

Empathear: A designed system to simulate auditory hallucinations

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Abstract. This design case presents the process to develop Empathear, a system that simulates the experience of “hearing voices”. Hearing voices can be a symptom of mental illness such as schizophrenia. The voices can affect greatly the life of voice hearers. Empathear aims to show family members a part of the experience their loved ones live everyday, with the goal of creating the conditions for empathy. Empathear consists of a wearable device that records environmental noise and wirelessly plays voices that react to the environment through subtle earphones. An App was developed with the same capabilities as the scarf. Initial testing with families of people with schizophrenia and assessments by the Supporting Families Organisation New Zealand indicate that Empathear can be a helpful tool for creating a better understanding of hearing voices.

Keywords. Industrial design, design for other abilities, app design, schizophrenia, hearing voices

Introduction

Hearing voices is a symptom common to people with schizophrenia and other mental conditions[1]. This symptom affects the schizophrenia sufferers and also the people around them. It can debilitate family relationships, in particular when family members do not know what it is like to navigate through everyday activities while hearing voices.

Since the 1960s there has been a shift from hospital care (undertaken by professionals) to home care undertaken by family[2]. This shift has caused family members to actively seek out information about their loved ones’ illness. Studies show siblings play a long-term role in their loved ones’ life, often taking over responsibility when parents pass on[3],[4].

This project suggests a design that simulates hearing voices. Its goal is to facilitate empathy and promote constructive family relationships. The system intends to improve the level of understanding of the effect mental illness has on a sufferer’s daily ability to function by giving family members the opportunity to witness first-hand their own reaction to hearing voices. The system was designed by Sarah Mokhtar as part of her Masters in Design Innovation at Victoria University of Wellington, supervised by Dr Edgar Rodriguez. Sarah’s sister is a voice hearer.

The specific audience that this design addresses is the families of people who suffer from auditory hallucinations. This is an interesting case study for Universal Design, which has the main goal of allowing access to the designed environment to as

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many people as possible. We raise the question of whether it is possible to define the “Universal” population as all of those who are likely to use the design. In this case, the design should allow universal access to all members of the families of people who hear voices.

1. Background

Symptoms of schizophrenia and other mental conditions frequently include psychotic manifestations, experiencing visual hallucinations and/or hearing internal voices[5]. This research concentrates on the symptom of auditory hallucinations or “hearing voices” as hearing voices is the most common hallucination among people with schizophrenia[6].

Within the past year, 20% of the population has experienced some form of mental illness[7] and around 24 million people diagnosed with schizophrenia worldwide[8]. Ralph Hoffman[9] of Yale university, states that around 70% of those with schizophrenia hear voices, meaning 16-17 million people hear voices worldwide. It is believed that between 3-5% of New Zealanders hear voices but only around 1% is diagnosed with an illness[10]. Hearing voices is not isolated to schizophrenia. Those with bipolar disorder and depression can experience voices. Voices can also be heard by people who are ‘healthy’ and do not require a diagnosis of mental illness[7].

Hearing voices can vary from one person to the next. The experience of hearing voices is not as alien as it is generally thought to be. Voices can often sound the same as a normal voice (or a physically exterior sound) through your ears. Neurological scans have demonstrated that the brain generates apparent voices in the right temporal lobe which are then “heard” or processed by the left side of the brain. Somewhere in this process, differentiation between ambient and internal voices is lost[11]. This confusion can be very disconcerting for many people when hearing voices for the first time. The content of voices can vary, with some experiencing very stressful loud and angry voices, others hearing voices with calming and motivating personalities and, most commonly, hearing sounds and undistinguishable whispers[7].

Research shows that families are consistently frustrated at the lack of information given to them by clinicians[3]. If families are expected to take on the role of caregiver (a role that historically has required a very high level of education) then useful information should be made readily available to them at the beginning of the enquiry into their loved ones’ illness[3]. When families want to get involved, often they have not been given tools to support and promote an active recovery of their loved one[3]. The Hearing Voices Workshop (HVW) is one of those existing tools, but it has its limitations.

1.1. The Hearing Voices Workshop

The HVW is a three-hour experience where each participant is given various tasks to do individually, for instance math and English questions, while listening to a looped recording of voices through headphones playing off an MP3 player. The workshop demonstrates the distraction that hearing voices produce when trying to concentrate on tasks in a controlled environment. In order to make this system available to as many people as possible, towards a Universal Design approach, there are some aspects where technology can help. The looping of tracks means the voices do not adapt to the users’

environment and after a time they become predictable and can be blocked out by the listener. Also, the workshop provides minimal time spent interacting with the general public, a task that is known to be very stressful while hearing voices. The facilitators of the workshop have expressed their desire to offer this workshop over a longer period of time and in public spaces to a wider audience. We suggest a design that can help the HVW address these issues.

1.2. Empathy

The literature defines several types of empathy. The first type is called “cognitive empathy”. A person with this type of empathy is said to be able to know how another person feels and what they might be thinking. The second type of empathy is called “emotional empathy” where the affected responds to another’s perceived emotional state by experiencing feeling of a similar sort. Emotional Empathy makes someone well-attuned to another person’s inner emotional world”[12]. The final type “empathetic concern” requires having a positive regard or a compassionate concern for the other person - to not only understand a person’s predicament and feel with them, but also be spontaneously moved to help, if needed[12]. An undesired effect that can occur through experiencing empathy is “personal distress”. Personal distress can happen to people when the empathetic experience they are having is so close to the other person’s condition that they begin to lack the ability to manage their own distressing emotions, leading to psychological exhaustion[12]. Personal distress can cause indifference, rather than well-calibrated caring. The type of empathy this research addresses is empathetic concern.

1.3. Design review

We searched for existing designs that intend to address mental illness, illnesses in general through wearable devices, and empathy. The WhiSpiral [15] is a shawl that allows the user to record short messages that can be replayed later as whispers to the next user (friends and family) upon touching and caressing specific areas of the fabric. It explores how we can enhance the way we evoke memories of loved ones.

“Jerry” from Childs Play gives its user (children with type 1 diabetes) the ability to look into their own illness and learn how to manage their condition. Jerry also elicits empathy in its user and with this an added sense of responsibility[14]. Jerry is said to “empower children with a chronic illness to take control of their own disease,”[14]. Together with the “Therapeutic Robots”[15] developed in Japan for the elderly, they have had great success in helping improve the lives of their target audience.

Apps for those with mental illness have been developed recently. The “Pause Emote” helps diagnose and treat patients with mental illnesses, allowing them to document their life as it is happening. Its aim is to aid in communication between the user and their psychiatrist [16]. Another app helps people with schizophrenia block the unwanted voices they hear, training them to focus on other sounds[17].

1.4. Stigma

For voice hearers and their families, we can divide the stigma into three distinct types: Society view, family self-stigmatisation and sufferer self-stigmatisation[18]. The key to addressing the negative feelings family experience towards their loved one is to change

their perspective on the illness. In other words, addressing the stigma family harbour towards hearing voices and create a positive path that allows them to let go of the negative feelings surrounding mental illness.

1.5. Persona

The persona most likely to affect positive change patients with schizophrenia are female siblings[4]. Sibling relationships are unique in that they are long-lasting and involve common social, genetic and cultural heritage. Research shows that “siblings provide more support when parents are not available, with sisters generally providing more care than brothers”[4].

Research has shown that case studies that interview siblings of voice hearers use similar criteria's for their recruitment processes. Barnable et al[19] describe most of their participants as having relatively frequent contact with their affected sibling. This research also recognises that, like with most illnesses, early intervention can greatly impact the recovery rate. As most schizophrenia diagnoses happen in the age range of 16-25 years old [20] we can assume that most siblings of patients will fall into this same age bracket. With this in mind we can surmise that it is logical to produce a persona that reflects female siblings of a young, tech savvy age group. Our design will address first the persona that is more likely to engage with the design. The learnings from this initial target group will be used to target harder to convince personae, for instance male siblings. This follows the persuasion principles of first addressing a target audience that is willing to comply[21]. The following stages would be to make the design more Universal according to the initial findings.

1.6. Criteria

According to the research above, we have identified a series of design criteria. The design should:

- simulate a voices experience as similar as possible to that of the voice hearer's real world experience
- provide an easily accessible experience that can be used by families at home when they require it
- target close family members, in particular siblings
- be managed by professionals. In this case, the Hearing Voices Workshop will have custodian access to the device
- use female siblings as a positive force in recovery
- address the improvement of empathy and avoid personal distress
- reflect appropriate persona's aesthetic (gender, age, relationship to voice hearer)
- avoid stigma that could be related to it
- express a celebration of sibling bond

2. Final design

The final design consists of a wearable device with microphones and computer controller that sends environment-sensitive voices to earphones that the user can wear

throughout the day. This would increase accessibility to the experience offered by the Hearing Voices Workshop, which currently lasts only around 10 minutes. The system also includes a smartphone app through which the user can interface with the device and the clinicians can monitor its use. Figures 1-5 show precedent images and initial design experiments for the system.



Figure 1. Precedent images of inspirational designs.

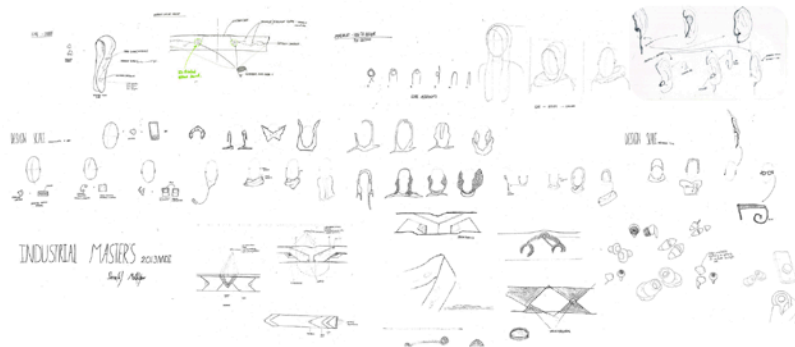


Figure 2. Sketches of different variations of wearable device and earpiece designs.

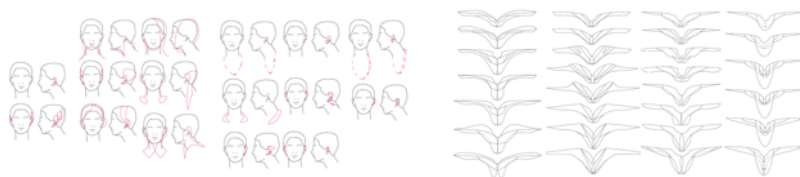


Figure 3. Explorations for earpiece design and of wearable device.



Figure 4. Explorations and pattern making process for wearable device.



Figure 5. Initial working prototypes of wearable device.

2.1. The wearable device

The wearable device consists of a scarf with embedded electronics that include microphones. The microphones can detect environmental noise. The computer processes the noise and defines whether it is a loud and stressful environment or quiet and calming. The computer sends a Bluetooth signal to the earphones, playing voices that respond to environmental conditions. The voices are also presented in randomised orders. The voices are recorded according to the hearing voices script used by the hearing voices workshop[22].

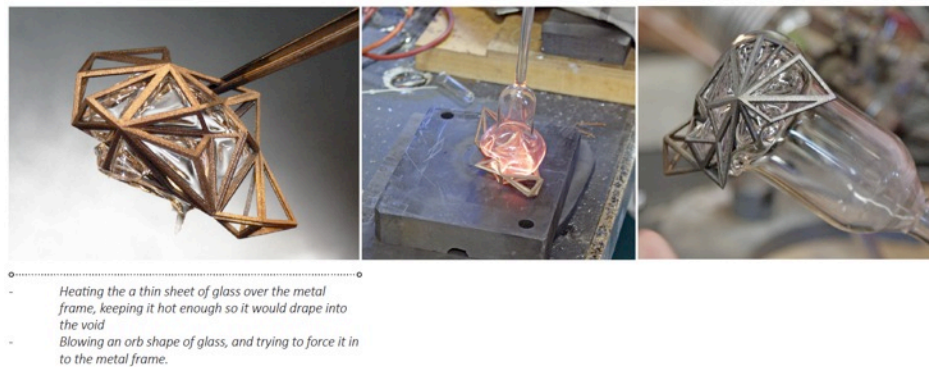


Figure 6. Experiment to create a glass housing for electronics inside the 3D printed pieces. The intention was to play with jewellery elements that would increase the beauty of the garment.

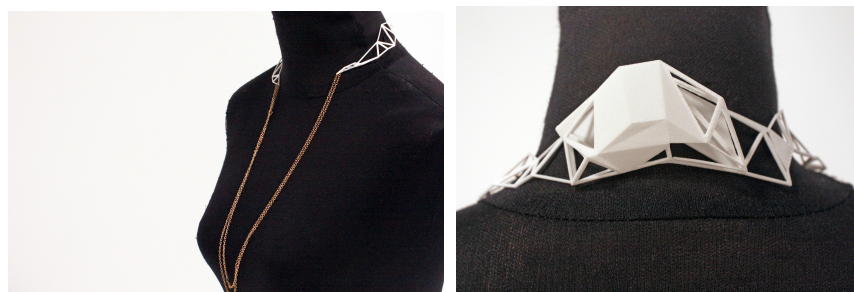


Figure 7. Final design for neckpiece wearable device that will house the electronics and microphones.



These images exhibit the exterior make-up of the third iteration and the two different ways the garment can be worn.

Figure 8. Final design of wearable garment with electronics embedded and subtly exposed.



Figure 9. Final design of wearable device. Showing subtly the electronics casing and the earphones as jewellery.

2.2. The earpiece

The earpiece consists of two parts: 3D printed earbuds for the mini speakers, and a jewellery like neck-piece that houses the bluetooth receiver. White wires connect these two elements as seen in the images provided. The earpiece was intentionally designed to be separate from the wearable scarf to allow siblings the opportunity to take the scarf off if needed (in hot weather etc) but still have a voices experience.

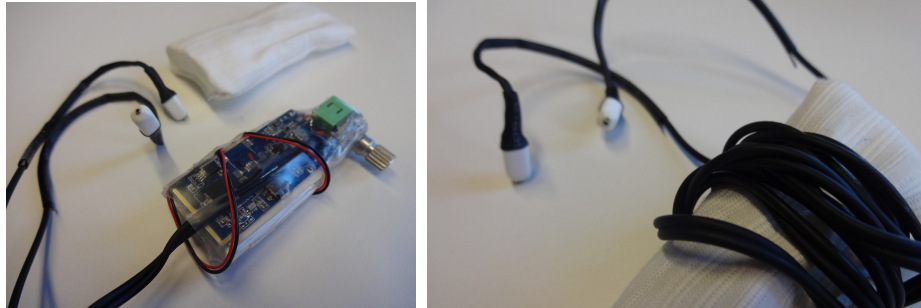


Figure 1. Working prototype of earpiece that was used for user testing.

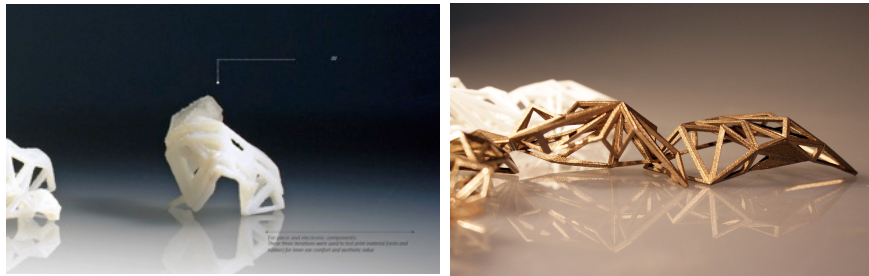


Figure 1. Experiment of 3D printed earpiece based on a 3D scan of an inner ear, and experiments 3D printed in metals.

2.3. *The app*

The App was developed in response to the durability issues, accessibility issues and production costs of the wearable technology scarf. Another important factor that lead to the App was to ensure that this voices experience could be accessible to a wider audience and therefore have the ability to affect constructive positive change in families all over New Zealand. With this wide audience across the country, small communities could start to bring down the barriers of stigma and discrimination. With more understanding comes more acceptance, therefore a development towards affirmation and amenity is surely a possibility.

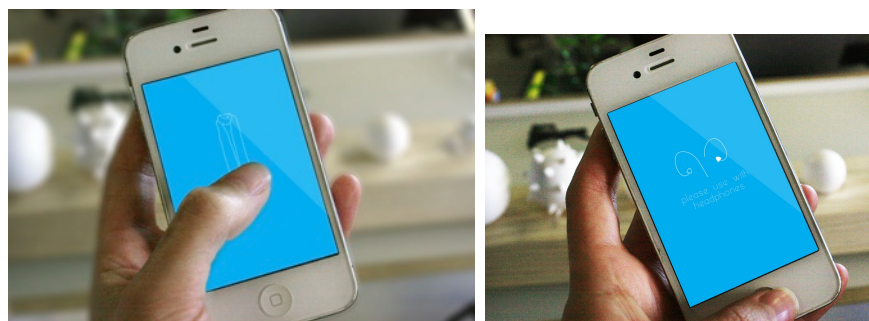


Figure 1. The computer App interface aesthetic was to be basic, light hearted in nature and exude hope. Ideally, it would not look like most health related Apps and allow the user and families to become light hearted in their approach to interacting with it.

App criteria and specifications:

- Simple layout for interface
- Allow the user to change volume, frequency of voices according to environment and how it listens to the environment.
- Allow family member more flexibility with their voices experience
- Have live questionnaires that clinicians and support workers can view afterward and tailor their support towards case specific needs.
- Accessible to a wide audience in multiple locations
- Not require constant maintenance for wear and tear

3. User testing

We tested the design during Schizophrenia Awareness Week in Nelson, 2014, with the Supporting Families in Mental Illness Group. The testing revealed that participants (n: 4) gained great insight and value from their voices experience. Participants were enthusiastic when talking about the App and its goals and their own growing personal interest in their family member and how they cope with voices.

The data analysis has produced four common themes expressed by participants interviewed.

- Distraction and concentration
- Personal adaption into a progressive experience
- Empathy and appreciation
- Positivity for the future

All participants commented on the great distraction the voices provided and how they had strained to concentrate on the conversations of those around them. Participants found the voices were not only, at times, disturbing in content but also inhibited them in social situations, preventing them from participating in everyday family conversations.

All participants attested to the change in empathy they felt within themselves but they also all recognised that this voices experience was a generalised mimic of the schizophrenia. Participants expressed that while this app was not a full, true experience of auditory hallucinations, just a small taste of what hearing voices could be like in their everyday lives, was better than not having experienced it at all. One participant identified that, while they have the privilege of going back to their normal lives their family member did not have the luxury. All participants' agreed that they cannot imagine living every day with voices in their head.

Two of the participants spoke specifically of their new curiosity towards exploring and creating situations that would lead them to talking to their loved one about the voices they hear. Three participants alluded to their positive attitudes for the future development of their relationship with their loved one.

This App has given these siblings the ability to assess situations in a constructive and informed manner, using their new found knowledge as a key to affect positive change in their loved ones life. Stalberg, Ekerwald & Hultman[4] acknowledged that 'care giving' is recognised as a positive coping technique, which helps siblings create better relationships with their affected love one.

3.1. Universal design

We assessed how the design fulfills the principles of Universal Design according to NC State University[23].

1. Equitable use. To ensure the users are not at risk of segregation or stigma during the voices experience, the app was developed to integrate into everyday wear and be in use while undertaking daily activities. All information gathered by the app is safe-guarded by password, available only to the Supporting Families in Mental Illness New Zealand group. This information is used to tailor support towards the user after their voices experience. The physical garment 'scarf' was developed to embody the celebration of sibling bond, allowing the user to reveal its beauty and wear the garment as a statement of pride.
2. Flexibility in use. The app provides flexibility of use by allowing the user to choose the types of voices they hear, the intensity of the voices and the frequency in which they wish to use the app. Each user can tailor their voices experience to their personal tolerances.
3. Simple and intuitive. The interface design of the app is simple, with minimalistic icons. It provides an intuitive process, which allows the user to self-select tracks, creating a personalised voices experience. While the icons for gender and temperament do have English titles, the app icons are universal, allowing people from different ethnic backgrounds to understand how the app functions.
4. Perceptible information. The App relates to this criterion by instructing the user on how to activate the voices. The icons for gender and temperament have titles for more clarity of their functions. Once voices are chosen, the app displays a screen telling the user to wear headphones during use.
5. Tolerance for error. The App addresses this criterion in four ways.
 - Upon turning on the app the user is given an overview of what the app does.
 - They are then asked to read and agree or disagree to the conditions of use.
 - If they agree, the app then asks for a name and contact details if they wish to be provided with a follow up service from the support community. This service is intended to include personalized support if they were to feel distressed by their voices experience.
 - Once the user has followed the app through to the final screen (chosen gender and temperament) the app tells the user to discontinue use if feeling overwhelmed during the experience.
6. Low physical effort. Apps are not physically demanding, requiring only a few taps of the screen to activate. Although the app does not require much physical strength it does incur a level of mental strength. To minimize the risk of personal distress, the user is encouraged to experience only as much as they can personally handle.

7. Size and space for approach and use. Physical space is not an issue for digital apps. More pertinent is the app's ability to operate on a range of cell phone types. The app was developed for both IOS and Android phones - the two dominant smartphone platforms.

4. Conclusion

This paper presents the process followed in the design of Empathear. The designed system intends to elicit empathy in family members of people who hear voices due to mental illness, normally schizophrenia. The design consists of a wearable scarf, an earpiece and a smartphone app.

Initial testing with family members of voice hearers and with the Supporting Families organisation in New Zealand indicates that the system helps users understand their loved ones better.

It is important to note that the system does not claim to offer a full experience of what it is like to suffer the symptom of hearing voices. It only offers a simulation of hearing voices. There is the risk that some users may assume they have experienced what an actual voice hearer's life is like. It would be impossible to achieve a simulation that would show us fully what it is like to live hearing voices without having the condition. Nevertheless, the Supporting Families organisation adamantly believes that it is better to offer some level of simulation than to avoid the issue altogether. As the testing has shown, siblings and family members understand that they cannot possibly know what it is like to live with the condition. However, they can understand some small but important aspects about their loved one. For instance, they can understand that their family member is sometimes distracted, and with good reason, by the voices. Participants are now more patient with them, having had at least a small taste of what their loved ones have to live with everyday. For these reasons, it is important that the release of this design and its app are well monitored by professionals in the area, in this case the Supporting Families organisation.

Universal design requires that designs are as accessible as possible to people with many different abilities. This design started with the intention to address a very specific segment of the population: female siblings of voice hearers. This paper is a case study that can help the Universal Design discipline to investigate how we can design for specific populations first and then make those designs more Universal. This approach raises questions. Should we start our designs with Universal principles in mind? What kind of problems can we address by trying to offer a solution to specific populations first? If the problem is meant to address a very specific issue that only relates to a very specific segment, how Universal should it be made? We suggest that if the problem is very specific, the design should still consider Universal Design principles, in order to make it as accessible as possible to that specific segment at least. Nevertheless, the design can benefit from using Universal Design principles and may benefit populations beyond its original market. For instance, Empathear has been used by people who do not have voice hearers in their families, and they have expressed their surprise at the experience and their increase in empathy.

The design has been very well received by the press and the Supporting Families organisation is using it as a prototype in New Zealand. There is still much work to do in the area of mental illness and designers have the opportunity to help our communities and our families maintain strong bonds that help support our loved ones.

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