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ONLINE INFORMATION AND HEARING VOICES

The need for acknowledging the psychosocial aspects of voice-hearing experiences: Review of online information and implications for public mental health education

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Abstract

Hearing voices is generally linked to biological factors, but its psychosocial aspects should

not be overlooked. The empirical literature indicates the need for acknowledging the psychosocial

aspects of voice-hearing experiences. We conducted a review of online health information about

voice-hearing experiences and examined if the most widely accessible websites equally covered the

biological and psychosocial aspects of voice-hearing. Forty-seven websites (including 23 English

websites and 24 Chinese websites) were reviewed and rated. The English websites did not adequately

mention trauma-related disorders as potential diagnoses for hearing voices, but there was a balanced

discussion regarding the causes and treatment options for hearing voices. In contrast, most Chinese

websites failed to acknowledge any psychosocial aspects of hearing voices. A comprehensive

approach that recognizes both the biological and the psychosocial aspects of voice-hearing

experiences is required to reduce stigma and ethically inform potential service users and the public

about the possible causes, diagnoses and treatment options for voice-hearing experiences.

Implications are discussed. Online information concerning voice-hearing experiences in the Chinese

context should be updated. Mental health information providers in both language contexts should be

familiar with the relationship between hearing voices and trauma-related disorders too.

Keywords: Hearing voices; Psychosis; Mental health literacy; Stigma; Psychosocial care;

Psychoeducation

The need for acknowledging the psychosocial aspects of voice-hearing experiences: Review of online information and implications for public mental health education

Hearing voices, also known as auditory verbal hallucinations (AVH), is generally linked to biological factors (e.g., genetic influences) and psychiatric conditions that are assumed to be biologically based (e.g., schizophrenia). Schneider (1959) proposed that Schneiderian first-rank symptoms including hearing voices are indicative of a psychotic disorder. In DSM-IV-TR, a diagnosis of schizophrenia could be made if the patient heard voices keeping up a running commentary, or voices talking to each other, with no other symptoms being required (e.g., delusions, disorganized speech) (American Psychiatric Association, 2000). Currently, biological interventions in the form of medications are the primary psychiatric treatment for patients who hear voices (Ross, 2020). However, it is generally accepted that voice-hearing experiences are related to complex biological, psychological, social, environmental and cultural factors. Even though voice-hearing experiences are associated with some biological factors (e.g., functional connectivity, genetic influences) (Bose, Shivakumar, & Venkatasubramanian, 2018; Vercammen, Knegtering, den Boer, Liemburg, & Aleman, 2010), the psychosocial aspects of voice-hearing experiences should not be overlooked for a number of reasons.

First, the literature has demonstrated a strong relationship between psychosocial adversities and psychotic experiences including hearing voices. In particular, psychological trauma is closely associated with voice-hearing experiences (Daalman et al., 2012; Read, van Os, Morrison, & Ross, 2005; Whitfield, Dube, Felitti, & Anda, 2005). Social stress in the form of high expressed emotions of family members is also a strong predictor of schizophrenic relapse (Butzlaff & Hooley, 1998; Ng, Yeung, & Gao, 2019).

Second, voice-hearing experiences are also very common in individuals with trauma-related mental disorders, including post-traumatic stress disorder (PTSD), borderline personality disorder (BPD) and dissociative disorders. More importantly, voices in trauma-related disorders and in psychotic disorders can be phenomenologically very similar (McCarthy-Jones & Longden, 2015; Moskowitz, Mosquera, & Longden, 2017; Slotema et al., 2012). It is argued that many voices may be better conceptualized as trauma-related dissociative phenomena rather than being psychotic in nature

(Moskowitz, Read, Farrelly, Rudegeair, & Williams, 2009); this idea has received empirical support in a recent cross-cultural study (Fung, Chan, & Ross, 2020).

Third, given the close relationships among voice-hearing experiences, psychosocial adversities and dissociation (as a core response to psychosocial trauma), psychosocial interventions such as trauma-informed care and psychotherapy should be considered in the management of voices, especially if the voices are accompanied by psychosocial trauma and extensive comorbidity (Ross, in press). Empirical evidence also supports the use of psychosocial interventions for individuals who hear voices (Thomas et al., 2014; Zanello, Mohr, Merlo, Huguelet, & Rey-Bellet, 2014).

The literature indicates that the psychosocial aspects of voice-hearing experiences are also essential in the understanding, assessment and management of voices. In the authors' opinion, while some voices may be caused by biological factors (e.g., brain injury, dementia, drug-induced psychosis), the possibility that psychosocial factors are involved in the development and maintenance of hearing voices should be acknowledged. As the psychosocial aspects of psychotic symptoms in general, and voice-hearing experiences in particular, are often ignored in the field (Read, Bentall, & Fosse, 2009), a greater acknowledgement of the psychosocial factors needs to be made. More importantly, a comprehensive approach that recognizes both the biological and the psychosocial aspects of voice-hearing experiences is required to facilitate research, improve clinical practice, and, more importantly, ethically inform service users and the public about the possible causes, diagnoses and treatment options for voice-hearing experiences. Keeping these considerations in mind, and inspired by the methodology of a recent study that reviewed the information about antidepressants on the Internet (Demasi & Gøtzsche, 2020), this preliminary study reviewed online health information about voice-hearing experiences and examined whether the websites equally covered the biological and the psychosocial aspects of voice-hearing.

Methods

In May 2020, we conducted a preliminary review of the first 20 English and first 20 Chinese websites based on Google searching results using the following search strings: "'hearing voices" OR "Auditory verbal hallucinations" OR "Auditory hallucinations" (for English websites) and "幻聽" OR "聽幻覺"" (equivalent meanings, for Chinese websites). In order to focus on public health information that laymen (potential service users and caregivers) would mostly likely access, academic papers and books were excluded for analysis; personal blogs, social networking sites and duplicate contents were excluded as well. There were no other exclusion criteria. The reason for mainly reviewing websites on Google was that Google was the world's most popular search engine, with a market share of 91.98%, and the second most popular search engine (i.e., Bing) only had a market share of 2.32% in 2020 (GlobalStats, 2020). The reasons for only reviewing English and Chinese websites were that these were the first two most spoken languages in the world in 2020 (Ethnologue, 2020) and that the research team only included Chinese and English speakers.

In order to cover more websites so as to increase the representativeness of the reviewed websites, we conducted some additional searches on Bing in June 2020 because, as mentioned, Bing is the second most popular search engine. The same approach was employed to review the first page of search findings in each language (one page included ten website results on Bing). Three additional English websites and 4 additional Chinese websites were found and included.

These 47 websites can be regarded as the most widely accessible online information resources for English-speaking and Chinese-speaking laymen who want to learn about hearing voices. The full list of the 47 websites is available in the Tables.

A 6-item checklist was developed to assess whether each website covered the biological and the psychosocial aspects of voice-hearing experiences. Two bilingual researchers (the first author and the second author) rated each website independently using the checklist. Among 282 entries in total (6 items for each website), there were 176 agreed upon entries (agreement rate = 176/282 = 62.41%) for the initial ratings. After further review, double checking, and discussion among the two researchers, the agreement rate increased to 92.20% (260 agreed entries).

Results

Overall websites' characteristics

The final rating results are summarized in Table 1 and Table 2, based on the first author's judgements.

Among the 23 English websites, both psychosocial (n = 14; 60.9%) and biological (n = 17; 73.9%) factors as possible causes of hearing voices were mentioned substantially; both psychosocial (n = 17; 73.9%) and biological interventions (n = 13; 56.5%) as possible treatment options for hearing voices were also mentioned substantially. However, while most websites (n = 20; 86.9%) mentioned psychotic disorders as possible diagnoses for individuals hearing voices, only seven websites (30.4%) mentioned trauma-related diagnoses as possible diagnoses.

More information imbalance was observed in the 24 Chinese websites. For instance, while biological factors as possible causes of hearing voices were mentioned in most websites (n = 18; 75%), only six websites (25%) mentioned psychosocial factors as potential causes. Similarly, although most websites (n = 17; 70.8%) mentioned biological interventions, less than half (n = 9; 37.5%) mentioned psychosocial interventions as possible treatment options. More importantly, most websites (n = 20; 83.3%) mentioned psychotic disorders as possible diagnoses for individuals who hear voices, but only one website (4.17%) mentioned a trauma-related diagnosis.

Biological and psychosocial factors as possible causes of hearing voices

In both English and Chinese contexts, many websites had a large amount of discussion regarding the potential roles of biological factors in the occurrence of voices. In particular, brain abnormalities were commonly mentioned as possible factors. Some examples are as follows: "changes to your brain chemistry can cause you to hear voices" (English No. 5), "findings (published in Science) provide insight into a common neural mechanism that may drive auditory hallucinations" (English No. 6), "one possibility considered over the years is that the brain might somehow lose its

ability to cancel out 'inner speech'" (English No. 16), "these problems (auditory hallucinations) may be caused by chemical imbalance inside the brain" (Chinese No. 14), and "the main factors (of hallucinations) are neurotoxic substances and abnormalities in dopamine and serotonin" (Chinese No. 22).

In addition, some other biological factors such as sleep deprivation (e.g., English No. 4, 22) and other medical conditions (e.g., fever, migraines, seizures, infections, brain injuries, dementia) (e.g., English No. 14; Chinese No. 13, 22, 24) were also mentioned as potential causes. Genetic influences (e.g., Chinese No. 1, 2, 10) and substance uses/misuses (e.g., English No. 22; Chinese No. 1, 6) were also mentioned in some websites. Interestingly, one website (Chinese No. 15) specifically discussed the differences between auditory hallucinations and tinnitus.

On the other hand, many English websites and some Chinese websites discussed the possible psychosocial causes of hearing voices. In particular, trauma and stress were the most commonly mentioned factors. Some examples include: "auditory hallucinations have been known to manifest as a result of intense stress" (English No. 1), "trauma or adverse life experiences" (English No. 2), "serious stress, as you might have after going through something traumatic, can cause hallucinations" (English No. 3), "if you have experienced trauma, your voices may be part of your way of dealing with this" (English No. 4), "environmental stress" (Chinese No. 2), and "childhood traumatic experiences may also result in hearing voices of the abuser" (Chinese No. 6).

It should be noted that both biological and psychosocial factors were commonly mentioned in the English websites, but only biological factors were commonly mentioned in the Chinese websites.

Psychotic disorders and trauma-related disorders as possible diagnoses for hearing voices

As shown in the literature, both psychotic disorders and trauma-related disorders can lead to hearing voices. However, in both language contexts, trauma-related disorders were rarely mentioned as possible diagnoses for hearing voices. Only 7 English websites briefly mentioned trauma-related disorders as possible diagnoses. For example, BPD and PTSD were mentioned in some websites (e.g.,

English No. 1, 2, 3, 9), while dissociative disorders were also mentioned in two websites (English No. 1, 11). Among the Chinese websites, only one website (i.e., No. 19) mentioned trauma-related disorders as possible diagnoses. In particular, this Chinese website mentions hysteria, which is now incorporated into DSM-5 (American Psychiatric Association, 2013) as dissociative and conversion disorders. No Chinese website mentioned anything about PTSD, BPD or dissociative disorders, although hearing voices is a well-documented symptom in patients with these trauma-related disorders.

In contrast, psychotic disorders were commonly mentioned in websites in both languages. Schizophrenia and bipolar disorders were the most mentioned diagnoses (e.g., English No. 1, 2, 3, 4, 6; Chinese No. 1, 2, 5, 7). Some examples include: "the condition (auditory hallucinations) is often a hallmark of psychosis, occurring in an estimated 60 to 70 percent of people with schizophrenia, and in a subset of those diagnosed with bipolar disorder" (English No. 6), "(hallucinations and hearing voices are) common in people with schizophrenia... hearing voices in the mind is the most common type of hallucination in people with mental health conditions such as schizophrenia" (English No. 7), "hallucinations are one of the common symptoms of mental illness, are most commonly found in patients with schizophrenia, and may also occur in patients with major depressive disorder, manic disorder, and alcohol intoxication after drinking..." (Chinese No. 7), and "hearing voices... is a common symptom of psychiatric patients, especially in those with schizophrenia" (Chinese No. 17).

Biological and psychosocial interventions as treatment options for hearing voices

As mentioned, emerging studies have revealed the benefits of using psychosocial interventions to support people who hear voices. Psychosocial interventions were more commonly discussed in the English websites than in the Chinese websites. Many English websites discussed psychosocial interventions as treatment options, but not many Chinese websites provided such information. For example, cognitive behavioral therapy (CBT) was commonly mentioned among the English websites (e.g., English No. 1, 4, 5, 8, 9, 10, 11). Psychosocial support (e.g., hearing voices groups or support groups, family interventions) was also discussed in some websites (e.g., English No. 4, 11, 13; Chinese No. 4, 8, 9). Some other contents include: "art or creative therapy" (English

No. 4), "humming or singing a song...listening to music" (English No. 8; Chinese No. 10), and "(learning) coping strategies" (English No. 8, 10; Chinese No. 7, 20).

On the other hand, it is interesting to note that biological interventions were more commonly mentioned in the Chinese websites than in the English websites. Medication treatments were the most discussed biological interventions for hearing voices. Some examples include: "to encourage the patient to take the medicine, we can explain to them, 'the medicine can regulate the endocrine of the brain'" (Chinese No. 12), "following the doctor's instructions, antipsychotic medications can effectively reduce the interference caused by the hallucinations" (Chinese No. 7), and "the primary means of treating auditory hallucinations is antipsychotic medications which affect dopamine metabolism" (English, No. 1). In addition, some websites also mentioned transcranial magnetic stimulation (TMS) (e.g., English No. 6, 9, 10) and electroconvulsive therapy (ECT) (e.g., English No. 9; Chinese No. 2).

Discussion

As highlighted in the introduction, there is a substantial literature showing that the psychosocial aspects of hearing voices should not be ignored (Cooke, 2014; Moskowitz, Schafer, & Dorahy, 2011; Read & Dillon, 2013). This includes studies documenting the etiological roles of psychosocial factors in hearing voices (e..g., Daalman et al., 2012; Read, Fink, Rudegeair, Felitti, & Whitfield, 2008), studies indicating the link between trauma-related diagnoses and hearing voices (e.g., McCarthy-Jones & Longden, 2015; Moskowitz et al., 2017), and studies showing the benefits of psychosocial interventions for hearing voices (e.g., Hazell, Hayward, Cavanagh, Jones, & Strauss, 2018; Zanello et al., 2014). However, our preliminary findings showed that the psychosocial aspects of hearing voices are relatively less emphasized on the Internet, which is probably one of the most accessible sources of health information today – it is estimated that one in three adults in the United States uses the Internet to learn about a health-related issue (Jacobs, Amuta, & Jeon, 2017). The English websites do not adequately mention trauma-related disorders as potential diagnoses for

individuals hearing voices, but there is a balanced discussion regarding the causes and treatment options. The situation in the Chinese context is much more problematic. Most Chinese websites fail to acknowledge the psychosocial aspects of hearing voices, indicating that the reviewed Chinese information is more outdated and biologically oriented.

This preliminary review has several limitations. For example, we did not judge whether the online information is "correct" because there are still many debates and much mixed evidence in the literature. Moreover, the search results may be affected and shaped by users' previous Internet behaviors. However, we made the first attempt to review the most accessible English and Chinese websites from a layman's point of view and examine whether biological and psychosocial aspects of voice-hearing experiences were equally acknowledged. The reviewed websites were reasonably representative of the online information for laymen in the two language contexts. There are significant implications for mental health practitioners and researchers.

First, regarding the imbalance between psychotic and trauma-related disorders as potential diagnoses for individuals hearing voices, the information in the websites may reflect the fact that the close link between trauma-related disorders and hearing voices is still not well recognized, even in the English context. This may result in delayed psychosocial interventions for people who hear trauma-related voices because whether trauma therapies are offered usually depends on whether the practitioner regards the voices as trauma-related and dissociative in nature, which is in turn related to whether the practitioner makes a post-traumatic or a psychotic diagnosis (Moskowitz et al., 2009; Ross, in press). It should be noted that the use of biomedical interventions (e.g., antipsychotics) for trauma-related dissociative voices may result in unnecessary side effects. More efforts should be made to teach not only the public but also mental health information providers about the scientific literature regarding the relationship between hearing voices and trauma-related disorders. This is particularly important because hearing voices may in fact be a stronger indicator of trauma and dissociation than it is an indicator of a psychotic disorder (Laddis & Dell, 2012; Ross et al., 1990).

Second, the overemphasis on the biological aspects and underemphasis of the psychosocial aspects of voice-hearing experiences on the Internet, especially in the Chinese context, may result in

further stigmatization. In fact, even the website of the National Alliance on Mental Illness (NAMI) (the largest patient support organization in the United States; https://www.nami.org/About-Mental-Illness/Mental-Health-Conditions/Schizophrenia) provides only biological causes for schizophrenia and no psychosocial causes, although this was not included in our review. Some studies have shown that education emphasizing psychosocial factors for mental health problems can reduce stigma and produce more prognostic optimism (Farrell, Lee, & Deacon, 2015). On the other hand, belief in the biomedical model may produce more prognostic pessimism (Gershkovich, Deacon, & Wheaton, 2018). In order to reduce the stigma related to mental health problems – including hearing voices – in the community, education regarding the psychosocial aspects of voice-hearing should not be disregarded (Longdon & Read, 2017). Moreover, information providers should consider using more real-life stories (e.g., human books) (Chan, 2019a, 2019b) to demonstrate how life experience can be related to voice-hearing experiences, which may help improve social inclusion and reduce prejudice.

Third, our preliminary review shows that there are considerable differences between the English websites and the Chinese websites, although the relationship between psychosocial factors and hearing voices may be occurring cross-culturally (Fung et al., 2020; Fung, Liu, & Ma, 2019). The Chinese websites overemphasize the biological aspects and fail to acknowledge the psychosocial aspects of hearing voices. As the authors have observed, the biomedical model still dominates the mental health field in the Chinese context, which is also consistent with our present findings. This implies that mental health information concerning voice-hearing in the Chinese context may need to be updated in order to reflect the emerging evidence in the literature. Future studies should investigate how the biomedical model affects mental health stigma in different cultures, and whether emphasis on the psychosocial aspects could also reduce stigma in the Chinese context.

Concluding remarks

The recent literature has provided strong evidence supporting the view that the psychosocial aspects of hearing voices should receive proper attention. This preliminary study reviews whether online information about voice-hearing experiences equally covers the biological and the psychosocial aspects. While the psychosocial aspects are adequately mentioned in the English websites, the

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Chinese websites fail to acknowledge the psychosocial aspects of hearing voices. Implications for mental health information and service providers are discussed. In particular, online mental health information concerning voice-hearing in the Chinese context should be updated and the psychosocial aspects should be acknowledged. Mental health information providers in both language contexts should be familiar with the scientific literature regarding the relationship between hearing voices and trauma-related disorders too.

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