes out for a walk, stating that when he walks, he feels that “the despair” coming from the voices he hears passes. This strategy is also related to the findings of Knudson & Coyle¹³, who in their literature review article found researches that indicate physical activities as a tool to deal with the voices, because they increase mental and physical excitement, and may help in the process of minimizing distress.

Participants also reported that interaction with the voices may often be necessary, either to understand what the voices want, what they are saying, or to try to somehow stop them, or even “beat them through exhaustion” (Salvador).

Salvador described a very elaborate way of dealing with the phenomenon. He seems to use creative resources and a mode of interaction that is as if it takes place in another world, to which he has access, and other people do not. Unlike reports in which people describe what they experience as “being from another world”, intruding into ours, for Salvador he actively accesses this other world. And in this world things happen that are beyond his control, but he is able to act in this world using the power of his imagination. Not only to respond to voices and establish a cordial relationship. Sometimes setting specific times to talk to them, but also attacking them and creating things in this world, being able to influence it. No such degree of interaction has been found in the specialized literature.

I also imagined destruction” from the west, like atomic bombs, acid rain, very cold, to see if I could kill these hallucinations. They reacted, with withdrawal and so on. It’s just that this West is a different world. It’s not here. It is in the hallucinatory world. [...] Well, you have to try not to pay attention, if it is impossible, pay attention and try to pass intelligence to them. There are some personalities, some hallucinations that have intelligence, so you can talk to them. Ah, there is one that came during a storm and settled there in the West, and he wanted to talk a lot; then in the morning I would take two hours to talk to him, where I would say what he thought, then I would make him talk in the hallucinatory world, and everybody listened. I didn’t use a real voice; it was a hallucinatory voice... I don’t know whose it was. (Salvador)

Other researchers corroborate these findings, having in their research, in a group in Italy, the perception that there was an orientation to change the relationship with the voices, talking to them, trying to understand and control them, starting from the assumption of overcoming fear and protagonism of life⁵.

Some authors encourage contact with the voices in a systematic way to establish a cordial relationship with them. Talking to the voices and trying to understand them helps to have more control of the situation, because the listener can decide what he really wants to pay attention to and choose what he considers beneficial in his life. This interaction with the voices can also contribute to a greater understanding of these experiences articulated with their history^{1,3,27}.

Additionally, in the work of Romme & Escher¹, the authors wrote about the possibility of some strategies involving structured contact with the voices, not only through conversations, but also through performing body or mental actions, as well as



performing rituals or rites. These authors realized that it was more beneficial for people to understand the phenomenon of voices and visions, accepting them and investigating the relationship of the voices with their life history, than to interpret them only as a pathology or something to be suppressed.

About the techniques that involve direct contact with the voices, listening to them and selecting parts of the dialogue, McNally, Goldberg³⁴ investigated, from qualitative research with people diagnosed with schizophrenia, possible cognitive strategies to deal with the voices, and found the following results: to create internal dialogues with one's own voice, seeking rationalization and negotiation; to try to apply one's will over that of the voices; to be self-consoling and self-assertive; and, finally, to use humor, that is, to laugh at oneself.

Finally, another strategy mentioned was religiosity. It was defined as a point of support and understanding, either to ask for help at the necessary moment or to present itself as an explanation, besides being described as an important space to frequent and socialize.

From the field diary records, Evangelicals, Catholics, and Umbandists were identified. It was also noticed that spirituality becomes a possible explanation for extrasensory phenomena, and can help in the process of self-understanding. A young man in the group, for example, sees some boys running around in his backyard and identifies them as spirits - he understood that he was in a mystical experience, and this gave a greater meaning to his experience, because it addresses something explainable and collective.

Other participants also believed that they were in contact with the world of the dead, having experiences with dead people, or, as Frida explained, when she said that "people in white" visit her and, probably, they are beings from other worlds.

In the studies of Romme, Escher¹, mystical and religious explanations are usually a possible way to understand these phenomena. McCarthy-Jones, Waegeli, Watkins³⁵ indicate that religiosity may not only offer a path of response to the phenomena, but also a whole community support.

However, these same authors also discuss that some people may feel oppressed and pressured by religion due to some explanations that may make the person feel bad for hearing voices³⁵. Religion can also reinforce bad feelings and stigma, particularly when it attaches a negative causal relationship to the experiences of the voice-hearers, e.g., possession, deviance, or lack of faith, blaming people rather than helping them.

Finally, voice-hearer groups were described as spaces of safety, belonging, and as a time to gain insight into the experience of hearing voices. They described that the group helps them come out of isolation, because, customarily, the experience of hearing voices is very lonely. The group also emerged as a place of hope, as people with more experience and more coping strategies can share their knowledge with people who are still at the beginning of their journey. We can state, then, that ombudsman groups can also be placed as a support strategy.

This finding is consistent with the literature, where participation in a group can also generate new strategies, through the exchange of knowledge and experiences³⁰.



The groups are also spaces where, in addition to new strategies, there may be sharing that helps in the re-signification of the experience, as well as in possibilities of recovery⁷.

This research has the limitation of having been conducted with a very specific group, which was in treatment due to psychological suffering in a specialized service of the public health network and that usually serves people with severe, complex and/or chronic conditions. It is possible that, because of this, most of the experiences involving listening to voices have been described as negative. Another limitation was the Covid-19 pandemic itself. The group had to be suspended in 2020, as it was experiencing the beginning of the increase of cases in Brazil, which postponed the interviews, which were only conducted 6 months after the closure of the group. Thus, it was not possible to conclude whether the coping strategies that are used to deal with the voices come directly from the participation in the group. The pandemic itself reduced the number of participants at the end of the study. Furthermore, the scope of this research does not allow us to fully cover the existing strategies, nor to extrapolate them to all people who hear voices.

Concluding remarks

With this research, we were able to access several strategies to deal with voices, visions and bodily sensations considered strange or bizarre. People who experience them use such strategies in their daily lives, including complex modes of interaction that tend to be left aside or little explored in health care. These ways of dealing with such phenomena go far beyond the classic treatment approaches, and, as they become known, they can be stimulated, developed over time, and shared. They are: reflecting and making one's own choices; using rationality; communicating with someone you trust; prescribed medication; relying on professionals; activities that involve concentration and creativity; interacting with voices, and religiosity.

At the same time, participation in voice-hearing groups ensures social interaction and reinforces the perception of not being alone. The stimulation and development of voice-listening groups can allow people to contain what they experience in a protected way, suspending, even temporarily, the social stigma in these spaces, to function as a place of learning and exchange of experiences, respecting the singularities of each individual, but, at the same time, helping to maintain hope, protagonism, mutual support and collective construction.

The diversity of people participating, with their varied experiences, coping strategies, life stories, and re-significations, can guarantee examples and bring hope for a better life for those who are facing such phenomena. Such an approach broadens the classic comprehensive paradigm of psychiatry itself, which sees the phenomenon as just a symptom to be controlled. This look, based on experience, on the contrary, allows the structuring of a solidary, communitarian network that does not depend on health services for it to happen.

Authors' contribution

All authors actively participated in all stages of preparing the manuscript.

Conflict of interest

The authors have no conflict of interest to declare.

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Resumo

O Movimento Internacional de Ouvidores de Vozes, surgido nos anos 1980, entende o fenômeno de ouvir vozes não apenas como um sintoma, mas auxilia o desenvolvimento de estratégias para lidar com essas vozes. O objetivo deste estudo foi compreender como pessoas que participaram de grupos de ouvidores de vozes no SUS lidaram com tais experiências. Trata-se de uma pesquisa qualitativa, realizada em 2020, coletando dados de entrevistas em profundidade e diário de campo, examinados utilizando-se análise de conteúdo. Os participantes adultos (4) frequentaram o grupo por mais de um mês. Foi possível explorar as estratégias de enfrentamento individuais desenvolvidas pelas vivências de cada um com as suas vozes. O grupo também foi instrumento de socialização, por meio da normalização da experiência, de maior autoaceitação e de redução do estigma.

Palavras-chave: Grupos de apoio. Assistência à saúde mental. Recuperação da saúde mental.

Resumen

El Movimiento Internacional de Oidores de Voces, surgido en la década de 1980, entiende el fenómeno de oír voces no solo como un síntoma, sino que auxilia en el desarrollo de estrategias para enfrentarlas. El objetivo de este estudio fue comprender cómo personas que participaron en grupos de oidores de voces en el SUS enfrentaron tales experiencias. Se trata de una investigación cualitativa, realizada en 2020, con colecta de datos, a partir de entrevistas en profundidad y diario de campo, analizadas utilizándose análisis de contenido. Los participantes adultos (4) frecuentaron el grupo durante más de un mes. Fue posible explorar las estrategias de enfrentamiento individuales desarrolladas a partir de las vivencias de cada uno con sus voces. El grupo también fue un instrumento de socialización y, a partir de la normalización de la experiencia, de mayor autoaceptación y reducción del estigma.

Palabras clave: Grupos de apoyo. Asistencia a la salud mental. Recuperación de la salud mental.