Hearing voices: a study on exchanges of experiences in a virtual environment

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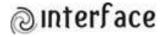[b] Instituto de Psiquiatria, UFRJ. Rio de Janeiro, RJ, Brasil. domserpa@ipub.ufrj.br

Through studying exchanges of experiences among people who hear voices in a virtual environment, this paper explored the ways in which these people create strategies for sharing their experiences in a group, thereby searching for an alternative to psychiatric knowledge regarding verbal auditory hallucination. It described the creation of the Intervoice network and its migration to the virtual environment. Use of netnography demonstrated that this environment is appropriate for exploring exchanges of experiences between people who hear voices and emphasizing the relationship with their use of medication and the ways in which they deal with the voices. This study also observed how people who hear voices use the virtual environment to create social bonds and a new way of existing in the world.

Keywords: Virtual environment. Hearing voices. Peer support.

Introduction

Our interest in the theme is related to our previous experience in providing care for psychotic patients assisted in different institutional contexts and who experience the phenomenon of auditory verbal hallucination. Our experience includes the research carried out in the Psychopathology and Subjectivity Laboratory of *Universidade Federal do Rio de Janeiro* and coordinated by professor Octavio de Serpa Jr.: *Ouvir Vozes: Um Estudo sobre Alucinação Auditiva Verbal* (Hearing Voices: A Study on Auditory Verbal Hallucination) (FAPERJ E-26/171.369/2004), which was inspired by an innovative initiative conducted in Holland.

This experience has indicated that many people who hear voices learn to live with them in a positive way, which contributes to demonstrate that the connection between the experience of hearing voices and the presence of a mental disorder is not that solid[1,2]. The hallucinatory
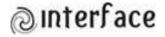
experience in the population in general has been discussed since the pioneering study conducted by Sidgewick in 1894[3] – which indicated that 8% of men and 12% of women, within a sample of 17,000 people, had already had some hallucinatory experience – up to the study carried out by Tien (1991)[3] – who found a prevalence of hallucinatory phenomena in 10-15% (2.3% heard voices) within a sample of 18,572 people.

Although traditionally classified by the Psychopathology manuals as an alteration of sensory perception, auditory verbal hallucination – the technical form of designating the experience of "hearing voices" – had already been noticed by some psychiatrists in the 19th century and in the beginning of the 20th century (Baillarger, Seglas, de Clérambault, Ey, for example). To these scholars, auditory verbal hallucination should be more appropriately related to some other sphere of the psyche, such as language or the control of one's own actions[4]. Contemporary studies in cognitive neuroscience[5], phenomenology[6] and neurophenomenology[7] seem to confirm this intuition, indicating that the experience of hearing voices derives from transformations in the most basic, pre-reflective aspects, as well as in aspects of self-conscience, more specifically regarding the feeling of agency: the subject attributes to others the origin of motor or mental actions that he himself generated. This understanding provides important clinical clues and suggests that creating conditions so that the subject who hears voices is able to appropriate his/her hallucinatory experiences, re-signifying them, may be a path to transform the painful and alienating character that frequently marks this kind of experience.

At the end of the 1980s, a relevant initiative in Holland was capable of placing the clinical practices for voice hearers in that direction, based on the meeting between the psychiatrist Marius Romme[1, 8, 9] and one of his patients who reported that she heard voices[1]. We will describe this meeting below.

In 1987, Marius Romme[1,8,9] and Sandra Escher[1,8,9] founded a movement that defends the employment of new approaches that have been used by people who have coped with the voices positively[1]. To better disseminate and promote the discussion of the theme of voice hearing, a formal organization has been created. It offers administrative support and coordinates the wide variety of initiatives in different countries. This organization is called *Intervoice* (The International Network for Training, Education and Research into Hearing Voices). There are national networks of voice hearers in 26 countries and the movement is one of the fastest-growing support groups in the world. These national networks of voice hearers are supported by *Intervoice*, which acts as an international coordination agency and is directed by a board constituted by voice hearers and specialized professionals. *Intervoice* organizes an annual World Hearing Voices Congress and a World Hearing Voices Day, on September 14. In 2007, a page was created in the virtual environment (*http://www.intervoiceonline.org*).

The digital era is a fertile territory where virtual environments connect people in real time. It has become conducive to the dissemination and sharing of the voice hearers' experiences in the perspective of peer support.

This study aims to investigate how the voice hearing subjects relate to one another and organize themselves in the virtual environment, and how the exchange of experiences can contribute to new treatment alternatives, taking as object of study the *Intervoice* website. To ground this study, we will provide a brief conceptualization of peer support, as well as a panorama of the development of the voice hearers' movement, including their forms of organization in the virtual environment. Subsequently, we will present the methodological framework, the results and the discussion of the nethnographic observation that was conducted.
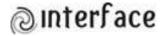
Peer support and mental health

According to Mead et al.[10], peer support is a system of giving and receiving help based on fundamental principles of respect, shared responsibility and mutual agreement. It is not based on psychiatric models and diagnostic criteria; rather, it aims to understand the situation of the other empathically through the shared experience of emotional and psychological pain. Peer support services provide individuals who are recovering from mental illnesses with the opportunity to help their peers to move forward in their journeys for personal recovery and to lead significant lives in the community. Peer support promotes the individual's personal responsibility for his/her recovery.

According to Dass et al.[11], peer support intends to normalize what has been pointed as abnormal. People marked by a psychiatric disorder become victims of social and cultural ostracism and develop a sense of self that reinforces the "patient" identity. The users' movement in the area of mental health searches for social justice through the understanding of mental diseases in terms of human rights, and also by facing the social suppression of difference, aiming to break the alienating stigma of the people who experience psychological suffering.

In the *"Cartilha Ajuda e Suporte Mútuos em Saúde Mental"* (Handbook of Mutual Help and Support in Mental Health), Vasconcelos[12] mentions that groups of mutual help and support offer not only information, but also exchange of affections, compassion and humanity; in addition, they emphasize the possibility of hope of mental health recovery. The mutual help and support groups are organized by people with similar experiences and problems. They provide comfort, as many participants have already overcome many difficult stages, learnt with their own challenges, recreated and reinvented their lives. Furthermore, they offer what conventional treatments are not able to offer: the possibility of exchanging experiences.

The hearing voices movement

Voice hearing has been experienced by many people in different times and sociocultural contexts and it is constituted as a mosaic of experiences with diverse meanings, which vary

according to the life history of the person who hears voices and to the system of ideas, values and beliefs of the culture in which the person is included.

In some cultures, voice hearing has the statute of an experience situated in the register of the sacred, of spirituality[3,13].
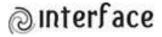
In modern western culture, voice hearing is commonly associated with the experience of "madness", situated in the scope of individuality, of subjective experience, and it has also been classified as a psychiatric symptom that can be treated[1].

Voice hearing groups emerged in Holland at the end of the 1980s with the aim of offering people with this particular type of experience the opportunity of sharing it in a collective space[1]. The initiative is based on the idea that the main problem is not the fact of hearing voices, but the difficulty in establishing some type of relationship with them. The exchange of experiences and the production of personal narratives about the matter emerge as an alternative to psychiatric knowledge about auditory verbal hallucination.

The new strategy enables voice hearers to share experiences and allows a different manner of being in the world, different from those of psychiatry manuals, which simply label a subject that manifests the auditory hallucination phenomenon and frames him/her into a diagnostic tag.

Rosenberg[14] highlights the central role that medical diagnoses have acquired since the 19th century and throughout the 20th century, naturalized and taken as existing entities, independently of any personal, cultural or historical perspective, unveiled through the advances of science. The author identifies three fundamental factors in the process of consolidation of the diagnostic categories in western culture: the development of biomedical technologies; the centrality that hospitals have acquired since the 19th century as places of treatment, but also of education and research; and the role of bureaucratic practices and structures, which depend on (or engender) operational and systematized classificatory procedures, such as randomized clinical trials, consensus conferences and the coded conventions of nosographic classifications (DSM and ICD).

The creation of mutual help groups composed of people who hear voices was one of the strategies proposed by the psychiatrist Marius Romme[1,8,9] to his patient Patsy Hage, who had been diagnosed as schizophrenic and had been hearing voices since she was a child. She had been looking for something that enabled her to understand her experience for a long time, and the reading of the book *The Origin of the Consciousness in the Breakdown of the Bicameral Mind*, by Julian Jaynes[15], gave her the answer she had been searching for. Jaynes argued that hearing voices, at a certain point of the history of the phylogenetic development of the human species, was a normal fact that derived from the "conversation" between the cerebral hemispheres. Dr. Romme[1,8,9] suggested to Patsy that she should find other people who heard voices in order to discuss her ideas with them. This experience led them to participate in a program of interviews that was very popular in the Dutch television at the time – 1987. The repercussion was immediate. They were visited by 700 people, 450 of whom said they heard voices. Of these, 300 stated that they did not know how to deal with the voices and 150 stated they had discovered some way to at least
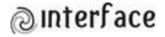
maintain the voices under control. Due to the positive response they obtained, they organized a workshop to gather these people together in October 1987, in Utrecht. This encounter produced a mutual support organization that was called *Resonance Foundation*, which has inspired the creation of similar organizations in other countries.

This initiative originated *The Hearing Voices Movement*, founded by Romme[1,8,9] and Escher[1,8,9], which defended the employment of new approaches, used by those who coped positively with the voices, in addition to traditional ones. To disseminate and promote the discussion of the theme of voice hearing, a formal organization was created, offering administrative support and coordinating a wide variety of initiatives in many countries: *Intervoice* (*The International Network for Training, Education and Research into Hearing voices*).

The work with voice hearers developed in Holland was presented by Romme et al.[1,8,9] in the congress *La Questione Psichiatrica,* which was held in 1988 in Trieste, and it aroused the interest of Paul Baker, of the MIND Association[c] (http://www.mind.org.uk/about/what_we_do/a_history_of_mind), from Manchester. The exchange of experiences that was established between them culminated in an invitation for Baker to participate in the Congress "Voice Hearers", which was held in Maastricht in the same year, jointly organized by the *Resonance Foundation* and the Social Psychiatry Department of the University of Limburg.

Following the steps of *The Hearing Voices Movement*, *The Hearing-Voices Network* was created in Manchester in 1989. It encompasses voice hearers, relatives and health professionals from several countries and has Romme's support. Today, it is the most expressive mutual support association for voice hearers, and it has more than 180 peer support groups.

The international community of voice hearers encompasses more than 80 countries, with groups in different regions. Although many of its members have a psychiatric diagnosis, the groups have an alternative view in which voice hearing is not necessarily seen as indicative of mental illness. The increasing production of studies about voice hearing, the wide variety of countries connected with *Intervoice* and with *The Hearing-Voices Network*, and other group initiatives not necessarily connected with the formal organizations point to the importance that the theme of voice hearing has acquired in different cultural contexts. In 2007, *Intervoice* created a page in the virtual environment, enabling a greater participation of people interested in the theme.

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[c] It was established as the National Association for Mental Health in 1946 through the merge of three large Mental Health organizations: the Central Association for Mental Welfare, the National Council for Mental Hygiene and the Child Guidance Council.

Virtual environment and voice hearers: other possibilities

The virtual environment is adequate to explore how the voice hearers' exchange of experiences is expressed. These groups, resulting from the current trend of emergence of decentralized organizations, constitute a powerful instrument of psychosocial intervention and change. A challenge to all who are interested in the promotion of wellbeing, health and social rights.
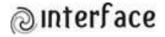
Lévy[16] says that interactive and collective communication is the main attraction of virtual environments, and this interaction is an instrument that begins in the social dimension, enables development, based on the sharing of memory, perception, and imagination, and results in collective learning and in knowledge exchange among groups.

Bauman[17] believes that the highest the degree of confidence among the members of a community, the highest the chances that the communities develop themselves towards fulfilling their objectives. The author does not approach virtual communities specifically, but he offers a sociological view of virtual environments in the networked society. The interrelation of individuals favors new knowledge, new yearnings and relationships, even new languages and patterns. This type of communication facilitates the discussion of important matters, opens space for individualities, breaks taboos and reduces time and "common" spaces.

In 2007, the website *Intervoice*, of public access, was created (http://www.Intervoiceonline.org/about-voices) with the proposal of starting an interactive online community that would be safe for voice hearers and would facilitate the exchange of experiences in the search for ways of overcoming the difficulties faced by people who hear voices. In this online community, they can highlight the most positive aspects of the experience and their historical-cultural importance.

In 2009, the *Intervoice* group was created on *Facebook* (http://www.facebook.com/groups/Intervoice/), and in May 2013 it had more than 1,700 members. The content of the posts is of public access, but enrolment in the group needs to be requested by users who are already enrolled in *Facebook*. After the group's moderator accepts the request, the participants can post comments, photos, videos and files in the group, which functions as a discussion forum and provides support, advices and information on hearing voices for anyone who is interested (voice hearers, relatives, friends and professionals). It is important to highlight that, in the Internet, some users prefer to use their real names, while others prefer to use pseudonyms. Open groups like this one appear in search results on *Facebook* or in search engines like *Google*.

Although disagreement about beliefs is normal, these groups are not places for attacks/personal jokes or insults. The discussions are not moderated in a strict way; however, there is a rule according to which posts containing insults/attacks will be removed. As Braga[18] reminds us,

"the possibility of anonymity and other characteristics of the network can function as facilitators for affable social bonds, and also for hostility and disrespect".

The ideas and opinions expressed do not reflect points of view of the *Intervoice* Board (http://www.intervoiceonline.org/about-intervoice/meet-the-board-2-) but of the diverse website participants. The interested audience is directed by the website itself to the *Facebook* group, which is considered a dynamic tool with intense information exchange.

There is a series of forums indicated by the website. "Discussion forum" is a tool for web pages targeted at promoting debates through published messages that approach the same issue. To participate, it is necessary to enroll by providing your email, user name and password.

With the expansion of the modalities of virtual tools and social networks, the page *"Hearing Voices Movement Media Watch"* (https://www.facebook.com/HVMMediaWatch) was created on *Facebook* in 2011. It has more than 470 followers (May 2013) and provides information on a regular basis on research and media coverage concerning topics related to voice hearers.

There is also a page on *Twitter* (https://twitter.com/VoicesUnLtd) with daily updates and 1640 followers (May 2013), and a channel on *YouTube* (http://www.youtube.com/user/v01ce5000), created in 2011. The channel presented, up to the registered moment, 4,745 broadcasts of its own 13 videos, without including the other 230 videos that are available on its 9 playlists. The playlists can be used as an organizational tool and the creators can use them as part of a linear visualization experience for their audience. They allow that a channel creates extended content for its spectators through various videos (https://www.youtube.com/yt/playbook/pt-BR/playlists.html).
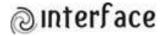
The videos available on *YouTube* contain experiences, media news, explanations provided by professionals in the area and songs about the matter.

A map has been recently created on *Google* indicating groups in 27 countries[d], and 22 countries are considered national networks: Australia, Austria, Canada[e], Denmark, England, Finland, France, Germany, Greece, Ireland, Italy, Japan, Holland, New Zealand, Norway, Palestine, Scotland, Spain, Sweden, Switzerland, USA, and Wales. Uganda, Tanzania, Singapore, Kenya and Bosnia have groups with activities of experience exchange.

The intention is to guarantee that users, relatives, friends and professionals get to know the innovative approach of sharing experiences in the virtual environment.

[d]https://maps.google.co.uk/maps/ms?msid=206854668906561198640.0004d62ee0abdfd28256e&msa=0&ie=UTF8&t=m&source=embed&ll=40.901058,-74.520264&spn=2.503504,4.938354

[e] Whose video *"Knowing You, Knowing You"*, launched on DVD, can be accessed in
http://www.youtube.com/watch?v=MB869Pk390U

The nethnographic observation of the *intervoice* website

The present study aims to research and analyze, in the virtual environment, expressions of the experience of hearing voices, and also to identify strategies that enable mutual help, so that other people get to know this experience in the virtual environment and that the society is acquainted with other forms of care that can be provided to voice hearers. It is a qualitative and exploratory study with an interpretive approach to the *Intervoice* website (http://www.intervoiceonline.org) through a nethnographic study.
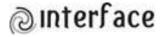
According to Kozinets[19], nethnography is a research method that derives from the ethnographic technique developed in the field of anthropology. This method has been increasing considerably due to the complexity of the experiences of digital society, and it has been constantly used by researchers in the areas of communication, marketing, anthropology and sociology. Hine[20] believes that the advance of the Internet has placed a significant challenge to research methods because it takes as object of investigation the new social formations that emerge when people communicate and organize themselves via e-mail, websites, social networks, mobile phones, etc.

The neologism "nethnography" (net + ethnography) was originally coined by a group of North American researchers[21] to describe the methodological challenge of preserving the rich details of observation using the electronic media as ethnographic field[18]. The term nethnography is related to the ethnographic method because it studies groups or cultures which, in the case of nethnography, are online[22].

The characteristics of observation in nethnography have been discussed by Braga[18,23], who considers that it is impossible to observe without participating. However, it is a very peculiar participation, as the researcher can become invisible and see without being seen and without interfering in the observed social interactions. This participation (even if it is invisible) will allow the description and understanding of the meanings shared by the members of the group under focus.

When we decided to conduct a research of observation of a virtual environment, we realized that nethnography is the methodological tool that meets our needs in the most adequate way.

The research was conducted through the nethnographic observation – performed from January to May 2013 – of voice hearers' interactions in a virtual environment. In the first stage, the *Intervoice* website was observed and analyzed so that we could obtain relevant information to the research's design. The information was complemented by a key informant (the moderator of the *Intervoice* group on Facebook) through the exchange of electronic messages. In the second stage, the observation of the interactions among the voice hearers was transcribed based on the communicational practices of the website's members. In the last stage, we identified strategies that allow to contribute to new alternatives to approach the voice hearing phenomenon.

The subjects selected in the research are men and women, adults and users of the above-mentioned virtual environment. Our priority was to identify the voice hearers' different views, as well as their different opinions about the phenomenon.

To this investigation, twenty messages of public access posted by the users of the *Intervoice* website were selected. The website offers the following tabs: "About Us", "About Voices", "Support & Recovery", "Young People", "Publications", "Research" and "News". In the tab "About Voices", there were 140 public access posts and in the tab "Support & Recovery", 113 public access posts. These tabs were the most consulted ones in this research because they present posts that deal with the categories described below (use of medication and form of coping with the voices), which promote a reflection on the voice hearers' search for the construction of a particular way of existing.

The voice hearing experience and how to cope with it

Based on the work of observation in the *Intervoice* website, we noticed that two categories stood out in the posts: "Use of Medication" and "Form of Coping with the Voices", considering that these themes indicated the actions of care and inadequate care in the traditional psychiatric treatment, according to the voice hearers' point of view.

Use of Medication

In the contemporary world, the pharmaceutical industry offers drugs for a wide range of mental states: to accelerate and decelerate, to stimulate and relax, to concentrate, to cheer up, to suppress fears, etc. Today, each type of discomfort fits into a diagnosis, and to each diagnosis there is a drug. Daily suffering and the setbacks of life are now "medicalized", coded as diseases that require treatment.

Although the medical appropriation of the experience of hearing voices and its categorization as auditory verbal hallucination (a symptom of mental disorder) are not recent events and do not fit entirely into Conrad's[24] definition for medicalization – "a process through which non-medical problems are defined and treated as medical problems" - , understood as a process that is characteristic of the second half of the 20th century onwards, the conventional approaches in psychiatry to auditory verbal hallucination have ignored the meaning of the voice hearers' experience and have focused on the removal of the symptoms (auditory hallucinations) by means of the use of medications[8].

Nevertheless, the frontiers between what should and should not be defined as a disease – medically treated – is not a natural fact, as they are constructed in a process[24] that involves negotiation among different groups of interest (doctors, pharmaceutical industry, insurers, patients,

relatives, etc.); therefore, medical categories can expand or contract towards medicalization or demedicalization, as we will see in the voice hearers' posts.

Although antipsychotic medication is useful for some people, there is a significant proportion (30%) that still experience the "symptoms" (like hearing voices), despite the use of very high doses of antipsychotics[25]. In addition, antipsychotic drugs do not necessarily enable emotional processing and the construction of meaning for the voices[9].

During the observation, some messages posted in 2011 and 2012 stood out:

Hearer 1

"Many people who are marked by a psychiatric disease don't have the opportunity of recovery. They are encouraged to remain sick by a system that, many times, prevents psychological growth through the excessive use of psychotropic drugs. The excessive use of medication also kills people. The drugs cause a long list of problems, such as: diabetes, obesity, heart diseases, etc."

Hearer 2

"I work at a state-run hospital where one of the units has medicine students and interns from the medical center of the State University. I attend the classes taught by two psychiatrists in the hospital and they don't teach anything, only medications, drugs, drugs! They have never learned how to listen or talk to people."

Hearer 3

"Psychiatrists and doctors are brainwashed by the doctrine they receive. It's hard for them to have open minds, hearts and spirits. It's also very hard for the people who can sincerely try to "help". People must have a choice in a free world. Where's the option for people who have been seriously damaged?"

Some allege that the voice hearing movement normalizes voices and other uncommon experiences, offering a true alternative to help people not to exist only as marginalized and medicalized, so that they can recover their condition of citizens in the community.

Hearer 4

"Traditional psychiatry doesn't support the hearing voices movement, as it wants to take us back to the sheepfold. Its message is: if we listen to the voice of reason, we'll see the mistake of our paths. Methods must be based on evidence and to achieve this it's important to respect the traditions established by the psychiatric paradigm. Our strength lies in doing exactly what we're doing, which is to refuse to obey the traditional psychiatric guidelines, and this implies a movement of civil rights. Or rather, we submit like slaves to their masters, who

have methods about how to free us. If we were to accept the guidelines and traditions of the psychiatric paradigm, our silenced voices would disappear once more, and we would remain as colonized patients. How can we avoid colonization?"

Hearer 5

"We need to create spaces of cure that don't imprison thought and stimulate understanding and inclusion."

We observed, in the virtual environment, a movement originated by the voice hearers marked by the creation of strategies so that they can free themselves from the excessive use of medication, which they view as an "imprisonment". They assume the posture of refusing the traditional psychiatric treatment in order to lead the construction of their lives, recover their civil rights and learn how to live with their voices.

Hearer 6

"I've decided to concentrate on one aspect only, the diversity, power and beauty of the music of our voices."

Form of coping with the voices

There are people who hear voices and have a positive relationship with this experience. The voices can be experienced in a way that is integrated into the daily routine of a person, without causing losses or hampering tasks. On the contrary, some consider that hearing voices is pleasant, a plus in their daily experience or even something that keep them company and whose presence is comforting. The way in which each person copes with this experience is more important than the fact of hearing voices.

Hearer 7

"You can have any relationship that you choose to have with the voices. In fact, I see them as guardian angels. What you have to do is to establish a work relation with the voices. This relation must be positive; the voices are our angels, where we can share all our experiences."

Hearer 8

"Thank you for creating this website. I've read some of its stories. I'm an engineer and also a scholar. I've been hearing voices for the last six years, and the voice tells me exactly what will happen in the future, in different parts of the world, and it also tells me what my colleagues are doing. Believe me, I feel safe, even against disasters, because the voice has warned me many times."

On the other hand, those who feel submitted to this experience in a passive way and who are not able to preserve their daily routine or maintain their activities are more likely to develop a negative relationship with the voices. It is important that these people find forms and spaces that help them to cope with this experience. Talking about the voices and trying to situate them in the context of their lives can help them to become the subjects of their experiences[26, 27].

Hearer 9

"I've been hearing voices for the last seven years. Sometimes they seem to be capable of predicting things, and sometimes they can't tell the truth and suggest many negative ideas."

Hearer 10

"Voices aren't always good and they shouldn't be treated as if they were normal."

Hearer 11

"I have many voices and I know they're mine, and I have some degree of control over them, but they quarrel with each other, generating a conflict. Most of the times they're useful, but I need to remain quiet. Any help from you will be welcome."

Hearer 12

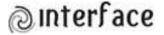"I consider my voice my only true family, as it's always here to help me."

Hearer 13

"I'm very interested in having discovered this website – it's comforting to see so many people who have decided to consider their voices as a normal part of their experience."

Hearer 14

"Just by reading some of the posts here, it has become clearer to me that the experience of each one is different."

However, we do not wish to give the impression that the experience of hearing voices is (or should be) seen as a banal, trivial, peaceful experience. It is not this that we have been witnessing in the daily routine of clinical practice. For many hearers, this experience is very painful, disturbing and disheartening.

Hearer 15

> "*Intervoice* has saved my life. I was on the verge of suicide. An enlightened perspective has brought me home, to my senses."

Hearer 16

> "Sometimes the voices are beneficial; sometimes, they aren't."

We noticed in the selected posts that the *Intervoice* network allows users to experience union, exchange and strengthening of bonds. Above all, they can search for individualized forms that help them to cope with the problems mentioned here.

Final remarks

Our field of interest was to analyze the way in which voice hearers express themselves and relate to each other in the virtual environment, searching for mutual support and for the exchange of experiences.

We observed that the voice hearers utilize the virtual environment to promote social bonds, which many times are difficult to be established in life in society, as a consequence of prejudice and of lack of understanding of the phenomenon.
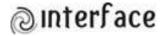
Hearer 17

> "I'd like to have e-mails from people who suffer like me. It's good to know that I'm not alone in this boat."

In addition, we perceived that they are against medication, as they believe they will be held captive in the condition of patients and are prevented from practicing autonomy and managing their lives. In this universe, a few posts reveal that the use of medication contributes to minimize psychological suffering and facilitates the relationship with the voices.

Hearer 18

> "Take her to see a psychiatrist; with the medication the voices will stop. It's not that the voices will necessarily stop, but it'll become easier to cope with them. (Answering a hearer's question)"

Hearer 19

> "At the beginning I lived without medication, until I couldn't stand it anymore, and I had to resort to medication. I tried five different types before I found one that worked."

There are people who hear voices and have a positive relationship with this experience. Others feel submitted to this experience in a passive way and are more likely to develop a negative relationship with the voices; however, they use the virtual environment to find ways and spaces that help them cope with their difficulties. An example is the answer of a member of the *Intervoice* website to another member who seeks help:
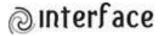
Hearer 20

> "You don't mention your son's age, so I can only imagine, but as a person who has already worked in a series of home services, I have found young people withdrawn from society, strongly medicated and managed through routines and structures, a large part of them institutionalized, which in fact is more harmful than beneficial […] You also haven't mentioned a diagnosis, but hearing voices in itself is not a diagnosis, it's not proof of psychosis, not even of a "disease"
> […]
> There still is a series of myths and stereotypes regarding the experience of hearing voices, and in fact there are numerous hearers who cope well with this, including myself. I've never considered my experience of mental illness as "suffering"; rather, I see it as a turning point in my life from which I was capable of defining myself as a person, identifying my areas of passion, which has taught me a lot about what Wellbeing really means to me. Never lose hope."

During the months of study and observation of the voice hearers' interaction in the virtual environment, we identified that this environment emerges as an important device to reach other forms of arrangement in the relations with the world, enabling new placatory solutions for psychological suffering, and creating conditions so that the hearers who participate in it understand and learn to live with their voices.

We detected that many voice hearers do not bother about them or else they have already found their own ways of coping with them outside psychiatric assistance. This is very significant, as it allows to design new studies in this direction. However, there is also a significant number of voice hearers who are overpowered by the negative and disabling aspects of the experience, which prevent them from leading a full life in society.
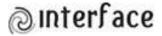
Diving into this new universe marked by the permanent search for answers to the issue that is presented here, the experiences of this study have fostered knowledge, reflections and crossings that point to new perspectives to this field of work.
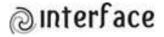
Collaborators

The authors Octávia Cristina Barros and Octavio Domont de Serpa Jr. participated equally in all the stages of the production of this study.

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