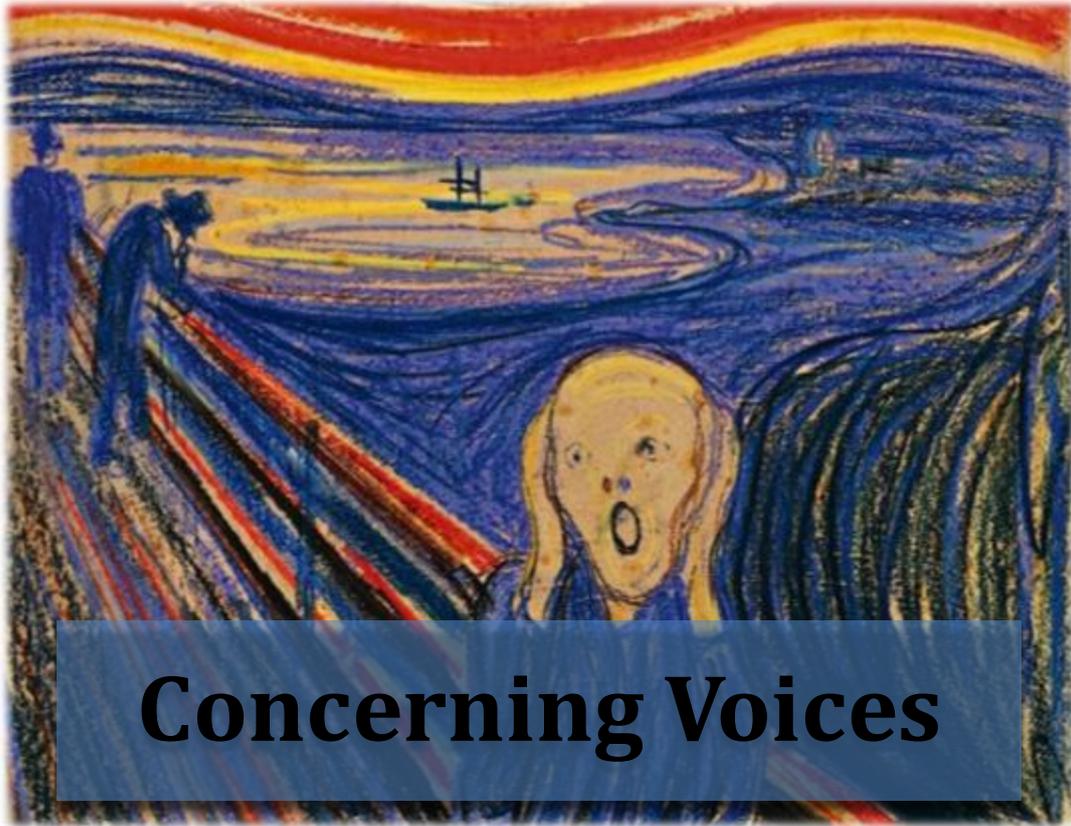


Master's Thesis
Medical Anthropology & Sociology



**An Anthropological Study 'at Home' on the Experiences,
Explanations and Agency of People who Hear Voices.**

Theodora Nicole Tatalas
Dorien.Tatala@gmail.com
Student nr. 0224049

Supervisor: **Marianne Vysma**
Second Reader: **Stuart Blume**

January 2013

University of Amsterdam
Graduate School of Social Sciences

Acknowledgements

I would like to thank all the participants in this research, without whom writing this thesis would not have been possible. Your openness has touched me deeply and your willingness to help me understand the experience of hearing voices has been a great source of motivation and inspiration. You have made my fieldwork a highly enjoyable and unforgettable experience, thank you! I sincerely hope that I have been able to do justice to your stories and that you will enjoy reading this thesis. I also want to thank the board of Stichting Weerklank for their help in my search for participants, and for letting me attend their – very informative – symposium on Hearing Voices.

Secondly, I would like to express my gratitude to Marianne Vysma and Stuart Blume. Thank you for your time and enthusiasm in supervising me, I hope you like the result of our joined effort.

Finally, I want to thank all my friends and family who have supported me throughout my student years. Marleen, Floor and Joozt deserve special mention for their help with the finishing touches to this thesis and for their mental, practical & technical support. This has been much appreciated, thank you!

Dorien Tatalas

Abstract

This research – an anthropological study ‘at home’ - examines what it is like to hear voices, how they are explained by the people who hear them and how troubling voices are dealt with. It explores the discrepancies between the dominant medical model and the lived experience of voicehearers in a contemporary Western context. Specific attention is paid to the perspective on hearing voices that is advocated by the Health Social Movement *Intervoice*. The core of the research data consists of fourteen in-depth semi-structured interviews, which were supplemented by online data collection through email and through the use of social media. Findings are presented and analyzed from three analytical angles: the individual body, the social body and the body politic.

Findings on the *individual body* suggest that the term ‘voicehearer’ is ambiguous; many participants describe experiences that go beyond auditory perceptions. The experience of hearing voices is phenomenologically very diverse, making it a highly complex and individual experience. The analytic level of the *social body* is used to illustrate how participants make use of a diversity of cultural repertoires while engaging in a process of theory-building. Their explanatory models are mostly *bricolages* that combine externalising and internalising explanations for what the voices are and why they present themselves. Finally, interaction with the *body politic* is examined by assessing to what extent participants accept or contest the dominant discourse and why they do so. Voicehearers in this study engage in biopolitics by actively working on sociocultural change through their work as experts-by-experience. They exercise *agency* on various levels; by becoming empowered over the voices (individual body), by actively raising awareness and fighting stigma (social body) and by seeking relief from the body politic through peer support in self-help groups and through the Intervoice community.

This thesis argues that voicehearers are *rational actors*; they adapt and dismiss explanatory models through a process of trial and error; different models are assessed pragmatically, philosophically and phenomenologically. Most of the participants in this research reject the biomedical explanation of hearing voices as a symptom of a brain disease. While explanations of the voices as spiritual or metaphysical beings are difficult to unite with the materialist paradigm of biomedicine, the Intervoice discourse is complementary rather than contradictory to such spiritual explanations. Intervoice is therefore a more appealing cultural repertoire for many participants in this study. The *narratives of transformation* in this thesis suggest that in dealing with concerning voices, psychotherapy provides a viable alternative to pharmacological treatment.

Table of Contents

Acknowledgements.....	3
Abstract.....	4
Table of Contents.....	5
1. Introduction.....	6
1.1 Irene.....	6
1.2 Intervoice.....	7
1.3 Research and thesis.....	9
2. Theoretical framework.....	11
2.1 The Individual Body.....	11
2.2 The Social Body.....	13
<i>Cross-cultural representations and explanatory models</i>	14
<i>Schizophrenia and its opponents</i>	15
<i>Media representations</i>	17
2.3 The Body Politic.....	18
3. Methodology.....	21
3.1 Research questions.....	21
3.2 Research methods.....	22
3.3 Methodological advantages, personal influence and biases.....	25
3.4 Ethics.....	28
3.5 Analysis.....	31
4. Introduction of participants.....	32
4.1 Gender and age.....	33
4.2 Living situation, income and education.....	33
4.3 Residence and cultural background.....	34
4.4 Psychiatric history.....	34
4.5 Intervoice & experts-by-experience.....	35
5. Experiences of hearing voices.....	36
5.1 Diversity.....	36
5.2 Problematic categories, paradoxes and ambiguity.....	38
5.3 Concerning voices.....	42
5.4 Narratives of transformation.....	44
6. Explanations for hearing voices.....	48
6.1 Explanatory models.....	48
6.2 Bricolages and rational actors.....	50
6.3 Research narratives.....	54
6.4 The biomedical model.....	57
6.5 Intervoice as a cultural repertoire.....	59
7. Agency of voicehearers.....	62
7.1 Accepting the biomedical discourse.....	62
7.2 Cultural relativism and rejection of the biomedical discourse.....	65
7.3 Intervoice and agency.....	67
8. Conclusion and personal reflection.....	72
8.1 Conclusion.....	72
8.2 Personal reflection.....	75
References.....	78
Appendix 1: Call for participants (in Dutch).....	84
Appendix 2: Interview topic-list (in Dutch).....	85
Appendix 3: Call for participants in Klankspiegel (in Dutch).....	86
Appendix 4: Terms-of-participation for Facebook group.....	87
Appendix 5: Online interview questionnaire.....	88
Appendix 6: Instructions for email interview.....	90
Appendix 7: Coding scheme.....	91

1. Introduction

1.1 Irene

At about 9 years of age I began hearing Master Ace, who was really aggressive and very abusive towards me [...]. By the time I was 19 he was ordering me to cut or burn myself regularly and calling me very vile names. By the time I was 22 he was claiming responsibility for all sorts of things - including a death of a friend, which he said he had done because I hadn't killed myself the night before. Once he started claiming he could do anything he wanted to anyone, including killing people, I was incredibly fearful and he was pretty much calling the shots.

When I was 19, I was admitted to hospital and that is when I began to hear Troublesome Companion. He lives inside my body and flies around inside me. When he first arrived he claimed he was the devil and that everyone around me were evil spirits that worked for him and were going to kill me. [...] He spends a lot of time screaming... blood curdling type screams. – Irene (26)

Irene has been hearing voices since she was a child. Her vivid description of the distress these voices caused her was selected as a prelude for this thesis for two reasons. First of all, in order to make the reader aware of the terror that voices can induce – and in doing so, to explain the title of this thesis. But more importantly, her narrative was selected because it resonates with me on a personal level, for it reminds me of one of my own clients¹; a young woman who is haunted by threatening voices and who, just like Irene, was diagnosed with schizophrenia. The psychiatric treatment this client is receiving hardly has any effect: in spite of the countless hospitalizations and heavy dosages of antipsychotic medication, the voices have never left her in peace. Seeing her struggle with the voices and being a frustrated witness to her suffering was the direct motivation to choose the topic of hearing voices for this Master thesis. While the medical anthropologist in me was curious to learn about other cultural interpretations and ways of dealing with voices, the caregiver in me was looking for a sign of hope in dealing with such existential suffering. Irene's narrative embodies both: after the medical road proved fruitless, she resorted to another approach in dealing with the voices. The treatment she now receives centres around understanding where the voices come from and on establishing a better

¹ I have worked in outpatient care for the past 5 years, first as a motivational therapist and currently in an assisted-living project.

relationship with them; they are still with her but they are now considered friends instead of foes. The work that Irene has done with her voices and her therapist is guided by the ideas of the 'Hearing Voices Movement' and 'Intervoice', which will be introduced in more detail in the following section.

Although this thesis will focus on the difficult experiences that voices can cause – and on the ways in which participants overcome these problems – it is important to mention that voices do not always cause suffering in the individual who hears them. An example of such a so-called 'healthy voicehearer' in this research is Peter (36). His voices have been with him as long as he can remember. They speak in gibberish and can cause a cacophony of unintelligible words, but they have never bothered him. They sometimes even inspire him – albeit in an indirect way – to write poetry. Like Peter, there are many voicehearers who never become psychiatric patients; epidemiological studies have estimated the lifetime prevalence of auditory hallucinations in people without psychiatric illness to be between 10% and 40% of the general population (Verdoux & Van Os 2002, Waters 2010). Because they never present any problems, such 'healthy voicehearers' are generally not visible to mental healthcare. In this master thesis research, most participants *do* have a history in psychiatry. This was an unintentional result of the sampling process which led to a narrowing down of the original topic: what started out as a research about hearing voices evolved into a study [on] *concerning* voices.

1.2 Intervoice

In Western societies most people who experience a dysfunction as a result of the voices they hear will become patients of the medical system. The medical specialist that deals with such complaints is the psychiatrist, who will label the experience as 'auditory hallucinations'. In the biomedical model, people who suffer from hearing voices are likely to be labelled with a psychotic disorder, of which schizophrenia is perhaps the best known and the most dreaded. An estimated 74% of the people who have been diagnosed with schizophrenia experience auditory hallucinations (Choong et al. 2007).

Patients that are considered to be mentally ill often do not agree with the illness label imposed on them by the medical world. They might deny that they

have problems altogether, or they have other explanations for the phenomena that psychiatry considers symptoms. In clinical terms, such patients are said to lack illness-awareness, which is in itself considered a symptom of mental illness.² From a medical anthropological perspective, the individual's rejection of the medical diagnosis indicates a discrepancy between the medical (or professional) discourse and the lived experience of people. Such discrepancies are expressed collectively by certain types of Health Social Movements (HSM). For example, there are deaf communities that do not see deafness as something that should be cured and are therefore opposed to cochlear implants (Blume 2000). Similarly there are autistic people who claim that autism should be regarded as a form of human variation, or 'neuro-diversity', rather than as a defect or disorder (Ortega 2009, Orsini & Smith 2010). Such claims to human diversity are also made by people who hear voices and who do not regard this as a symptom of a brain disease or mental illness. These people collectively identify themselves as *voicehearers* and together with healthcare professionals who oppose the psychiatric discourse they form the Hearing Voices Movement, or Intervoice³. This HSM advocates that hearing voices is not an abnormal or pathological phenomenon but rather a form of human variation, which involves coping rather than curing.

The Intervoice movement started with the Dutch foundation *Stichting Weerklank*, which was founded in 1987 by social-psychiatrist Marius Romme. The movement has grown significantly over the past decades and has local networks in over 20 countries worldwide. According to the Intervoice philosophy on hearing voices, the content of the voices is important because it often relates to the person's history and possible traumatic experiences. *What* the voices say

² According to the Diagnostic and Statistical Manual of Mental Disorders, the handbook of psychiatry, "A majority of individuals with schizophrenia have poor insight regarding the fact that they have a psychotic illness. Evidence suggests that poor insight is a manifestation of the illness itself rather than a coping strategy" (DSM-IV-TR, American Psychiatric Association 2000: 304).

³ The Hearing Voices Movement is the umbrella term for the movement, which formerly consisted of several local networks of voicehearers who were inspired by the same philosophy. In 1997 a formal organizational network was formed in which these local networks united: The International Network for Training, Education and Research into Hearing Voices (Intervoice). Intervoice provides administrative and coordinating support to the wide variety of initiatives in the different involved countries and it was incorporated in 2007 as a not for profit company under UK law (Source: website Intervoiceonline.org).

(i.e. name-calling, commenting on one's behaviour, accusations, threats, exhortations to hurt themselves) and *when* (i.e. continually or only in times of stress) is considered relevant; the Intervoice movement argues that it is important to listen to what the voices say and to work with them instead of trying to suppress them. This is in contrast to the mainstream psychiatric approach in which little attention is paid to the content of the voices, or in which patients are even discouraged to pay attention to what the voices say (Al Issa 1995: 371, Gagg 2002: 159, Beavan & Read 2010, Aschebrock et al. 2003). The following excerpt is taken from the Intervoice website and it summarizes their stance on the phenomenon of hearing voices. The emphasized segments indicate where the Intervoice approach differs from general psychiatric practice:

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

This alternative vision on hearing voices has attracted my attention and directed me to the Intervoice community for the recruitment of participants. It was in this context that I met Irene. Thanks to her psychotherapist, who treated her according to the Intervoice approach, Irene has learned how to be in control over her voices. The two voices that were introduced in the beginning of this chapter, Master Ace and Troublesome Companion, actively participated in my research: they communicated with me via their own Facebook account. Irene has picked up her life again and is currently enrolled in university. I can only hope that the client who inspired this research might have an equally bright future.

1.3 Research and thesis

This thesis is the result of a fieldwork period of three months, during which fourteen participants were interviewed and another nine participants were involved in the research through an online community. All of the participants currently hear voices, or have done so in the past. The majority of participants receive or have received psychiatric treatment and about two-thirds of my sample population are members or sympathizers of the Intervoice community.

The central questions on which my research is based are: 'How do people experience hearing voices, how do they explain this phenomenon and how do they deal with them?' By focussing on these questions, this research aspires to generate more insight into what it is like to hear voices and on how people overcome the problems associated with troubling voices. It also examines the explanatory models used by voicehearers themselves, and it intends to shed light on the discrepancies between the dominant medical discourse and the lived experience of hearing voices. This information is not only relevant for medical anthropologists but could also be used by mental-healthcare professionals to improve care and to bridge the gap between the experience-based knowledge of patient and the medical knowledge of the professional. Although countless studies have been done on psychosis and schizophrenia, there is no medical anthropological paper in which only the phenomenon of hearing voices – in a contemporary Western context – is studied. Therefore, this research is unique in that it deals with the subjective experience of hearing voices exclusively and it intends to fill a lacuna in social science literature. By focussing on the phenomenon of hearing voices instead of on the psychiatric category of schizophrenia, I place my research outside the assumptions of the medical paradigm and I take a cultural relativistic stance towards medical science in general, and psychiatry in particular. The subject of hearing voices will be studied from a medical anthropological perspective that looks at human experience in a sociocultural context.

The next chapter (2) will discuss the theoretical framework that guided my research and analysis; chapter 3 will describe the methodology and recruitment process in more detail. Before presenting my findings, a short chapter (4) will be dedicated to the introduction of my participants. Chapters 5 through 7 form the core of this thesis; they contain the findings and analysis of my research concerning voices. Each of these chapters correlates to a different analytical level: the individual body (5), the social body (6) and the body politic (7) - this analytical distinction will be further explained in the next chapter. The final chapter (8) will contain both a conclusive summary and my personal reflections on the outcome of this research.

2. Theoretical framework

In this chapter the theoretical framework that guides this thesis will be discussed and three analytical perspectives will be introduced. The first section (2.1) deals with the phenomenological approach that studies the lived experience of voicehearers; the second section (2.2) will discuss the cultural representations of hearing voices and it will introduce the concept of explanatory models; the last section (2.3) links the theoretical concepts of discourse and agency to the experience of hearing voices.

In their influential article, 'The Mindful Body', Scheper-Hughes and Lock (1987) suggest three analytical levels to study the body and mind in relation to sickness and health. The first level – the *individual body* – focuses on the lived experience of the individual and is approached from a phenomenological angle. The *social body* represents the second level of analysis, which examines how cultural norms and values can be deduced from the ways in which a society explains and expresses health and ill-health. This level is studied from a symbolic anthropological approach. Lastly, the *body politic* refers to the cultural forces and social structures that are used to control the individual body. This third body is studied from a post-structuralist approach, and it is 'the most dynamic in suggesting why and how certain kinds of bodies are socially produced' (ibid.: 8).

This thesis follows the analytical division of the *three bodies*. Each of these levels corresponds to a chapter in the findings and analysis section. My reason for choosing this analytical approach is that it neatly corresponds to the questions I was interested to study and to the findings that resulted from these questions. 'How do people experience the voices?' naturally led to phenomenological descriptions; 'how do people explain the voices?' linked such personal experiences to sociocultural explanations (or the rejection thereof) and finally, the question 'how do people deal with voices?' shed light on power relations and agency – of the voicehearers vis-a-vis the dominant discourse but also of the voicehearer versus his or her voices.

2.1 The Individual Body

The philosophical movement of phenomenology was developed in the beginning of the 20th century by the German scholar Edmund Husserl, as a reaction to objectivist

scientific ideology. Husserl criticized the objectivist gaze for taking the scientific world-view uncritically for granted. The alternative he proposed in phenomenology is that all knowledge – including scientific knowledge – is grounded in lived experience, which he called the life-world. Merleau-Ponty further developed phenomenological philosophy by adding the concept of *embodiment*. (Desjarlais & Throop 2011, Lindseth & Norberg 2004, Silverman 1980). According to Merleau-Ponty, the body is the basis for all experience and therefore an essential aspect in our life-world. He claimed that the life-world 'is constituted by means of the lived body's experience in interaction and communication with other people and things' (Kvigne et al. 2002: 62). The concept of *embodiment* has become a central concept in medical anthropology, and to elicit descriptions of the life-world of my respondents was one of the aims of this research.

Larsen remarks that there has been remarkably little attention for the subjective experiences of people suffering from mental illness (Larsen 2004: 47). His perspective is inspired by the *cultural phenomenological* approach as proposed by Csordas (1994) and by the anthropological discussions on *embodiment* that build on the ideas of Merleau-Ponty (1962). Larsen adopts an approach that 'integrates the experiential reality of the individual suffering from *mental illness* with their individual attempts to find meaning in first episode psychosis' (Larsen 2004: 451- italics mine). Contrary to Larsen, I explicitly avoided the term *mental illness* in studying the phenomenon of hearing voices: this category can be seen as prejudicial understanding that taints the understanding of the life-world of my respondents.

The work of Els van Dongen (1994, 1998 & 2002) is exemplary for medical anthropological research that *does* take the patient perspective into account. In her 'oddnography of mad people's work with culture' (2002), van Dongen writes:

I am not aiming at understanding madness, or schizophrenia. I try to understand culture through madness. The underlying question is: what can one say about a culture when one studies the stories and the lives of mad people. [...] Now, I must admit that madness taught me more about the power of culture and the power of people than about madness. (2002: 9)

My research resembles van Dongen's work in the sense that it deals with a topic which in our culture is linked with the domain of psychiatry. Van Dongen too, regards psychiatry as a cultural system which 'kidnaps' the stories of her respondents by transforming and reinterpreting them into medical stories (ibid: 25). With a few minor adaptations, the above citation suits my research on voicehearers: this thesis is not only about the

phenomenological experience of hearing voices but it also explores how the narratives of voicehearers relate to culture and power. This will be further explained in the section on the social body. There is, however, an important difference between van Dongen's topic and mine. Van Dongen's research was done on a closed ward of a psychiatric hospital; her respondents were severely disabled and chronically hospitalized. She refers to her respondents as 'mad people' and she studies their 'mad stories'. Although the term madness is used as an alternative to the medical term schizophrenia, I wish to avoid both. The connotation of the term madness with a state of disabling detachment from reality does not reflect the situation of my participants; their narratives do not qualify as 'mad stories'. In this thesis, I will illustrate that my participants are rational actors with non-ordinary experiences. Furthermore, their narratives suggest that to be called 'mad' is painful and stigmatizing: it is a form of 'othering' that I wish to avoid in this thesis.

2.2 The Social Body

The analytical level of the *social body* deals with the social and cultural *representations* of phenomena such as hearing voices. According to Nichter (2008), representations are 'meanings that are commonly shared by members of a social group' (ibid.: 4-5). The most pervasive representation of hearing voices is that it is a symptom of schizophrenia, which is considered a mental illness. This contrasts with the Intervoice representation, in which the voices are not symptoms but meaningful messengers. In order to study the representations used by my participants, I have operationalized the concept by focussing on the *explanatory models* that my respondents use to make sense and give meaning to the voices. In the following section I will highlight some cultural representations of hearing voices with the use of medical anthropological literature⁴. By showing diversity in cultural explanations for the phenomenon, I encourage the reader to take a cultural relativistic stance to the medical model: the biopsychiatric explanation is but one among many representations of hearing voices.

⁴ Since literature dealing exclusively with hearing voices is scarce, I also had to resort to sources that refer to the broader categories of psychosis, psychotic symptoms, mental illness, schizophrenia, madness and insanity. While these categories encompass hearing voices, they also include phenomena such as delusions, visual hallucinations and cognitive impairment. This again demonstrates the lacuna in social science literature when it concerns hearing voices.

Cross-cultural representations and explanatory models

Hearing voices can be an expected response that falls within the cultural norms of a particular group. Kleinman (1987) illustrates this with the example of mourning American Indians who hear the voice of the deceased person during the first month of grieving. 'Hearing the voice of the dead is an expected experience in bereavement among a number of American Indian tribal groups; this experience does not portend psychosis or other abnormal complications of bereavement' (Kleinman 1987: 453).

It is not uncommon for people to have more than one explanatory model to explain misfortune of illness; Nichter (2008) refers to this as *multiple causality*. This concept also applies to the research of Saravanan et al. (2007) on belief models of schizophrenia in South India. One-fifth of the respondents 'held more than one model as an explanation for their psychosis' and the authors emphasize that folk beliefs are 'not stable but dynamic, complex, shifting entities.' (Saravanan et al. 2007: 449). Another common finding in cross-cultural studies on schizophrenia is that participants from non-western cultures attribute schizophrenia to spiritual and mystical factors: the explanatory model of possession is common in many parts of the world (Helman 2001 [1984]: 172-173, Kleinman 1991 [1988]: 123, Castillo 2003: 14-15, Betty 2005: 15-16). Saravanan et al. report that, in India, the folk causes that were reported most were 'black magic and evil spirits' (Saravanan et al. 2007: 448). Betty (2005) illustrates that belief in spirit possession is not limited to Third-world countries. He introduces an American psycho-therapist who treats mental illness as possession. According to the author, he is not the only one. (Betty 2005: 25)

Of course, 'Western culture' is not a homogeneous entity. One of the variables that contribute to the heterogeneity of 'the West' is the diversity in ethno-cultural backgrounds of the population. In their study, Carpenter-Song et al. (2010) explore how the understanding of mental illness – in the United States – varies along ethno-cultural lines and how these explanatory models influence the response to mental health services. In this study, the European-Americans were most aligned with the biomedical explanatory model and therefore most compliant in the use of medication. Among the Afro-American participants, 'explanations for problems included supernatural or demonological forces', and this group often voiced their frustration with the health professionals' focus on medication (Carpenter-Song et al. 2010: 237, 246).

Schizophrenia and its opponents

The representation of hearing voices in the biomedical model is that voices – when they are problematic – are symptoms of a psychotic disorder⁵, which is a type of mental disease⁶. Of these psychotic disorders, schizophrenia is the most severe and therefore perhaps also the most well-known and stigmatized.⁷ In this representation of hearing voices, the illness that causes the voices is regarded as treatable but incurable; the *positive symptoms* (hallucinations and delusions) can be suppressed with the use of psychotropic medication but there is not considered to be a solution for the *negative symptoms* (blunted affect, poverty of speech and lack of motivation); there is no cure to 'fix' the schizophrenic brain. Patients have to learn to live with a chronic disability, which involves taking medication for the rest of their lives in order to prevent relapse into psychosis. Although the exact aetiology remains a mystery to science, what is generally agreed on is that schizophrenia has a genetic base and can be triggered by environmental factors such as stress (Jobe & Harrow 2010, Kyziridis 2005, Read et al. 2004, Bentall 2003, Jablensky 2000). This representation of hearing voices is used by influential organizations such as the World Health Organization and the American Psychiatric Association and it is also the model taught to medical students: it is the model from the main diagnostic handbook for psychiatry, the Diagnostic and Statistical Manual IV (American Psychiatric Association 2000 & 1994, Jablensky 1992, Cohen et al. 2008, WHO 1979, Kyziridis 2005).

⁵ The medical dictionary defines psychosis as “a symptom or feature of mental illness typically characterized by radical changes in personality, impaired functioning, and a distorted or non-existent sense of objective reality. Patients suffering from psychosis have impaired reality testing; that is, they are unable to distinguish personal subjective experience from the reality of the external world. They experience hallucinations and/or delusions that they believe are real, and may behave and communicate in an inappropriate and incoherent fashion. Psychosis may appear as a symptom of a number of mental disorders, including mood and personality disorders. It is also the defining feature of schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder, and the psychotic disorders (i.e., brief psychotic disorder, shared psychotic disorder, psychotic disorder due to a general medical condition, and substance-induced psychotic disorder).” Source: medical-dictionary.thefreedictionary.com/psychosis.

⁶ The idea that healthy people can also hear voices has become accepted in psychiatry. Psychiatry therefore does not claim that voices are always a sign of pathology. However, when the voices are threatening and when they cause distress they are regarded as symptoms of mental disease. (Choong et al. 2007, Verdoux & Van Os 2001, Waters 2010)

⁷ Hearing voices – or auditory hallucinations, in psychiatric terminology – is a symptom of several psychiatric categories. This thesis will focus on the biomedical representation of schizophrenia because it is the diagnosis that occurred most in my research population. Furthermore, to go over all the biomedical representations in which auditory hallucinations are considered a symptom is beyond the scope of this thesis.

In spite of its dominance in the medical world, the concept of schizophrenia is contested – not only by patients but also from within the discipline of psychiatry. Dealing with mental illness is not the prerogative of biologically oriented psychiatrists: social psychiatrists, cognitive and clinical psychologists, psychoanalysts and transpersonal psychologists also operate within this field. As Luhrmann (2000) illustrates in her book 'Of Two Minds', the discipline of psychiatry is wrought by contradiction. She distinguishes two major paradigms in American psychiatry; one that is rooted in bioscience and focuses on pharmacological treatment, the other is based on psychodynamic assumptions and psychotherapeutic interventions. Whereas the latter paradigm is more social in orientation – because it is based on the potential healing effects of inter-relational dynamics – the biomedical paradigm is much more individual. Luhrmann acknowledges that pharmacological treatment can be effective for many people. However, she is very critical of the healthcare system in which pharmacological treatment is valued for its 'quick-fix' and in which psychotherapy is disregarded because it would be less cost-effective. Although Luhrmann writes about the American healthcare system, similar critical sounds exist about the economic stakeholders in mental healthcare elsewhere. Insurance companies and pharmaceutical businesses are important stakeholders in dealing with mental illnesses - their influence has also been said to taint the objectivity of scientific research programmes. (Sismondo 2007, Dehue 2008)

Academics who oppose the biomedical representation question the biopsychiatric 'fact' that hearing voices is a symptom of a brain disease, for which medication is the most effective treatment. Bentall (2003, 2011) argues that schizophrenia is neither valid nor reliable as a diagnostic category. He suggests abandoning psychiatric diagnoses altogether and proposes a 'complaint based' (or symptom based) approach to treating patients. He criticizes the biomedical model for not treating patients as rational agents and for not taking what they say seriously. Read et al. (2004) also criticize the concept of schizophrenia for its lack of scientific validity and reliability. The authors blame mainstream psychiatry for an overemphasis on genetic explanations, which according to them has led to the neglect of psychological trauma as a causal factor in the development of psychotic symptoms.

It is difficult to draw an analytical line between the social body and the body politic and to mark where one begins and the other ends. Rather than forming distinct

entities, these fields merge into each other; sociocultural representations – the domain of the social body – become political when such representations exert a certain amount of power and when they are contested. The dominant discourse on the biological causes of mental disease is not only pervasive in the medical world but also in other societal institutions, such as the media. The next section will explore the relation between the media and the biomedical representation of mental illness.

Media representations

In the media, the phenomenon of hearing voices is predominantly associated with violent crimes. By searching the newspaper archive with the key term ‘hearing voices’, one retrieves articles with headlines such as ‘murder-suspect hears voices’⁸. Countless other examples can be found of voicehearers who make local newspapers after having committed – or being a suspect of – a crime. Although such newspaper articles connect violence and crime to psychiatric disorders, the mentioning of hearing voices seems to have a sensational rather than educational function. Such articles give a simplistic suggestion of cause and effect: people are portrayed as having committed a crime because of the voices they hear, while an explanation for what the voices *are* remains largely unexplained.

Whereas newspaper articles on hearing voices are usually brief and superficial, the notion of the biological basis of mental disorders – and indeed of *all* human behavior – is receiving considerable media attention. According to Racine et al. (2010), much media coverage on neurotechnology is characterized by what they call *neuro-essentialism*: ‘a combination of biological reductionism and enthusiasm for neuroscience research’ (ibid: 728). In the Netherlands, this neuro-essentialism is reflected by the popularity of neuro-scientists like Dick Swaab⁹ – whose book ‘Wij zijn ons brein’ (We are our brain, Swaab 2010) is a national bestseller. Brain-scientists who write for a lay public – such as Swaab, Victor Lamme or René Kahn – often appear on television or in newspapers where they are consulted as experts on the biological basis of human behavior and mental distress. Lamme is currently writing columns for a major Dutch newspaper (NRC-Next) and Swaab has done so in the past; these neuroscientists have

⁸ “Moordverdachte hoort ‘stemmen’” – Algemeen Dagblad, 28-7-09

⁹ Dick Swaab is a professor of neurobiology at the University of Amsterdam and is associated with the Netherlands Institute for Neuroscience.

become public figures. Even though their neuro-essentialist view is often countered by other experts within the same media¹⁰, a close examination of the science sections in Dutch newspapers will confirm that brain-science is 'hot'.

The neuro-essentialist representation of schizophrenia in the media is reflected in headlines such as: 'New genes discovered that play a role in schizophrenia'¹¹ and 'Nerve cells with schizophrenic traits from a test tube'¹². The biological explanation of schizophrenia is also pervasive in media that are directed at improving public mental health. For example; the Dutch NGO 'Fonds Psychische Gezondheid' (Fund Mental Health) aims to increase mental health by raising awareness through public campaigns. Their information booklet on schizophrenia states that 'the basis of the disease is probably a disorder in the brain that already occurs before the sixth month of pregnancy'.¹³ This brochure appears as one of the first hits when searching for 'schizofrenie' on a search engine; it is likely to reach many people who are looking for help and explanations. These are examples of how the media play a role in promoting the view that human distress can be reduced to genes and brain activity. As a sociocultural institution, the media are involved in a dialectic relationship with the dominant discourse; shaping it while at the same time being shaped by it. The next section will further explore the concept of the dominant discourse and its dynamic interaction with cultural institutions.

2.3 The Body Politic

The analytical level of the body politic explores how the individual and social bodies are regulated, governed and in which way they become objects of surveillance; the body politic analyses relations of power (Scheper-Hughes & Lock 1987). The work of Foucault has been of great importance in this field. Foucault illustrates that in modern-day western societies, the nature of power has shifted from *sovereign power* (the power to take lives) to disciplinary or *biopower*. Biopower creates a *discursive practice* or a body of knowledge and behaviour that defines what is normal and what is deviant. The Foucauldian concept of power is not a coercive singular force, but a diffuse and

¹⁰ For example, by philosopher/physical Bert Keizer

¹¹ "Nieuwe genen ontdekt die rol spelen bij schizofrenie" – Volkskrant, 19-9-11

¹² "Zenuwcellen met schizofrene trekjes uit de reageerbuis" – Volkskrant 16-4-11

¹³ Translated from Dutch. Source: Information flyer 'Schizofrenie' by Fonds Psychische Gezondheid, freely downloadable from <http://www.psychischegezondheid.nl/schizofreniebrochure>

embodied concept; power is no longer yielded by autocratic rulers but it refers to the norms that are embedded in discourses and that cause individuals to discipline themselves without being forcefully coerced by others. (Foucault 1973, 1975, 1979, 1991). Closely related to the concept of biopower is Foucault's use of the term *biopolitics*, which involves 'the governing of ways of living through normative practice' (Nichter 2008: 152). According to Foucault, knowledge is both the creator and the creation of power, and discourse is the medium through which that knowledge operates. Therefore, studying power-relations entails studying discourses.

Biopower extends to many elements of our society, such as the educational system, the media, the criminal system and the realm of medicine. The discursive practice that deals with hearing voices is psychiatry, which is assigned the task of correcting such deviant experiences. Medical knowledge is attributed with a high degree of authority, and as a part of the medical system, psychiatry yields a significant amount of biopower. Although presently the medical discourse can be said to be the dominant discourse in dealing with troubling voices, this has not always been the case. Foucault describes how Western explanations for extraordinary perceptions, thoughts and behaviour changed over the centuries: what was explained as possession in the Middle Ages and as moral error in the 17th century came to be explained as a mental illness with the development of psychiatry in the 19th century (Foucault 1954). The dominance of the medical discourse should be viewed in connection with societal processes of modernisation and rationalisation, in which

[t]he disappearance of traditional cultural idioms for the expression of individual and collective discontent (such as witchcraft, sorcery, rituals of reversal and travesty) have allowed medicine and psychiatry to assume a hegemonic role in shaping and responding to human distress. (Scheper-Hughes & Lock 1987: 27)

According to Butin (2001), the work of Foucault has often been misappropriated by academics. The overemphasis on the oppressive and disciplinary nature of power leads researchers to commit three types of what he calls '*Foucauldian fallacies*: the negation of agency, the exclusion of the potential for resistance to domination, and the capitulation to radical relativism' (ibid.: 157). Butin argues that Foucault's work can also be used to study resistance within relations of power. Gaventa (2003) agrees with this notion and stresses that 'discourse can be a site of both power and resistance' (ibid.: 3). In order to avoid the pitfalls of the *Foucauldian fallacies* that Butin has pointed out, I will not focus

on the oppressive forces of biomedicine and medicalization. Instead, this thesis will examine how participants *resist* the dominant discourse and in doing so, in which ways they exercise agency within the existing power structures. This also resonates with my drive to find hope and optimism for voicehearers and to overcome feelings of powerlessness.

Discursive practices in society can be resisted by people who deviate from the sociocultural norms that are embedded in that discourse. When such protest is organized collectively, we speak of a social movement (Tilly 2004). In our recent past, collective protest has indeed instigated a modification of the body politic and a process of sociocultural change. Examples of such successful agents of change are the feminist movement and the gay-liberation movement; although it can be argued that, in some areas of society, the process of emancipation of women and homosexuals has not been completed, these movements have achieved a considerable shift in biopower. (Johnston & Klandermans 1995, Taylor & Whittier 1992, Jenness & Broad 1994, Noonan 1995) Social Movements consist of people who share a *collective identity*: 'the shared definition of a group that derives from members' common interests, experiences, and solidarity' (Taylor 1989).

A specific type of social movement has proliferated during the past decades, aided by the recent revolution in information technology such as the internet: the Health Social Movement (Allsop et al. 2004, Brown & Zavestovski 2004, Hess 2004). Intervoice is such a Health Social Movement, in which members' *collective identity* centres on a shared experience, rather than a disease category. One of its aims is to change sociocultural norms on hearing voices; this is reflected in the aim of de-pathologizing and normalizing the experience. It attempts to instigate sociocultural change by offering an alternative discourse. The Intervoice discourse on hearing voices cannot be seen as separate from the biomedical discourse: psychiatry is a product of western culture – and movements such as Intervoice try to emancipate the experience of voice-hearing from the discursive practice of psychiatry. Collectively, the members of the Intervoice movement engage in biopolitics. My research explores the ways in which individual voicehearers relate to the medical discourse; how they engage in biopolitics; and in which ways they exercise agency.

3. Methodology

This chapter will describe which methods were used during data collection and analysis. First my research sub-questions will be introduced (3.1), after which the fieldwork methodology will be described (3.2). In the third section I will reflect on the advantages and possible biases that are connected to my research methods (3.3). Ethical issues involved in this research will be the topic of the fourth section (3.4). Finally, this chapter will be concluded by a brief description of the analytical methods used. (3.5)

3.1 Research questions

The central questions that prompted this research are: **How do people experience hearing voices, how do they explain this phenomenon and how do they deal with them?** During the data-collection and analysis process, a set of more elaborate sub-questions crystallized. These sub-questions can be divided into three themes, each of which corresponds to a subchapter in the theoretical framework, as well as to a specific chapter in the findings and analysis section.

1) The individual body: the experience of hearing voices

- What is it like to hear voices?
- When does hearing voices become problematic?
- How do participants overcome such problems?

2) The social body: representations of hearing voices

- How do voicehearers themselves explain the voices?
- What is the appeal of the Intervoice representation of hearing voices?
- Why do people accept or reject the medical representation of hearing voices?

3) The body politic: biopolitics, discourses and agency

- Do participants accept or contest the medical discourse?
- How do participants exercise agency?

3.2 Research methods

Three methods for data collection were used during this research. The core of the data consists of fourteen semi-structured, in-depth interviews. This data was supplemented by two types of online data collection: through email and through the use of social-media. All of these methods will be described in more detail below.

Fourteen subjects participated in an in-depth, semi-structured interview. Although a topic-list¹⁴ was used to guide the interview, there was ample room to deviate from the questions in order to enhance the natural flow of the conversation. The interviews lasted 1.5 hours on average, and were done either at the participant's home or in a public place such as a café or a park. Participation in my fieldwork was done on a voluntary basis: none of the participants received a remuneration of any kind. All of the interviews were recorded and verbally transcribed; this resulted in over 300 pages of textual data.

Eight participants were recruited¹⁵ through my own social- and professional networks.^{16,17} The remaining six interview participants were recruited with the help of the Dutch branch of Intervoice, *Stichting Weerklank*. When I first emailed this organization with a request for their help in recruiting participants, they were helpful in suggesting how I could reach their members. My poster was placed on their website and a message was posted on their online forum. Before getting my call for participants published in their quarterly magazine, *de Klankspiegel*, I had to first gain the trust of the editors. They asked me to elaborate my initial introduction of myself by taking a stance regarding the psychiatric assumption that hearing voices is a symptom of a serious disorder, adding that they do not want to associate with people who promote such a view. After adding a paragraph about the relativistic nature of anthropology – in which I

¹⁴ See appendix 2.

¹⁵ My call-for-participants was a poster on which I introduced myself and my research topic. This poster was spread digitally in my social network with the use of social media such as Facebook, which resulted in the recruitment of five participants –all of whom are friends or acquaintances of someone in my direct social network. See appendix 1.

¹⁶ My professional network consists of the employees and clients of two out-patient mental healthcare locations of the Amsterdam-based healthcare organisation *Cordaan*. These are the locations where I have worked as a motivational and residential mentor during the past four years. Since I know the 'gatekeepers' to these locations personally, it was relatively easy to obtain access to these locations.

¹⁷ Both Cordaan locations printed my call-for-participants in their newsletter, and my poster was put up in the 'living room' area in both places. In one of the locations – the day activity centre where I used to work – an information afternoon was organized, during which clients could ask questions about my research. From this location I recruited one participant. The location where I currently work – an assisted-living project – provided me with two additional interested participants.

stressed that I regard the biomedical view as a cultural product of western society and not as 'the truth', and in which I emphasized that I have a critical attitude towards the medicalization of human distress – my call for participants was approved and published in the *Klankspiegel* magazine¹⁸. This process of gaining access to Weerklank illustrates that the relation of hearing voices to psychiatric diagnosis is a sensitive topic to this group.

In the search for voicehearer participants I came across an online community of Intervoice sympathisers on Facebook. The people in this community – which currently counts 1400 members – interact with each other through a public¹⁹ Facebook group, which is not open to voicehearers alone, but to anyone who is interested in the Intervoice movement. Concerned family members and open-minded healthcare professionals make regular contributions. An intriguing aspect of this group is that the voices themselves also contribute to the discussions: some voicehearers have created Facebook accounts for their voices, enabling the voices to communicate in ways in which other people can also 'hear' them. After becoming a member of this group I introduced myself as a researcher and started to read some of the conversations that were posted. I soon became fascinated by this digital platform, through which voicehearers from all over the world share stories of struggle and frustration but also of hope and recovery. Their exchanges of support and sympathy moved me deeply. My discovery of this group was quickly followed by enthusiasm and an intention to somehow involve this community in my research. When I tried to gain access to this group as a researcher – I was already a member but I was not using any of the information for my research yet – I encountered a lot of resistance from the community. In dialogue with a number of members from this group, I concluded that there was no way in which I could use this internet platform for my research in an ethically sound way²⁰. Even if I would approach members individually to ask for their permission to quote or paraphrase them, my presence as a researcher would be a threat to the open peer-support purpose of the group and to the safe environment that it offers to its members. Therefore, I refrained from doing so.

¹⁸ See appendix 3.

¹⁹ 'Public' in this sense means that anyone with a Facebook account can become a member of the group. The messages are only visible to members.

²⁰ I realize that it would be interesting to include excerpts of this conversation here. However, since this exchange took place in the Facebook group itself, I cannot cite anything from it – to do so would disrespect the privacy of the members who did not consent to participate in this research.

However, the attempt to involve the Intervoice group in my research was not fruitless. Some of its members suggested that I make a separate Facebook group, especially designed for the purpose of my research. This idea was put into practice. This newly created Facebook group was baptised 'Experts-by-Experience: Anthropological Research for Master-Thesis' and it was announced in the 'mother' group, so that interested members could sign up. People who became members first read and agreed to my 'terms-of-participation', which included all the information (about privacy and being able to withdraw from the research) that I normally give people at the beginning of an interview.²¹ This construction ensured that people participated in the group with informed consent. The group is private – only accessible after receiving an invitation from me – and has thirteen members. Group-members could participate in my research by responding to the topics I raised – which were similar to the questions of my interview topic list – or by bringing up a topic themselves. Mostly, people waited for me to ask something. Not all members participated to the same extent; some people never said anything, others only wrote very brief answers that, added together, were not enough for thematic analysis. Therefore I selected the nine members (out of which two are voices) with the most frequent or voluminous contributions and I copied all their answers into separate text documents, which were then treated as a transcripts and analysed in the same way as the interview transcripts.

Although the Facebook-group was private in the sense that its content was only accessible to members, posting in the group meant that one's story would be visible to the other twelve members. In order to give online respondents the chance to share their story with me in private, I designed an 'email interview', in which four people participated. This consisted of a questionnaire²² that was sent to the participants via email, after they had read and agreed to the aforementioned 'terms of participation'. The questions closely followed the topic-list used in my interviews²³ and mainly elicited open answers. It came with detailed instructions and a deadline of sending back the questions. The people who completed the interview were also contributors to the Facebook group; the data therefore complements each other. The written answers were copy-pasted into text-documents, which were again treated like the other interview transcripts.

²¹ See appendix 4.

²² See appendix 5.

²³ See appendix 3.

3.3 Methodological advantages, personal influence and biases

The different research methods used each have advantages and limitations, which will briefly be elaborated on below. Any ways in which I could personally have influenced the data will also be discussed.

The interview method is well suited for eliciting the narratives of participants. However, it is important to realize that the interview itself is an artificial setting; it is not the natural way in which information is exchanged in everyday life. Furthermore, the interview is a hierarchical situation, in which the flow of information follows a one-way course. The researcher directs the conversation to her own areas of interest, in this case with the use of a semi-structured interview, guided by a topic list. The interview is a representation of reality, which is somewhat distorted by what the participant chooses to disclose and what not and equally distorted by the directing of the researcher.

Sometimes I experienced a communication barrier during the interviews. As a non-voicehearer it is difficult to imagine what it is like to hear voices, whereas for most participants, hearing voices is a taken for granted experience. Conveying something which is taken for granted, or perhaps difficult to describe because it is an elusive phenomenon, is not easy, especially when the researcher asks very open questions, such as 'can you describe what it's like to hear voices?' Where I tried to elicit phenomenological descriptions with this question, more often than not respondents resorted to describing the effects the voices had on one's life. In order to get to the information I was looking for, I therefore had to make the question more and more directive, and ended up asking more closed questions than I wished. 'Where do you hear the voices, do they have an identity, are they positive or negative' are all examples of such directive questions.

The internet is a vast and largely unexplored terrain for medical anthropologists. Although some literature exists on doing online research (Wilson & Peterson 2002, Meho 2006, Green & Thorogood 2004), clear guidelines on how to approach this terrain – ethically as well as methodologically – are lacking. The methods I have used for this thesis can be described as experimental; not knowing whether it would work out, I felt it was worth giving a try. It proved to be a lucky shot, because my internet data became as valuable as my interview data. There were several advantages to the online data gathering. First of all, it gave participants the opportunity to participate in the research

on their own pace, without constricting them to a time-frame or appointment. Secondly, it was an attractive method for those participants who tend to be shy and who prefer to write down their experiences instead of sharing this in a face-to-face interview. It can be seen as a more safe way of participating, also because it is more anonymous. From the perspective of the researcher, the internet provides a medium through which she can communicate with participants in various countries, without the costs of travel. The online information was more easily processed into a transcript than the interviews – which had to be verbally transcribed – making it a time-efficient research method.

The issue of anonymity is a double-edged sword. While it contributes to feeling of safety and privacy, it can be a pitfall for the reliability of the data. In a face-to-face interview, the researcher can also be deceived, but the internet greatly increases the likelihood of people ‘acting’, exaggerating or making up stories. The researcher has to be extra careful and critical in evaluating the trustworthiness of an online source. The sincerity of the participants is a judgement call that has to be made carefully by the researcher. For this fieldwork, I had no reason to assume that my online participants were not genuine. They had all posted in the Intervoice group about their experiences and the content and tone of these posts matched with what they contributed to the research group. Furthermore, most of them knew each other from the parent group, which added an element of social/peer-control to the group. The Facebook method was interesting because it allowed people to react to each other’s story, adding a certain dynamic to the data. Of course, the ‘public’ nature of one’s answers might have inhibited people from sharing aspects that they might have shared in a private interview. It might also have worked the other way around; other members’ openness might have encouraged people to tell their own story.

As my own research instrument, I carry biases that might have influenced the collection and analysis of data. My scepticism of the biomedical discourse on mental illness and my personal preference for holistic treatments – for physical pain as well as mental distress – guided me in choosing this topic. My world-view is in many ways opposed to the materialist and reductionist paradigm that forms the basis of biomedical thinking; the lens through which I interpret the world is heavily influenced by Buddhist philosophy and is characterized by awe for the infinite depth and complexity of the human mind and consciousness. Although it is impossible to remove these coloured glasses, I have strived to remain aware of this bias at all times.

During the interviews I refrained from making any references to my own thoughts or explanatory models on hearing voices. Instead, my approach in the interviews was as neutral as possible; neither using the vocabulary of psychiatry in my questions (by avoiding words such as psychosis, schizophrenia and other diagnoses), nor using other 'coloured' vocabulary. Only after the participant him/herself used a certain diagnosis or explanatory frame, did I follow suit. I sometimes did express shock and sympathy, for example when people told me about attempted suicides, traumatising experiences in psychiatry, or when they gave examples of discrimination. In this respect I abandoned the position of a neutral researcher, but followed my human and caregiver instincts by reciprocating their openness with a healthy dose of empathy. Towards the end of the interview, many participants will have felt that I am indeed 'on their side'.

In order to gain access to the Intervoice-related participants, I had to disclose more of myself than I initially intended. The Intervoice community showed some signs of distrust towards researchers. This attitude is understandable, since people feel misunderstood by mainstream psychiatry - indeed by the majority of society - and are wary of researchers who intend to perpetuate the dominant discourse on hearing voices. The term 'medical' anthropology might have been a factor that adds to this wariness. The following citation illustrates the cautious attitude of some participants. This question was posted in the 'Experts-by-experience' Facebook group:

I think that it would be helpful for us all, Dorien, if you could explain where you are coming from in this research. For example, do you consider that voice hearing is a form of psychosis? If you do, then I'm afraid I can't help you any more than I already have done. If you are truly, honestly, open-minded, then that would be different. And what do you truly intend to do with the findings of your research? If you are looking from honesty from us, I think that it is reasonable to expect it from you. (Thea)

In response to this question I emphasized that I am not a representative of the biopsychiatric view and that my personal interests lie with a more holistic view of mental health. Once I made clear that I was on the right 'side', people were more than willing to help me.

Another personal factor that could have influenced the data is my professional background in mental healthcare. In fact, the very reason for focussing on the topic of hearing voices has been inspired by the client mentioned in the introduction. She struggles with the threatening voices she hears and needs to be hospitalized several times per year. After each hospitalization it becomes clearer to my colleagues and me

that 'mainstream' psychiatric treatment is not helping her. My interest in alternative ways of dealing with voices is therefore not only an intellectual endeavour, but also a professional and a personal one. I have witnessed the damage that voices can bring from up close and I have felt powerless to *really* help such people. My enthusiasm for the Intervoice method is related to the hopeful message it carries; this hope could potentially have been a distorting factor in my analysis.

My professional background has been a benefit in helping me to be more sensitive to the vulnerability of my participants. In other ways it might have been a limitation. First of all, respondents who are antagonists of the current mental healthcare system might have felt wary of my professional association with it. Not all participants knew about my professional background, but the ones who did could have felt the need to stress their negative experiences with psychiatry and downplay the positive experiences, while doing the opposite for their experiences with the Intervoice approach. Similarly, an awareness of my critical stance towards psychiatry might have skewed the narratives of respondents to give 'desired answers'. However, judging from the nuances in the respondents' narratives, this bias is probably negligible.

3.4 Ethics

Although hearing voices does not have to lead to mental distress or ill-health, the majority of my participants has received or is currently receiving psychiatric care. Ethical issues were thoroughly considered before and during my fieldwork, in order to protect this vulnerable research population. These considerations will be discussed in the following paragraphs.

Recruitment did not take place in hospitalized settings but instead focused on outpatient and non-patient settings. All participants were mentally stable enough to talk about their experiences in a coherent manner; no one showed signs of cognitive disturbances - that are often associated with psychosis - during the interview. Most participants live independently. For the few individuals that live in an assisted-living project, both the personal tutor and location manager were first asked for permission to interview their client. Together with the personal tutor, an after-care plan was designed. This after-care was provided both by me - a few days after the interview - as well as by the residential

attendants – directly after the interview. The residential attendant on duty would make some extra time for the client, during which they could reflect on the interview together and take the necessary precautions in case it caused some imbalance.

For one participant, the interview caused the voices to be more pronounced and disturbing in the hours right afterwards. The residential attendant was there for extra support and recommended her to follow her resting schedule, which helped. When I came back three days after the interview, she had regained her balance told me that she had been glad to participate in my research. She appreciated the after-care. Another participant evaluated the interview as having contributed to her healing process; she hardly ever talked about her experiences and the interview brought back some memories that were difficult, but valuable in the processing of her past. This was revealed in the after-care with the residential assistant, as well as during the follow-up moment I planned with her a few days afterwards. Both these participants are also my clients, with whom I have a relationship of trust. This contributed to their feeling of safety and allowed me to be sensitive to their limits – for example, by keeping the interview relatively short or by formulating my questions in a certain way.

What I learned from the pilot interview was that the voices can object to being talked about and that they can interact with me, indirectly. During my first interview, the voices expressed their dislike by becoming more dominant. They sabotaged the interview, so to speak; the interview had to be paused and shortened in order to quiet them down. Their screaming was distracting my participant and our interview. Together with this participant, we decided on an extra precaution measure to minimize the risk of mental decompensation²⁴ and in order to safeguard the well-being of future participants. In interviews that followed, I always started the interview by asking if it was possible that the voices would interfere with or dislike the interview. I requested participants to warn me if the voices were causing extra trouble so that we could pause or terminate the interview. However, only the pilot interview subject was unlucky in this sense; in none of the other interviews it was necessary to pause or stop prematurely. That the voices managed to sabotage my pilot interview shed some light on this participant's inability to deal with the voices: they were clearly in control. Although some voices reacted to me

²⁴ In mental healthcare, *decompensation* refers to the deterioration of mental health by the worsening of symptoms and a diminished ability to carry on daily activities.

during other interviews – expressed their dislike even – it was never in a way that was perceived as (more) disturbing by the participant; the voices were not granted control.

Before starting the interview, I emphasized to the participant that his or her wellbeing is more important than my research. I tried to be flexible in my interview-style, paying attention to verbal and non-verbal clues indicating vulnerability. In this sense I believe that my experience in mental healthcare has allowed me to be sensitive to the needs and limits of my participants. Sometimes I felt it was necessary to give participants the space to tell their stories, even if they were not directly related to my research topic. For example, if people started to talk passionately about the human right violations that they experienced during hospitalisations, I was not very strict in redirecting the conversation back to the topic list. This sometimes led to interesting detours, taking me through what the participant felt was important to tell; this interview style therefore also contributed to the data gathering process.

In order to ensure the privacy of the participants, all names have been replaced by pseudonyms. Names of voices, references to locations or other aspects that could give away a participant's identity have also been replaced. The interviews were recorded – everyone was asked for permission and nobody objected- and the recordings were deleted after transcription. Already during the recruitment process, my intentions and the purpose of the interview were made clear to participants. All forms of participation in my research – whether in the (email) interviews or in the Facebook group – are based on informed consent. Before starting each interview, I repeated the purpose of the research and I informed participants on their right to withdraw from it at any given moment – during as well as after the interview. The online research followed the same principles; each participant was sent a 'terms-of-participation²⁵' and was asked to confirm having read and understood these terms. The few individuals who have failed to do so are not included in the data. Although I am a member of the Intervoice Facebook group, I have not used any of the personal messages posted by other members. I have used this group for thematic inspiration and for references to literature only, and I have not gathered any textual data there. Because the purpose of the group is to provide a safe-place for peer-support, I have refrained from using any of the information in it.

²⁵ See appendix 4.

3.5 Analysis

The transcripts of all the interviews and the online research were coded thoroughly with the help of MAXQDA 10.²⁶ The coding scheme that was developed started with the main topic list categories of *experience*, *explanations* and *coping* and gradually became more intricate. The most relevant and interesting categories (such as internalising and externalising explanations, paradoxes and ambiguity, narratives of transformation and cultural relativism) will be discussed in more detail in the following chapters, as they form the core of my findings and analysis.²⁷ Relations between codes were explored with the help of the software programme and themes were distilled from the data. These themes were connected to theory both inductively and deductively; by going back and forth between data and theory, the structure for this thesis was developed.

²⁶ Computer Assisted Qualitative Data Analysis software.

²⁷ The entire coding scheme has been attached in appendix 7.

4. Introduction of participants

Before presenting the analysis of my findings, this chapter will briefly introduce my participants and it will give some demographics of my sample population.

As the table below shows, twenty-one people were involved in my research. Two voices, belonging to one of my online participants, also participated. I was interested in their perspective and included their comments in my textual analysis but excluded them from demographic calculations; the data below is based on the twenty-one human participants.

	Name *	Age	Connection Intervoice **	Country of Residence	Has been hearing voices since age:	Data collection (FB = Facebook)
1	Sara	22	-	Netherlands	11	Interview
2	Natalie	23	Yes - B	Australia	5	Email interview & FB
3	Layla	25	Yes - S	UK	17	Email interview & FB
4	Irene	26	Yes - B	UK	9	FB
5	George	27	Yes - B	Denmark	4	FB
6	Tim	29	-	Netherlands	Early 20's	Interview
7	Alice	31	Yes - B	Denmark	8	Email interview & FB
8	Emily	32	-	Netherlands	21	Interview
9	Emma	34	Yes - A	UK	Late teens	FB
10	Nicolas	36	Yes - A	Netherlands	25	Interview
11	Peter	36	-	Netherlands	Childhood	Interview
12	Tamara	41	Yes - A	Netherlands	28	Interview
13	Erik	48	-	Netherlands	26	Interview
14	Ingrid	48	-	Netherlands	10 ***	Interview
15	Gaby	48	-	Netherlands	? ***	Interview
16	Olga	52	Yes - S	Netherlands	44	Interview
17	Thea	54	Yes - S	Scotland	?	Email interview & FB
18	Samuel	54	Yes - S	Netherlands	7	Interview
19	Lilly	58	Yes - A	Netherlands	26	Interview
20	Chantal	58	Yes - B	Netherlands	19	Interview
21	Clara	65	-	Netherlands	40	Interview
	Voices					
22	Troublesome Companion	-		UK		FB
23	MasterAce	31		UK		FB

* To protect the privacy of my respondents, all these names are pseudonyms

** **A**ctive member / **S**ympathiser / Has **B**enefited from the Interveroice approach

*** This participant currently hears no voices, but has done so in the past.

4.1 Gender and age

Although it would have been preferable to have an equal ratio of male to female respondents, I only managed to find six male participants. Whether this unequal ratio reflects a difference in the occurrence of hearing voices in the population at large; whether it points to the suggestion that women are more willing to talk about their experience; or whether it is perhaps just a matter of coincidence remains unclear. A more equal distribution can be seen in the ages of the participants; with the youngest being twenty-two and the eldest sixty-five years old and all the others spread out evenly throughout the different age groups. The age at which people first started to hear voices is also spread out: 28% heard their first voice before the age of ten, 24% first heard voices in their teenage years, for another 28% the voices first appeared in their twenties and only 10% of participants started to hear voices after they became thirty.²⁸

4.2 Living situation, income and education

When looking at the living situation of my participants, one could conclude that hearing voices does not necessarily affect daily life to the extent that people cannot look after themselves anymore; 80% of my participants live independently or with a partner or spouse, and only 15% live in a supervised facility (5% unknown). In terms of financial resources however, the majority of participants indicate that they are not economically independent: 71% receive some form of disability pension. Note that this financial dependence should not be interpreted as a disability to work – since many of the participants are very active in a variety of voluntary jobs. It does, however, suggest that they are unable to find a suitable paid job. The reasons for this should not only be sought in the potentially disabling effects of the voices, but in a combination of personal and societal factors that are likely to include the effects of stigmatization.

My research population is further characterized by a high level of education. More than half (52%) of my respondents have ever attended or are currently attending university. Almost a quarter of all participants (23%) has earned a university degree or has completed higher vocational education. This high level of education is reflected in the often very eloquent narratives of my participants and the references they make to (social) scientific or academic literature.

²⁸ Data on first onset of the voices is missing for two participants; this accounts for the missing percentage (approximately 10%).

4.3 Residence and cultural background

All the in-depth interviews (14) were done in the Netherlands. Of the Dutch participants, six live in Amsterdam and the remaining eight live elsewhere in the country.²⁹ All of the Dutch participants –except one³⁰ – share a non-immigrant Dutch ethnic background and all are native to the Netherlands. Their narratives sometimes contain evidence of either a Catholic or Protestant Christian upbringing – one participant reports having been brought up a Jehovah’s Witness. However, in none of the interviews did the *original* religion seem to play a significant role –the majority of participants speak of other religious and spiritual orientations as having become important for them at a later point in life. Their narratives contain references to eastern spiritual traditions such as Buddhism, yoga and Hindu gurus and also to more western mystical orientations such as Kabbalah, Freemasonry and New Age spiritual practices. Where relevant, these spiritual orientations will be discussed in more detail in chapter 6. The internet participants were all recruited through the Intervoice Facebook community. They live in Denmark (2), the UK & Scotland (4) and Australia (1). I do not have a lot of information about their ethnic or cultural background.

4.4 Psychiatric history

Although I did not explicitly ask about their psychiatric history, often the participants volunteered this information. For the majority of the participants, vivid descriptions of hospitalisations and references to psychiatric diagnosis were an important part of their narrative. About half of the participants have been hospitalized because they could not control the voices, and were driven to self-harm by starvation, mutilation or even suicide attempts which were directly related to the voices’ threats. These people will be the last ones to deny that hearing voices can be a horrible and disabling experience. However, the narratives of my participants illustrate that the problems associated with hearing voices can also be overcome; not by eliminating the voices but by changing the relationship with the voices. The phenomenology of the negative voices and specifics about this process will be described in more detail in the next chapter.

²⁹ Seven out of the twelve Dutch provinces are represented: interviews were done in Noord-Holland, Zuid-Holland, Zeeland, Friesland, Gelderland, Limburg and Brabant.

³⁰ One participant has Polish roots: her father migrated from Poland, although she herself has always lived in the Netherlands.

I decided to highlight these *narratives of transformation* in my analysis, because they contradict the notion – one deeply entrenched in psychiatry – that schizophrenia is a chronic disease with a very poor prognosis. (APA 1994, 2002, Jenkins & Carpenter-Song 2006, Jobe & Harrow 2010). Whether schizophrenia is a valid diagnostic category or not, is not relevant here. The social fact is that many voicehearers receive this diagnosis. This is also reflected in my sample population: eleven of my participants have at one point in their lives been diagnosed with schizophrenia (52%). Out of all the people who mentioned their diagnosis, 15% have a borderline-personality diagnosis (of which one person in combination with Post Traumatic Stress Disorder (PTSD) one in combination with schizophrenia and one in combination with schizotypal disorder). One person mentioned a bipolar disorder. Only two participants do not have a psychiatric history. They are the so-called ‘healthy voicehearers’. Two other participants do not currently hear voices, but have done so in the past.

4.5 Intervoice & experts-by-experience

A little over half of my participants (52%) have mentioned or are in some way connected to Intervoice (the international participants) or to Stichting Weerklank (the Dutch participants). I have divided these people into three categories: people who have been helped by the Intervoice *and* who are active members of the movement (19%), people who have benefited from the Intervoice approach (19%), and people who sympathise with the movement (14%). The remaining 48% of the participants have not mentioned Intervoice, which does not imply that they do not know the organisation –although this might be the case – but rather that it plays no role in their narrative. A significant percentage of participants (52%) works as ‘expert-by-experience’³¹. Mostly this is a volunteer job, but a few participants earn a salary with this, or even have their own company or organisation for helping others with mental distress. Note that, although the same percentage of people has a connection to Intervoice, this is not the same group of people. There is a great overlap though: out of the eleven experts-by-experience, only one person has no connection to Intervoice. Another four participants have a connection to Intervoice but do not work *for* the movement: they are experts-by-experience for other organisations in mental healthcare.

³¹ *Ervaringsdeskundige* in Dutch.

5. Experiences of hearing voices

In this chapter, the findings to the questions ‘what is it like to hear voices’, ‘when do voices become problematic’ and ‘how can such problems be overcome’ will be presented and discussed. The level of analysis of this chapter is the *individual body*, which focuses on the lived experiences of my participants. This chapter deals primarily with phenomenological data, which will be presented and analysed by grouping similar aspects of the experience of hearing voices together. Already in an early phase of my research, it became clear that there is no such thing as ‘the’ voice hearing experience. Hearing voices is a phenomenologically very diverse experience, as will be illustrated in the first section (5.1). Furthermore, a lot of the findings are ambiguous and are therefore not easily categorized; this is the topic of the second section (5.2). The third section (5.3) echoes the title of this thesis and it will look into several phenomenological characteristics of hearing voices that can make the experience problematic or disturbing. Lastly, some aspects of the before mentioned *narratives of transformation* will be highlighted (5.4).

5.1 Diversity

If someone would introduce himself as a music lover, it would not reveal a lot about the lived experience of that person. What type of music does he like? How does he listen to it, where, with whom? Is he perhaps a musician or a dancer or does he sing? Does his favourite music evoke beautiful or sad memories? Has his taste in music evolved during his life? Similarly, if someone introduces him or herself as a voicehearer, we still know very little about the lived experience of that person. There might be as many variables to the voice-hearing experience as there are types of music; to describe the complete phenomenology of hearing voices would require making twenty-one categories: one for each participant. What I did not realise fully before starting this research, is that the experience of voice-hearing is so different for everyone; it is a highly complex and individual experience.

In order to give an impression of all the variables involved in the phenomenology of hearing voices, I will sum up the variables –along with *a few* corresponding values – that can be distinguished from my data. 1) The perceived *location* of the voices can be inside the head; outside the head; or both. 2) The *number* of voices can range between 1 to hundreds, and everything in between. 3) The *frequency* of hearing voices can be anything from 24 hours per day (even continuing during sleep in one’s dreams) to a few

times per week, and it can be increased by emotional or stressful events. 4) The *gender* of the voices can be male; female; neutral; or not distinguishable. 5) The *identity* of the voices can be of a familiar person (deceased or alive); it can be the voice of the perpetrator of sexual or physical abuse; the voices can have no fixed identity; or be a mixture of all of the above. Some voices have names, others do not. 6) The *tone* of the voices can be positive; negative; neutral; or ambiguous. 7) The *age at which people first hear voices ranges* from early childhood to middle age. 8) The *content* of the voices can be gibberish; symbolic; threatening; commenting on one's thoughts or actions; related to one's biography; unintelligible; or a combination of all of the above. 9) The person may be able to *interact* with the voices or not. 10) The voices may also be *seen or perceived in other ways*- for example by feeling them in the body. Sometimes the voices can take over one's consciousness. 11) The voices may talk *in third or first person* and they can react to each other as well.

I would like to emphasize that this list is not exhaustive and that the lived experience of hearing voices is not static. Many participants report changes in the experience between the onset of hearing voices and the present experience. It is a very dynamic experience that often ties in with aspects of the biography of the person and with the emotional state that he or she is in. If the person is undergoing a process of transformation, as will be explained later, this also influences the form and content of the experience. In order to further illustrate one of these dimensions in hearing voices, the variable 'identity and character of the voices' will now be discussed in more detail using respondents' citations. As the examples below will show, many participants experience their voices as recognizable identities; some voicehearers are able to describe the character of their voices in detail, while others do not recognize a fixed identity. Finally, there are also participants who hear familiar as well as unfamiliar voices.

George is a 27 year old former gardener from Denmark. He introduces all of the five voices he hears in great detail, providing information about their character, their appearance and his relationship with them. All of these voices have the same first name as him, followed by a surname that refers to a species of plant.

George Fernsen: my protector, he has been there since I was around 13 I think [...] is the chief in command [...] he is currently 2 years and one month older than me.

George Ficussen: he is the scared guy [...] he is always afraid to be left alone and that I will be left alone... he always talks with a little soft and almost crying voice... is very tall and very slim just like a match he looks and feels fragile...

George Palmsen: don't know his age but I think it is around the start 20's, he is the wild child so to speak [...] he is a jester, and a joker... if I'm down he tries to make me laugh and he is a kind spirit, just needs to show off at times and be wild...

George Lavendersen: is neither male nor female, he has no gender, but he also has them all. He is very old and very wise [...] he moves fast and slow at the same time, he is soft and nice, a very pleasant personality I will say, he loves to read and he knows a lot, only reads something once and then he remembers, he loves libraries and he is basically the opposite of his twin, but also still the same [...]

George Cypresen [...] I would guess he is around 3-4 years old, he is very childish, but loves to climb in trees (yes he can do that). He loves to play and he likes toys and games, he appears as a child, (elven child) he has been with me since I was 10. (George) ³²

Contrast the detailed character sketch that George provides of his voices, with the following description by 36 year old Nicolas:

*I've very often asked for names and I've asked: who or what are you? But it always remains quiet. That has been frustrating; that I felt the need to know who or what they are and that they didn't answer me. Most of them I hear in my head. Those are the voices that I will recognize at a certain point, by the sound, the vocabulary and the intonation. But like I said, I don't know a single one by name. / **And can you estimate how many there are?** / Well, throughout the years I've heard hundreds of voices. (Nicolas)*

And finally, note that a voicehearer can hear a mixture of 'regulars' and 'visitors', such as Alice – a 31 year old voicehearer from Denmark – describes below:

I hear/sense 12 regular voices/presences which means that I communicate with them regularly (daily/weekly/monthly). Some of them I have heard as far back as I remember some since the age of 8-10, some since my teenage years and the most recent of the regulars came 2 years ago. I also have visitors and sometimes a visitor turns into a regular. There are important regular voices in my past I only heard for a couple of years and don't hear anymore. (Alice)

5.2 Problematic categories, paradoxes and ambiguity

A 'typical' voice hearing experience does not exist and the narratives of participants are fraught with ambiguity. Hence my findings contain many references to 'grey areas' that do not lend itself to easy categorization. The phenomenon of hearing voices is not an either/or experience but rather a continuum of experiences, that come in a wide range

³² Citations in this thesis have been adapted where necessary to enhance the flow of reading. Quotes from Dutch participants were translated into English. The citations that derive from the online-data gathering have been corrected for grammar, punctuation and spelling mistakes. This slight modification of the data has in my opinion not resulted in a significant loss of information.

of hues rather than in primary colours. To examine all these ambiguities would be beyond the scope of this thesis, therefore I have selected the most interesting – perhaps the most remarkable ones.

One of the most surprising findings is that voices are not always verbal. This paradox undermines the very essence of my research topic by suggesting that the term ‘hearing voices’ is a too simplistic way of describing the phenomenon. Many voicehearers appear to experience a whole spectrum of non-ordinary experiences and ‘voice hearing’ really entails much more than auditory perception alone³³. Often the voices are felt and seen by participants, suggesting that they are experienced as ‘presences’ rather than voices. The comments of George and Alice are exemplary of this paradox:

I have 5 (7) voices. I will explain why there are 2 numbers: 5 is the number I hear and (7) is the number that is there, inside [...] It's because the last two are monks I think... they walk around in a monk robe and have a big hood over their heads [...] I have never seen their faces and I have never talked with them, I think they are just there to observe and maybe taken the vow of silence. (George)

Some of them I can mute. This means that I can sense their presence but not hear them. (Alice)

Although the participants identify themselves as voicehearers – or else they would not have responded to my request – they do not always use the term ‘voices’ to describe their experiences. What I have hitherto referred to as ‘voices’, are in the lived experience of my participants referred to as ‘vibrations’, ‘presences’, ‘beings’, ‘spirits’ and so on. This vocabulary suggests that the phenomenological experience merges into the explanations people have for what the voices are. Irene points out that the term ‘voice’ does not do justice to the full experience:

I experience a vision of a young girl who is with me constantly and plays and talks to me so I have conversations with her. So would that be hearing voices and visions merged? I am more inclined to refer to her as a being I see. (Irene)

³³ This finding reminded me of the email exchange I had with a board-member of *Stichting Weerklank*, in which she asked me if I wanted to research voice-hearing only. She explained that *Weerklank* is extending its audience by including all ‘other extra-ordinary mental experiences’. This is reflected in the new subtitle that appears on the *Klankspiegel* from 2012 onwards: (translated from Dutch) ‘*By and for people with extra-ordinary perceptual experiences and personal beliefs*’. At the time of writing my research proposal, I chose to demarcate my topic by focusing on the phenomenon of hearing voices. However, as the research progressed I came to realize that hearing voices is not an isolated experience and that it is far more complex than I originally assumed.

Not only is it a false assumption to think that voices are only *heard*, another misconception is that voices communicate intelligibly. Several participants indicate that they cannot always hear or understand what the voices say, because they speak too soft, in gibberish or even in another language, of which Natalie gives an example:

The Polish girl looks dead; thin gaunt long black hair; floats, whispers only in Polish. I only speak English so it's hard to communicate with her. From translation most of the things she says are warnings; a sense of urgency about it all. (Natalie)

Another problematic dichotomy is the classification of the voices as positive or negative. When I primed my respondents to describe their voices in these terms, they often corrected me by illustrating that the experience is too complex to fit simplistic dichotomies. Although some participants gave clear examples of positive and negative voices – many people have both – others emphasized that their experiences are not easily categorized in such terms. In the examples below, George makes a distinction between the character of the voice (who has some good sides) and the resulting cognitive effects that it has on him (which are both positive and negative). Tamara explains how the voices sound negative while their intentions are good, and one of the Voice participants points out why the positive-negative dichotomy is too simplistic.

But I don't categorize him negative or positive: I believe that he has some good sides, but they are mostly hard to find, sad to say. But he has a good ability: he makes me see the consequences of my choices, but makes it harder for me to make up my mind and also choose. (George)

Well you can call them positive or negative voices, but I think that in this case they are the same. They respond to unhealthy behaviour. They come across as negative, but they mean well... they just don't know how to communicate well. They are like; 'why can't I reach you, why don't you listen?' (Tamara)

I don't like the terms 'positive' voices and 'negative' voices. You don't refer to people as positive people or negative people. Everyone has great aspects to them and difficult aspects to them. But no being can be all good or all bad. (Troublesome Companion)

The following paragraph will elaborate the paradox that voice-hearing is not limited to auditory perceptions. It will also attempt to delineate the topic of this thesis by drawing a clear line at the psychotic episode. This line is perhaps arbitrary and artificial, because the voice-hearing experience – in the wide, multiple-sensory meaning of the term – can be argued to be in the same spectrum as florid psychosis. However, in order to prevent the topic of hearing voices to become too fluid and unspecific, the line needs to be drawn somewhere. Although I was careful to never be the first to mention the term psychosis,

once the participant used this terminology in his or her narrative – many did – I continued to ask questions in order to disentangle the voice-hearing experience from psychosis. What is the relation between hearing voices and psychosis? What does this term even mean, from the perspective of the participant? Why do people mention the term psychosis, even if they clearly reject the illness label and express a dislike for psychiatric diagnoses? These questions could easily form the topic of a whole new thesis, and I do not have the illusion that I know the answer. However, a brief attempt will be made to separate the two concepts.

My participants hear voices, see visions, have tactile experiences without an observable source and sense presences – without being psychotic. Many of them however, describe having experienced psychoses. What psychosis is then, according to the narratives of my participants, is a completely different experience of reality, which makes them unable to function, look after themselves, or feel safe. Emma defines psychosis as:

A state of mind, [...] a state of altered awareness and certainty that is out of step with my usual way of being. For me it's not about voices, visions or even unusual beliefs... although these can be woven in with it. When I'm experiencing psychosis I'm flooded with things in my environment 'sticking out' and feeling important.... Psychosis is a weird term, though. [...] For me, it's not about brain chemicals or genetics - it's what happens when I'm feeling extremely unsafe and pushed beyond my limits. Nowadays [...] I'm less likely to weave the webs I used to weave. I'm more likely to look to see what's making me feel unsafe, and be interested in the metaphors I'm creating (rather than follow them around and around until I get lost). Maybe, for me, psychosis is getting temporarily lost in meaning. (Emma)

Other participants refer to psychosis as a result of ineffective coping with the voices (like Tamara) or a period in which the voices become so intense that it impedes normal functioning (Erik):

Well, when you do not cope with them [the voices] well. Then you move into a wrong direction, towards a psychosis. (Tamara)

You have used the words schizophrenia and psychosis a few times. What do those words mean to you? / *Well, schizophrenia is when you... when you hear voices, or see visions, or feel sensations in your body. When that becomes **very** intense... so that you cannot function normally anymore, that's what I would call a psychosis. (Erik)*

A psychosis can then be seen as – among other things – an inability to deal with the voices in a constructive way, an escalation of hearing voices. Although this is a very simplistic analysis, it is a means of delineating the topic of this thesis by suggesting that psychosis can be a *consequence* of voices, instead of the other way around. It is important

to stress that psychosis is an ambiguous term that is also used by participants who reject the medical model. The term refers to a state of mind, a state of being, which is acknowledged to be dysfunctional but which is not explained in medical terms. Adding to this, a psychosis can also have positive elements.:

I've experienced many psychoses, but they were actually quite nice [...] In the past eleven years I've regularly had very beautiful spiritual experiences and insights. It varied. But I think that sometimes my behaviour must have seemed quite bizarre to others. (Nicolas)

Concluding from my research data, psychosis is an ambiguous category that interacts in complex ways with hearing voices. It distinguishes itself from hearing voices by the greater distance it causes between the individual and 'everyday reality' and is characterized by dysfunctional behaviour.

5.3 Concerning voices

This section will illustrate what it is about hearing voices that can make it a difficult and disabling experience. While many of my participants do not regard hearing voices as a symptom of disease, they do acknowledge that the voices can cause disturbance and that they can make one dysfunctional or sick. The negative effects that the voices have (had) on participants are often the reason they ended up in psychiatric care. At least half of them have been hospitalized at one point in their lives. Others have received or are still receiving some form of outpatient treatment. First the more 'innocent' negative effects of hearing voices will be described, building up to the more disturbing and dysfunctional influence of voices.

Dealing with the voices can take a lot of energy. An often mentioned negative effect is tiredness or exhaustion. The voices can also be very distractive, and result in a lack of concentration. Simple tasks like reading a book or watching television can become very challenging, if not impossible.

For two years I had voices continuously, from early in the morning until late at night. Continuously. Dead-tired each night, dead-tired. (Erik)

The voices caused a lot of unrest. It's very busy in your head. (Ingrid)

Well, it just distracts you a lot. It's difficult to read a book or something like that. (Tim)

So I suppose at times it can be overwhelming, I can't stand radio, I only watch television if there's subtitles, I find group conversations difficult sometimes (Natalie)

Voices can also become involved in feedback loops with associations and delusions:

Insane movies, about drugs, the third world war.... I thought I had to save the world. He was playing with all my fears. (Erik)

Troublesome Companion can be extremely frightened and has an incredible imagination and often comes up with all sorts of conspiracy theories etc. which, in the past I have latched onto and believed myself. There have also been situations when I have instigated the theory myself and [he] has latched onto it and we would feed very heavily into each other's fears. (Irene)

I couldn't even look at a license plate. I couldn't even look at a tree! Everything came with associations. Given to me by the voices. (Lilly)

When the voices are able to convince the person that terrible things will happen, or worse, that the person will be responsible for those horrible things, it is easy to understand that this can induce intense fear and anxiety. This fear can then trigger the worst of all negative effects: the person can start to listen to the voices and perform all sorts of assignments and compulsive rituals. More than half of the participants have experienced intense fear and anxiety due to the voices and one third of them have obeyed the voices in carrying out self-destructive assignments. These assignments vary from auto-mutilation and starving oneself to attempting suicide. Such deeds need not always be in obedience of the voices, they may also be an attempt to stop their terror. To conclude this section, a number of citations have been selected to illustrate the cascade of disturbances that voices can cause. Whereas Layla expresses mostly annoyance and frustration, Sara and Lilly explain how anxiety and terror can escalate into what are often the precursors to psychiatric hospitalization: obeying the voices.

I do not have experiences of negativity in my voices... It is positive or neutral meaning me no harm. HOWEVER, it causes harm as it is there ALL THE TIME and this frustrates me, and makes me angry (I have been to anger management therapy because of this in my past)... I try not to, but it's hard... (Layla – capitals hers).

And that man he... he mostly threatens me. He says that he... will kill my boyfriend or that he... well, he often threatens to kill people. And that it would be my fault. [...] When my father had a stroke five years ago, he also said that was my fault. And for a long time they told me to cut myself. And well... that's what I did, because terrible things would happen if I didn't. (Sara)

Those voices were with me day and night. I didn't eat, didn't drink.... At a certain moment I only weighed 38 kilo. [...] The voices forbade me to, and I obeyed them. At the same time, I couldn't eat because I did not trust it there [in the psychiatric hospital]. Only by looking at food I would be told what was in it. How bad it was, how poisonous it was. (Lilly)

5.4 Narratives of transformation

This section will present the evidence from my participants' narratives that negative situations with hearing voices can be transformed into more manageable, even positive, experiences. Such *narratives of transformation* were presented by almost half of the participants and they are characterized by a number of key elements, which will be illustrated in more detail below.

For many participants in this study, the onset of hearing voices can be regarded as a *biographical disruption* (Bury 1982). For those participants who have been hearing voices since (early) childhood, the biographical disruption often presented itself when the benign voices turned into hostile or abusive voices. Others described their first hospitalization as a *fateful moment* (Giddens 1991); it was their first encounter with psychiatry and (involuntary) pharmacological treatment. What sets the *narratives of transformation* apart from the other narratives in this research, is that they are marked by biographical disruptions in the form of a traumatizing event. The narratives of transformation were further characterized by an emphasis on biographical context. In response to the question 'can you describe your history with the voices, when did it start?' participants often gave detailed descriptions of periods of their life in which they did not hear voices yet. Before recounting the onset of the voices, a detailed biographical context was described; these narratives illustrate that for these participants, one's life history is directly related to the voices. In giving such biographical contexts, the traumatic experience was highlighted as a causal factor for the onset of the voices. These traumas often – but not always – occurred in childhood and they vary from sexual abuse (Irene & Chantal), emotional abuse and neglect (Ingrid), having an alcoholic parent (Tamara), to the suicide of a parent (Nicolas) and being bullied (George). One participant also mentioned involuntary hospitalization as a traumatic factor in her narrative. (Lilly).

The narratives of transformation are further characterized by a process of learning to gain control over the voices. Participants emphasize that this was not learned overnight; it took a lot of hard work and effort. Although for one participant this resulted in the disappearance of the voices, for the other participants the objective – and result – was to improve the relationship with the voices. Aided by psychotherapy or on their own account, participants not only worked *with* the voices; they mostly worked very hard on themselves. This hard work consisted of dealing with the past trauma; reclaiming and

expressing suppressed emotions; developing one's identity; and improving one's self esteem. Irene (26), who was sexually abused as a child, illustrates some of these aspects in the following citation.

I have changed my relationship with my voices with a lot of support from my psychologist. We have worked on me reclaiming emotions that voices hold. For example, Master Ace was a voice that held all my anger at the world. When I first started working in this way with voices (as the medical road proved fruitless), I would describe myself as someone who just didn't get angry. I would say a lot "it takes A LOT to get me angry" but this was because Master Ace was holding it all for me. So I worked on identifying and expressing my anger. I took up boxing and that was something that really marked a turning point with Master Ace...although it didn't solve the fact that he was abusive completely, he did begin to relax a lot because I was matching his angry energy and reclaiming it. (Irene, capitals hers)

Ingrid (48) had a severe accident when she was eight, which left her disabled. Furthermore, she suffered severe emotional neglect during her childhood, which caused her to flee into a fantasy world. At ten years old she started hearing voices, which she called her little dolls. First they were here friends, but later they became very ruthless. She was hospitalized at twenty-two, after a suicide attempt. It was not until she started therapy that she realised that other people do not have such little dolls. After an intense psychotherapeutic process, her voices disappeared completely and she has not heard them for over ten years. Ingrid emphasizes the effort that her healing process took:

I've had to break myself down completely before I could piece myself back together again. I was in therapy until I was 35... When I recollected all that [childhood trauma] – I didn't receive any medication but I had to process and relive everything – re-experiencing all that sent me through hell and back. (Ingrid)

From her adolescent years onwards, Lilly (58) has been struggling with a very low self-esteem and depressive episodes. After attempting suicide she was hospitalized for the first time at twenty-six years old, which she described as a major traumatic event. Right after being committed to the hospital, without having been able to say goodbye to her parents, she heard her first voices. Lilly has a very critical attitude towards psychiatry; she feels that it has failed to help her. Below she describes how she managed to gain control over the voices. Again, the aspect of strengthening one's own identity is highlighted:

*When I found and strengthened my own self, it became possible to learn how to cope with the voices. That's what I mean with coping: if at a certain moment I can **win** over them. [...] I think that, beside hearing voices, it is important to discover what your **own** voice is and that you stick up for that voice and defend it... not to let it be pushed aside. (Lilly, emphasis hers)*

The final key element in the transformation narratives is that participants listen to the voices and try to understand them. George learned to understand why his dominant voice was so abusive through a Voice Dialogue³⁴: *'The voice came to know that I was scared of him. And he got to tell me why he was angry with me: it was because I stopped listening to him. [He wanted to] help me live my life for myself and not for others.'* George describes this as the first step in his recovery. The voice now helps him to make decisions and he now regards him as his *'best friend and my big bro'* and the *'boss of my other voices'*: the dominant voice became an ally. Since that day, George has been able *'to be home alone and sleep alone'* and he is *'finally able to live a good life'*.

Chantal explains that ignoring the voices did not help her: *'that didn't work at all, it was like they would only become louder and louder. Ignoring really doesn't work. It is a piece that needs attention.'* For Chantal, dealing with her sexual abuse past was a very long and intense process. She describes that by repressing the memories of her trauma, she developed a conversion disorder³⁵ which put her in a wheelchair for twelve years. Nowadays she helps other people to recover from mental health problems with her own company. The voices do not control her anymore, because she has developed a stronger sense of self and because she makes agreements with them:

*I'm that much stronger now that I do not argue with them, I just let them go. And I make time for them. For example, I make agreements: guys, I'm busy with other things that need my attention – but tonight I will sit down on my couch and then you can complain to me for fifteen minutes about everything that's bothering you and about all the things I did wrong. And I will listen – I will not act on what you say, but I will listen to you. And that works.
(Chantal)*

Although Chantal uses a low dose of antipsychotic and antidepressant medication to remain stable, most narratives of transformation are marked by abstinence from neuroleptics and an emphasis on psychotherapy. As will be described in a later chapter, Irene has very negative experiences with anti-psychotics. She has come off medication completely and focuses on psychotherapy instead. Contrast Irene's following citation

³⁴ Voice Dialogue is a method by which the therapist addresses the voices and talks with them instead of the voicehearer. Of course the voicehearer is still the one who speaks; he literally 'translates' what the voices say.

³⁵ The medical dictionary defines conversion as "an unconscious defense mechanism by which emotional conflicts that ordinarily cause anxiety are repressed and transformed into symbolic physical symptoms that have no organic basis. Loss of sensation, paralysis, pain, and other dysfunctions of the nervous system are the most common somatic expressions of conversion." Source: medical-dictionary.thefreedictionary.com/conversion.

with the opening words of this thesis, to get an impression of the depth of her transformation narrative:

I have done A LOT of work on understanding these voices and listening to them. Master Ace and Troublesome Companion are now great allies and fantastic friends. I have only just recently started working with Angie so I am still in the early days with her but I am starting to gain a much deeper understanding of her and her role and I am sure she will become just as much of a pleasure to be with as Master Ace and Troublesome Companion. (Irene, capitals hers)

The fact that both Troublesome Companion and Master Ace have participated in this research is a direct result of Irene's hard work with them. Instead trying to eliminate her voices, she has acknowledged their existence and she has even created a Facebook account for them so that they can communicate with the 'outside world'. This approach is working well for Irene. She is still in the process of learning to understand all her voices but she has made immense progress, thanks to the efforts of herself and her psychotherapist. Irene is now studying psychology in university, with the aim of helping others.

I have chosen to illustrate these narratives of transformation in such detail, because they contradict the standard biomedical approach of treating voices as meaningless symptoms. These narratives show that, for these participants, there is merit in an alternative approach that focuses on psychotherapeutic work instead of, or complementary to, pharmacological treatment. Such 'success stories', in which respondents are in control of the voices instead of the other way around, show how the concept of agency works on an individual level: by learning how to exercise agency over the voices, the voicehearer becomes empowered over his or her own experience. How agency works on the social and political levels will be further explored in chapter 7. Finally, these narratives resonate with the anthropological axiom that studying context is essential for understanding a phenomenon. For many participants, relating the voices to their biographical context is a way of giving meaning to the voices. The following chapter will continue with the subject of giving meaning. It will analyse how participants make sense of their experiences by finding fitting explanations for the voices.

6. Explanations for hearing voices

This chapter will present the findings on the question how voicehearers explain their experiences. The level of analysis is *the social body*; this chapter deals with the representations that participants use for the phenomenon of hearing voices while also analysing which representations they reject, and why. In the first section of this chapter (6.1), the explanatory models that my participants use will be divided into externalising and internalising models, after which I will argue that participants are rational actors who engage in a process of theory-building (6.2). The third section (6.3) will highlight how conflicting explanatory models can create a paradox, which some participants actively attempt to resolve in their *research narratives*. Section (6.4) deals with the critique that participants have expressed towards the medical representation of hearing voices, while the last section (6.5) will distill the appealing characteristics of the Intervoices representation from the narratives of my participants.

6.1 Explanatory models

In the literature on explanatory models, the distinction between externalising and internalising belief systems is made (Young 1983, Nichter 2008). Externalising factors ‘involve agents of misfortune that may or not intentionally cause harm’ (Nichter 2008: 42) while internalising factors refer to causes of illness within the body. My analysis of explanatory models builds upon this externalising/internalising distinction. Because hearing voices is not regarded as a symptom of an illness by most of my participants, I would like to emphasize that the following categories should be regarded as explanatory models for non-ordinary (sensory) experiences, instead of illness categories. The explanatory models of the two respondents without a psychiatric history are included in this part of the analysis.

When participants refer to externalising factors, they may or may not be presented as ‘agents of misfortune’. For people who ascribe the voice to another person, who is said to enter one’s consciousness via telepathy, this active agent is often indeed regarded as an ‘agent of misfortune’. This type of explanation I will refer to as the *paranormal explanatory model*. Olga is one of the participants who use this model:

I know who it is, but he will always deny it. [...] I have to add that he himself is fully paranormally gifted. Because otherwise, it would not be possible [...] So it's actually a form of telepathy... but well, a very annoying form. (Olga)

For other participants the evaluation of the external agent is more dynamic: the voices are first interpreted as harmful, but this evaluation often shifts to a more neutral or even positive evaluation. This seems to be the case in particular for the respondents who refer to (some of) their voices as spirits, deities or non-human entities. The following citations each correspond to a further subdivision into what I have called *spiritual-, religious- and metaphysical explanatory models*.

Spiritual: Well, my father is just a helper, a guide (Tamara).

Religious: I generally have two voices; the voice of God and the voice of the Heart-master, Adi Da. And sometimes the Goddess also appears briefly, but she is very modest and always very sweet. (Erik)

Metaphysical: They are also children of nature; they are a mix of the angelic and the forest spirits and creatures. We do not have a human word for their species, they are spirits but also consciousnesses of themselves. [...] They are a great mix of the best around, both visible and invisible (George).

For simplicity's sake I may refer to all these explanatory models (paranormal, spiritual, religious and metaphysical) collectively as *externalising models*.

The internalising factors that participants have described in explaining what their voices are and why they are there, can also be subdivided. When people use the *bio-medical model*, their explanations contain biological terminology such as brain disease, brain-activity, neurotransmitters and genes. Sara is one of the participants who use the bio-medical model: 'I think that... it's actually something physical. That it's just a problem in your brain. Something with neurotransmitters in your brain.' In contrast, the *psychosocial model* reflects the psychological and social psychiatric perspectives (such as described by Luhrmann; 2000, Bentall 2003, Read et al. 2004) on mental conditions where respondents describe their voices in terms of survival mechanisms, the psyche, the mind, trauma and repressed emotions. A small subcategory within the psychological model is the *imagination* explanation. Participants who use this model refer to the inherent creative capacities of the mind, without labelling this capacity as pathological.

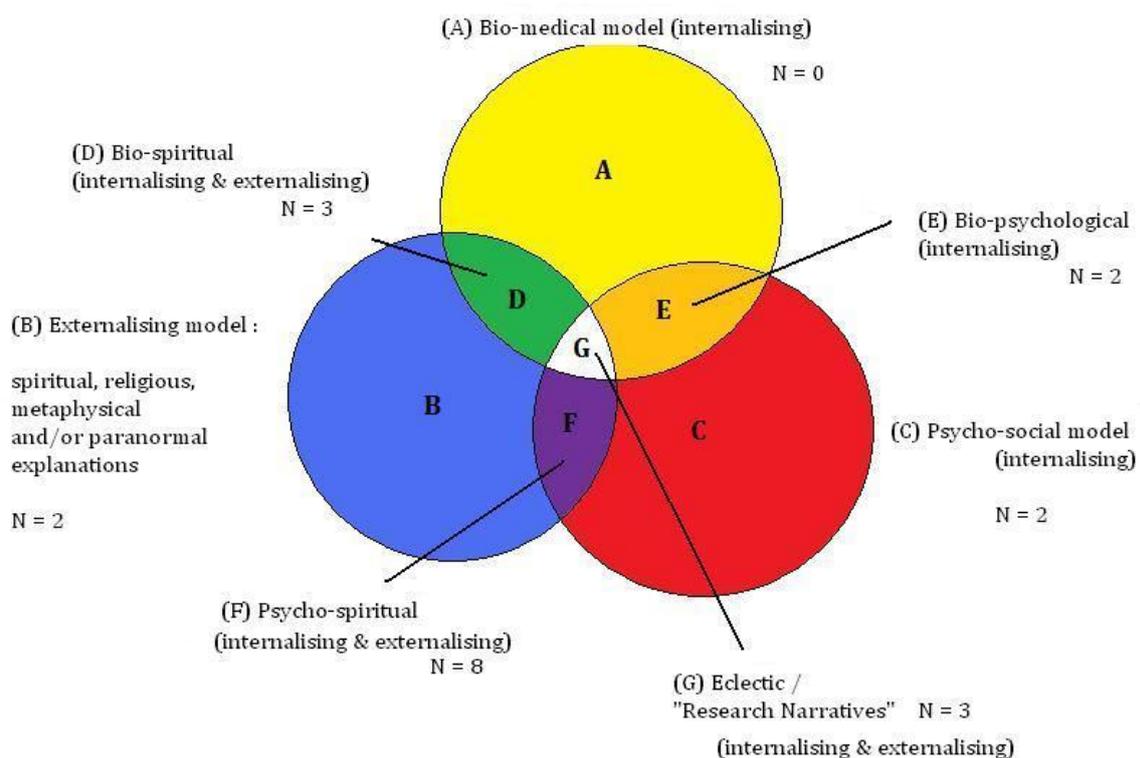
I explain the majority of my voices from a psychological point of view: they are split off parts of myself that hold emotions I have repressed (Irene).

I don't regard voices as something like, hallelujah, it's a wise counsellor or something. No: it is purely a survival mechanism. (Ingrid)

Oh you mean if I have to analyse it? If I would have to explain it, I'd turn to both my psyche and my brain. But... what I'd rather do with it, doesn't have anything to do with neither brain nor psyche, but with the Imagination. (Peter)

As will become clear in the following section, internalising and externalising explanations are not mutually exclusive: they interact with each other. This dynamic becomes more visible when we further dissect the term 'explanatory model'. When people are asked to explain the phenomenon of hearing voices, two types of answers are elicited: 1) *Why* do you hear voices and 2) *What* are the voices. My findings suggest that voicehearers often use one explanatory model to answer the 'why' question and use another model for the 'what' question. How people combine different models will be the topic of the next section.

6.2 Bricolages and rational actors



Schematic presentation of (overlapping) explanatory models used by participants³⁶

³⁶ This scheme includes only 20 out of 23 participants. The two voice-participants have been excluded, as well as one participant who did not give sufficient information about her explanatory model to make valid conclusions.

The previous section described how voicehearers use internalising and externalising explanatory models and how their explanations were categorized into an externalising, a psychosocial and a biomedical model. Although some individuals' explanations fit neatly into one category, the majority of participants used a combination of these categories to explain what the voices are and why they are there. In the schematic drawing above, the resulting overlapping fields are illustrated. The main categories in this scheme – represented by the circles A, B and C – have already been introduced. The categories that result from the overlapping of the circles will be referred to as explanatory *systems*: D) the bio-spiritual system, E) the bio-psychological system, F) the psycho-spiritual system and G) the eclectic system. As is illustrated in the scheme, only four participants explain their experiences with reference to one model only, and not a single participant used the bio-medical model on its own.

Larsen (2004) aptly describes the process by which his participants combine different explanatory models in order to make sense of their mental illness. Although his focus on mental illness is not in accordance with my emphasis on extra-ordinary sensory experience, his theoretical concepts are directly applicable to my research findings. The mixing of different categories of explanations is described as 'innovative theory-building work', which he calls 'a strategy of *bricolage*' (ibid.: 461-462). Larsen explains that '[w]hat distinguished these explanations from delusions was that they found resonance in the wider *cultural repertoire*, that is, the myths, traditions and institutional bases of authority in the wider society' (ibid.: idem).

My participants also engage in a strategy of bricolage, during which they make use of a diversity of cultural repertoires. Medicine can be regarded as the most pervasive cultural repertoire when it comes to dealing with human distress; we are all exposed to the medical paradigm in some extent. In this paradigm, disease is explained in mostly biological terms, and it is closely connected to the scientific and materialist paradigm. When it comes to mental distress, another cultural repertoire that offers explanations is the domain of psychology and psychoanalysis. Although in the professional world, medical science might have established authority over psychoanalysis, in lay and popular culture the psychological repertoire is still very much alive. A third cultural repertoire that people can draw from when dealing with distress, is religion. Although western societies have become more secular in the past decades and institutionalized

Christianity has rapidly lost support, this does not imply that people stopped believing in spiritual forces or higher powers.

Max Weber has suggested that 'the fate of our times is characterised by rationalisation and intellectualisation and, above all, by the "disenchantment of the world" (Weber 1918). However, judging by the rapid proliferation of Eastern spiritual practices such as yoga, meditation and tai chi and the popularity of New Age literature, we can perhaps conclude that people have become disenchanted with the institutional Church of the major denominations, but that the interest in spiritual matters is very much alive. This idea is supported by humanistic and social scientific research on secularization and religious change. A mere glimpse at the following titles reveals that Weber's notion of disenchantment is being questioned: 'Why do Churches become empty, while New Age grows?' (Houtman & Mascini, 2002), 'Oriental religion in the secular West: 'globalization, New-Age and the reenchantment of the world' (Aupers & Houtman, 2003), 'How magic survived the disenchantment of the world' (Hanegraaff, 2003) and 'New Age spiritualities as a secular religion' (Hanegraaff, 1999). Whereas institutionalized religion is on its return in contemporary Western society, spirituality seems to be gaining ground. This is also reflected in my research data. In my participants' narratives, spirituality is an important cultural repertoire. Some people express that they had been interested in and engaging with spiritual practices before the voices started – for example by doing yoga (Clara), by reading about shamanism (Nicolas & Erik) or by studying theology (Erik) or esotericism (Tim) in university. Others became interested in it as a result of their extraordinary experiences; in their search for fitting explanations they became exposed to certain spiritual repertoires, which were then judged on their merit.

The internet plays an important role in exposing people to particular cultural repertoires; it is like an exotic library from which people can select books that resonate with their personal experiences. In this globalization of information, cultural repertoires from all corners of the earth become available to participants. Some participants draw explanations from western repertoires such as Parapsychology or Western Esotericism, while others refer to more 'exotic' philosophies such as Buddhism, Hinduism or Shamanism. For Sara, the cultural repertoire from which she draws is related to a hobby. She believes her voices are from another dimension and she says she knows '*that this is due to my interest in astronomy*' which made her '*come to the conclusion that they are*

actually from another dimension'. When she was asked if she would have explained them differently if she hadn't known anything about astronomy, she answered:

Yes, I think so. At the voices-poli³⁷ I heard many other people about their explanations. One would say: it is telepathy; while someone else would say: it is God... So yes, I think that had I been a strict protestant – had I been very religious, then I would probably have thought it comes from God.

Hereby Sara expresses an awareness of cultural relativism; the explanation people have for their voices, is influenced by their cultural setting. Participants also demonstrate that culture is not a given 'thing' that one 'has', but a dynamic process in which people can engage. Olga - one of the participants who has never been a psychiatric patient – explains how she used the internet to connect with subculture that resonates with her experience.

And then you start to look for information, you do research about telepathy – because that's what it is. This led me to an [internet] forum – initially while looking for help. I visited a forum-day and I just talked to people. And to my surprise, people there did not even act weird about it. (Olga)

The internet-forum she refers to is a forum about spirituality, where people from all over the country meet. In this online community, Olga's experience of hearing a voice was not regarded as pathological but paranormal. Although she is a 'healthy voicehearer', it does not imply that the experience is positive: the voice she hears has always been very bothersome and negative. However, she has learned to become in control and she does not allow him to have any power over her. The paranormal explanation works for her, and it is reinforced by the online community of which she is a member. There is therefore a certain *logic* involved in adopting a particular explanatory model.

This logic is also reflected in other participants' narratives. Most of them have actively looked for explanations that suit their experience. Even though non-ordinary experiences are not usually associated with rationality, I want to propose that my participants are rational actors. The theory-building work in which they engage is a form of agency, through which the individual tries to get a grip on what can be an overwhelming and difficult experience. The process of finding an explanation for one's experience is in itself a manner of coping with it. This search for meaning is a dynamic process in which people are exposed to various cultural repertoires; through a process of

³⁷ Voices-policlinic (*Stemmenpoli*): a talk & support group within the medical setting of an academic hospital in the Netherlands.

trial and error, certain explanations are adopted while others are dismissed. The reason for sticking with such an explanatory system is to a certain extent pragmatic: a specific explanatory framework gives direction to ways of dealing with voices, and when this method has proven to be effective for the individual, the underlying explanatory model has proven its worth.

For a number of participants (especially those aged over 40), the theory building process has been completed. They have chosen a particular explanation through a process of trial and error and now use it because it best suits their experiences and/or worldview. For other participants (especially the younger ones), negotiating a fitting theory for hearing voices is an on-going process. They present more ambiguous descriptions of the explanations, using a multitude of representations and they often indicate that the voices remain, to a certain extent, somewhat of a mystery to them. These participants are represented in the core of the schematic diagram. While some of these individuals – like Irene, below – explicitly mentioned that they do not have a clear explanation because they do not want to analyse the experience too much, others are very actively engaged in finding a fitting explanation. I came to regard this last category of respondents as my fellow researchers, whose mission is quite similar to my own, with the difference that they are ‘insiders’ to the phenomenon of voice-hearing. Their narratives will be discussed in more detail in the following section.

I also see a being of somebody I once knew who died (to me she looks as real as anyone else but others cannot see her) and I haven't really come to a conclusion whether it is her (i.e. her spirit) or whether it is my projection. I try not to get bogged down with explaining what my voices ARE as it can distract from the experience itself (Irene).

6.3 Research narratives

Nicolas en Tim, two of my interview participants, presented what I would like to call *research narratives*. Both are young men with a bachelor's degree, in psychology and cultural anthropology respectively, who first started hearing voices in their twenties. Both have been diagnosed with psychosis and schizophrenia; whereas Tim accepts the illness label, Nicolas rejects it. Although their *bricolages* contain elements of the biomedical and psychosocial models, both participants also draw on spiritual repertoires to explain the voices. What touched me personally about their narratives, is their expressed struggle with the two conflicting paradigms of materialist science and

spiritual/metaphysical reality. As a researcher with an interest in (Eastern) metaphysical philosophy, I embody this split between materialist and non-materialism, and I was particularly interested in how these participants – my fellow researchers – attempt to resolve the paradox. Both participants draw on the cultural – academic – repertoires they have encountered during their academic training, as well as the spiritual and metaphysical repertoires that they have explored as a result of their interest in spirituality. Tim has followed a course in western esotericism and is now using Kabbalistic rituals as a form of coping with his voices. However, he also uses biomedical methods in the form of antipsychotic medication. Nicolas too, has been interested in spirituality, particularly shamanism, for many years. He now combines the use of a low dose of medication with spiritual coping techniques such as praying, and psychological techniques such as developing his inner speech.

Although Tim accepts the psychiatric label of schizophrenia, he also believes that the voices could be metaphysical entities. He emphasizes that - although it does help him - the antipsychotic medication that he is taking is not a cure, and that psychiatry does not have a real explanation for schizophrenia. The cultural repertoires that Tim draws from are influenced by his academic training as a cultural anthropologist: the conflict between his spiritual worldview and the biomedical explanation for voices is approached from a cultural relativist angle.

Are those voices auditory hallucinations... or are they metaphysical entities? [...] In many cultures they will say the last, and science will of course say the first.... but perhaps it is both... well, I don't know. As a scientist - and as someone who wants to do research on this - I believe that it is best to have an agnostic attitude. I do not know, it could be both, and I want to leave the question open. (Tim)

Tim is actively looking for an explanation and his anthropological training serves as a tool for his personal quest. However, also within the anthropological perspective, Tim feels the trap of Cartesian dualism: *'as an anthropologist you cannot say that you believe in metaphysical entities because... it affects your academic credibility'*. Therefore he has chosen another field from which he approaches his quest: he is currently working on the pilot version of a television programme, in which he will explore how other cultures deal with the phenomenon of hearing voices. He hopes that his research into hearing voices can form a bridge between spirituality and science. For the present moment, however, he admits that he does not have a clear answer as to what the voices are and where they come from; his current attitude is that of an agnostic scientist.

Nicolas also draws on the cultural repertoires which he encountered as a student. For him the materialist paradigm and the spiritual paradigm are not mutually exclusive. In his explanations for the voices he uses neurological concepts such as brain-hemispheres, dopamine activity and brain-plasticity, but just as easily describes psychological processes and para-psychological concepts such as telepathy. For him, all these explanations are pieces of a puzzle. Like Tim, he also values science but expresses that it has its limitations. Nicolas too, is looking to unite materialist neuro-scientific explanations and the para-psychological paradigm. For him, this paradox is resolved with reference to the concept of the collective consciousness:

I think it's important that all those different perspectives exist, but it's also important to be really aware of the collective and cosmic consciousness. [...] Consciousness can take many forms. And reality as we know it, well, that's only what we can perceive with our five senses.... [but] reality is infinitely bigger and it can exist in countless forms about which we might not know anything yet. (Nicolas)

Both participants are very much engaged in process of theory building. Their academic training both facilitates their quest – by introducing them to cultural repertoires – but it also problematizes it; the quest for an explanation is complicated by a clash between the materialist and the spiritual paradigm. Integrating these different perspectives is a challenge that they actively try to overcome. An additional dilemma is that spiritual explanations for non-ordinary experience are often regarded as a delusional symptom of psychiatric disorder:

When you become a voicehearer, the world appears to be different from what you thought it was. And you have to find an explanation for that. And because we don't have an explanation in our culture, except that it is a symptom of psychosis or something... well, that's why those explanations [that I have] often seem far-fetched to other people and why they are regarded as delusions. (Nicolas)

Nicolas and Tim both recognize that the medical model is only *one* perspective on hearing voices. They do not completely reject this perspective, but they recognize its limitations and therefore complement it with other perspectives – on a pragmatic level this poses no problems, although the theoretical combination presents a challenging clash between philosophical paradigms. The limitations of the medical model – practical as well as philosophical – were a widely discussed topic in my research. Many of the Intervoice supporters contrasted the limitations of biopsychiatry with the advantages of the Intervoice model. These two explanatory models will be discussed in the following sections.

6.4 The biomedical model

Participants were generally critical of the medical model of hearing voices. Even the few participants who (ambiguously) accepted the illness label expressed that the medical model has certain limitations. Common themes in this critique of the medical model and biopsychiatry are: its overemphasis on medication, its denial of spiritual reality and the emphasis on pathology. Each of these characteristics will be discussed in more detail.

The majority of participants have experience with antipsychotic medication and their attitudes towards pharmacological interventions for disturbing voices are ambiguous. Most people do not fully reject the use of medication; they acknowledge that neuroleptics (anti-psychotics) and anxiolytics (tranquilizers) can be useful temporary tools to decrease the fear and acute crisis that the voices can cause. However, they are critical towards the long-term use of such medication and object to the common psychiatric treatment in which medication is offered as the *only* treatment. Many participants warn against the adverse effects that long-term use of anti-psychotics can have; not only can they cause horrible side effects, but they can also obstruct recovery and learning to cope with the voices in a more constructive and sustainable way. Fascinatingly, one of the voice participants also shared his experiences with medication:

When Irene (my voice hearer) was on medication it was like trying to talk to someone who had their fingers in their ears and humming a tune. It frightened me and made us all very vulnerable. We [the voices] are all much happier now that [she] is no longer on medication. :) (Troublesome Companion)

Irene also comments on the use of medication, from her perspective:

Psychiatric drugs robbed me of 5 years of my life and I am still very angry about it. Like Troublesome Companion said, it made me even more dissociative and very vulnerable. It did nothing to help me with my experiences and added to my problems by causing massive weight gain (about 8stone), made me incontinent, made me dribble, sedated and foggy among so many more horrible adverse effects. It made me completely unable to make any sense of the experiences I was having and actually drove me to commit suicide so many times I can barely count. (Irene)

The following citations from George and Natalie represent the ambiguous attitude towards medication shared by most participants:

Sometimes it can be necessary, but I am strongly against it, I am medicated, but it is my experience that it doesn't stop the voices. It keeps us voicehearers from interpreting them, but it also muffles the world so it feels like you are inside a bell and everything is weird and you can have problems with dealing with the world. (George)

Medication can be helpful through certain periods, yes, but other resources MUST be utilized (Natalie, capitals hers)

Another feature of the psychiatric model which is lamented is its materialistic nature and the consequent denial of a spiritual reality. For many participants, hearing voices – and related other non-ordinary sensory perceptions – are essentially spiritual or metaphysical experiences. The voices are often not just experienced as voices, but as beings, entities or spirits. Psychiatry, as a branch of western medicine, is a product of western rational and reductionist science. Important premises upon which western medicinal science is based are rationality and materialism (Scheper-Hughes & Lock 1987); it is bound to clash with a more spiritual worldview. Not being taken seriously by psychiatrists and being informed that the voices are a meaningless symptom that should be eliminated, is a painful and frustrating experience for many participants. The frustration of having religious experiences being explained away as psychotic symptoms is conveyed by Erik (48).

*The **doctors** here... at the most they believe in God, but that God is actively **involved** in human lives.... that doesn't appear in their textbooks. [...] Yes, they deny religion! [...] But for people who are stuck – and psychiatry that says; God doesn't exist, it's an illusion.... it's part of schizophrenic delusions – well, then you will never get unstuck, and you will spend the rest of your life on pills in a room, and you will never be able to function in society. And you also deny **every** religion worldwide that has ever existed, you know. [...] So yes, that would be my message to the Netherlands: get lost with your concepts of reality; reality is **very** different from what we learn in schools and universities. Religion is being laughed at and ridiculed, you know. But it's a hundred per cent true, a hundred per cent. (Erik, emphasis his)*

The worldview of many participants is radically different from the western materialist gaze. Sometimes this worldview was instigated by one's experiences, while others described an interest in spirituality before having non-ordinary experiences.

Related to the previous points of critique is psychiatry's focus on voices as a symptom of brain pathology³⁸. According to many participants, the problems with hearing voices arise from the inability to deal with the voices or the underlying cause of the voices – such as traumatic experiences and repressed emotions. The perceived pathology is therefore in the *relationship* with the voices and an incorrect *response* to the voices, and treatment should focus on reliving past trauma, strengthening one's identity

³⁸ The idea that healthy people can also hear voices has become accepted in psychiatry. Psychiatry therefore does not claim that voices are always a sign of pathology. However, when the voices are threatening and when they cause suffering, they are regarded as symptoms of mental disease. (Choong et al. 2007, Waters 2010, Verdoux & van Os 2001).

and self-esteem. This will help to let the voicehearer become in control of the voices, which will then become more benign. In the psychiatric model, voices that cause suffering in the voicehearer are per definition pathological. The locus of pathology is in the brain, and the voices are a symptom that disease. What the voices say is regarded as meaningless and treatment focuses on elimination of these symptoms. Although for some people this way of looking at the voices is helpful, most participants reject the idea that voices are meaningless signs of pathology and many feel disrespected by this view:

When I was first introduced to the medical way of thinking of voices as a symptom of something wrong to be corrected I was horrified. Really, truly, deeply horrified. I felt completely lost because so much of my life, my inner world, my perception, cognition and reflection and my identity has always revolved around hearing voices. So being told it was something that I needed to get rid of to feel better or to function better just made me feel I was not being seen as the individual I was. I found it very disrespectful. (Alice)

6.5 Interoice as a cultural repertoire

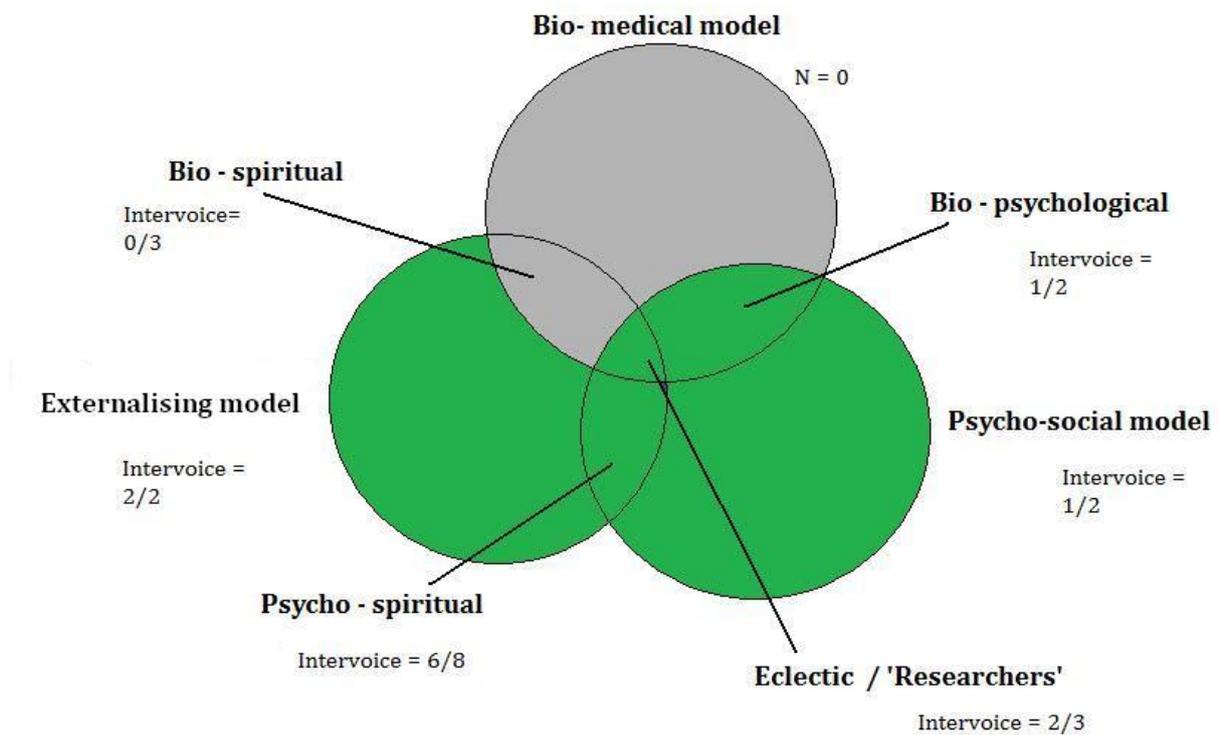
The Interoice approach takes a special position in my analysis, because it is not a clearly delineated explanatory system. Compared to the biomedical model, Interoice represents a cultural repertoire that is more flexible and less restrictive in describing *what* the voices are. Whereas it provides a detailed answer to the 'why voices' question (voices are caused by unresolved emotions resulting from traumatic life events), it fails to provide a detailed answer to the question 'what are the voices'. Rather than a weakness, this appears to be the strength of the Interoice approach. By not explicitly excluding spiritual explanations, it leaves room for voicehearers to engage with both a psychological (trauma based) and a spiritual explanation (voices are metaphysical beings). For example, Tamara explains her voices as spirits; deceased people. This spiritual explanation is complemented by a psychosocial explanation; the voices are connected to unprocessed emotions and trauma.

I am convinced that most people who hear voices cannot deal with their emotions; that they have never learned how to do this. [...] And this means that the voices will keep on coming continuously, because they want to be heard. They say: "do something about your trauma's!" That is what you have to deal with. They want to be heard. (Tamara)

Rather than conflicting, these explanations can be regarded as complementary. This as opposed to voicehearer who wants to combine a biomedical explanation with a spiritual explanation: combining those explanatory models creates a materialism-spirituality

paradox, which cannot always be resolved. Making such a bricolage is more likely to leave the voicehearer betwixt and between.

The Intervoice approach remains vague on the ‘what’ question whereas it is very specific on the ‘how’ question: how to deal with (negative) voices. The emphasis in the Intervoice approach lies on changing the relationship with the voices, which can be done by learning to understand the voices and by addressing the underlying trauma. Although the preferred method to achieve this is through psychotherapeutic methods and Hearing Voices groups – i.e. by *talking* - the use of medication is not completely rejected.³⁹ Participant-members of the Intervoice movement were remarkably nuanced about the use of medication. This marks another flexible characteristic of the Intervoice approach, which makes it accessible also to voicehearers who wish to use medication. While welcoming people who use (low doses of) medication, the Intervoice approach also offers an alternative to people who have negative experiences with anti-psychotics.



Schematic presentation of the position of Intervoice supporters and sympathisers

As shown in this scheme, Intervoice supporters and sympathisers (in green) can be found in almost all the explanatory systems. This reflects the flexibility and non-restrictive nature of the Intervoice approach.

³⁹ In this, the Intervoice approach differs from the ‘classical’ anti-psychiatric movement, which it is often compared to and to which it certainly bears some resemblance.

The cultural repertoire of the Intervoice approach is not as pervasive as the medical repertoire; it does not reach all voicehearers. The fact that the medical model has much more exposure explains why the most common route for voicehearers – when they need help - is to first try biopsychiatric treatment. For participants like Sara and Gaby this is a satisfactory and effective way of coping. For most of my participants, however, the experience with bio-psychiatric care was ambiguous or downright negative. These people abandoned the biomedical model and looked for alternatives. For this group, the Intervoice method often proved more effective.

Beside the pragmatic and flexible characteristics of Intervoice, many people also sympathize with this movement because it aims to normalize voice-hearing. Many participants resent that voices are mostly described as pathological and counter this view using normalizing statements. Samuel, for example, compares himself to ornithologists, who also listen to the voices (of birds) in nature: *I do something like that too; I study events through my voices*. Similarly, Thea would like other people to know that hearing voices is *'not pathological, it's entirely natural, and in its own way, quite wonderful!* People explained that to have their experiences described as pathology has deeply hurt them and that they have felt disrespected by such classifications. Therefore, Intervoice's effort to emancipate the experience is appreciated.

To conclude: the appeal of the Intervoice approach can be explained by its non-restrictive and non-excluding explanatory nature, which makes it easy to combine with other explanatory models. Furthermore, the pragmatic psychodynamic solution of how to deal with the voices has been effective for voicehearers in this research who have been disappointed by bio-psychiatric treatment. Finally, the Intervoice mission of de-pathologizing the experience of hearing voices and its suggestion that is a form of human variation increases its base of sympathisers.

7. Agency of voicehearers

This chapter will examine why some voicehearers use the biomedical discourse to describe themselves and why others reject it; participants' interaction with the body politic will be discussed and illustrated. The first section (7.1) will examine to what extent participants accept the medical discourse and it will demonstrate that there is a certain logic involved in identifying with it. The second section (7.2) will discuss how participants use cultural relativism to reject the dominant discourse on hearing voices. Finally, section (7.3) will assess how participants are involved in biopolitics, what role Intervoice plays in this and on which levels participants exercise agency.

7.1 Accepting the biomedical discourse

My research reveals that the relation between using a biomedical explanatory model and accepting a medical diagnosis is not as straightforward as might be assumed.

Participants who use biological explanations in their *bricolage* do not automatically identify themselves as having a psychiatric disease. At the same time, people who use spiritual explanations can identify with the biomedical discourse *and* use medical diagnoses to describe themselves. Some participants show an ambiguous identification with the dominant discourse: on some level they identify with it, on another level they disassociate from it. The following section will demonstrate that there is a certain logic involved in identifying with the dominant discourse.

Only four participants unambiguously used psychiatric diagnoses⁴⁰ to describe themselves. Of the people who were diagnosed with schizophrenia, only Tim and Sara called themselves 'schizophrenic'. Tim (29) has only recently started using this label:

Usually I would say: I've had a heavy psychosis and I still hear voices. And only six months ago I thought: well, ok... I'm actually just schizophrenic. (Tim)

Tim's narrative was interpreted as a 'research narrative' earlier on; he is still actively looking for a fitting explanation for the voices and with his television programme he will explore the cultural repertoires of 'exotic' cultures. His ambition is to unite the

⁴⁰ Other than psychosis, which I have explained to be an ambiguous category which respondents use as an umbrella term; it describes a state of mind or an escalation of mental crisis, rather than a disease category.

materialist biological paradigm with a more spiritual or metaphysical paradigm; his acceptance of the biomedical label can be seen as unexpected, in that regard. However, when examining his narrative in more detail, certain clues come to light as to why he chooses to identify with the disease category schizophrenia. First of all, he is satisfied with the (heavy) antipsychotic medication he is receiving. The medicine he takes – Clozapine – causes unpleasant side-effects. Yet, he prefers taking the medication to being psychotic – he has tried to do without it, but this did not work out well. For Tim, choosing to take medication is a choice for the lesser evil. He does not regard it as a cure but as something which suppresses the symptoms, but, he says, '*it works*'. If the price he must pay for this medication is to accept the psychiatric diagnosis of schizophrenia – and to accept living with the side effects – it is a price he is willing to pay.

Furthermore, Tim points out that 'being schizophrenic' comes with some benefits too. Because of his diagnosis, he was granted priority in the social housing sector. He now lives in a popular neighbourhood in a house for which '*other people have to be on a waiting list for 16 years*'. Because he receives a disability pension, he can spend all his time on making music and on developing his television programme. Tim says he is now '*sowing the seeds*' and that he hopes to be able to make a living from these activities in the future – it is not his ambition to live on State benefits his whole life. Tim's narrative suggests that identification with the dominant discourse is a dynamic process: it is a negotiation in which the price and the reward are weighed out against each other. For the present moment, Tim accepts that he is schizophrenic. However, his search for a better suited explanation is ultimately connected with the quest for a better suited treatment. If he finds these, he might abandon the disease label again.

Sara (22) describes a cyclical process of accepting and rejecting her psychiatric diagnosis. At times when she forgets that she has schizophrenia, the voices intimidate and scare her. She explains that for her, knowing that she has a disease helps to decrease her fear: *Because when I... know for sure that it's a disease... then I also understand that they cannot kill my father just like that*. Sara's narrative illustrates that accepting the disease label can be a form of agency; by declaring the voices as a meaningless symptom of a brain disease, her fear lessens and her sense of control increases. However, she also explains that this acceptance comes at a cost:

And then the moment arrives when I realise that it's schizophrenia [...] and a little later I become very sad and I think... why do I have to get this disease? It's difficult to have to realise this, time and time again. Because, well, it's a disease and you'd rather not be sick.

Again, Sara's narrative indicates that accepting the disease label is a negotiation. Like Tim, Sara is also taking the heavy anti-psychotic Clozapine, and the price she pays in the negotiation is having to live with the side effects of the medication. The grief of accepting the disease is an additional cost for feeling less afraid of the voices. Sara uses the diagnosis of schizophrenia as an instrument to take away the power of the voices; reducing them to symptoms of a disease makes them less real for her. It empowers her over the voices. For Sara, this process of negotiation is also dynamic: times when she forgets about the diagnosis alternate with accepting that she has schizophrenia.



Cartoon made by Sara⁴¹

Chantal and Ingrid both accept the diagnosis of borderline personality disorder. Chantal takes a nuanced and above all pragmatic approach to psychiatric diagnoses. She explains that for her the diagnosis was a relief because it gave her hope of successful treatment; her acceptance of the illness label is directly related to the treatment options that she knew exist for borderline. She adds that she would not have accepted a diagnosis such as schizophrenia or bipolar disorder because “*they only weigh very heavy on the person,*

⁴¹ Interestingly, deaf people have reported to ‘hear’ voices by having visions of someone communicating with them in sign language. (Critchley et al. 1981, Atkinson et al. 2007) In psychiatric terminology this would classify as ‘visual hallucinations’, but to me it emphasizes the fluidity of the concept of ‘hearing voices’. This echoes the findings in chapter 5 that voices do not have to be auditory to be perceived as voices.

without giving a good treatment perspective". This suggests that identification with the medical discourse depends on the diagnosis people receive, as well as on the prospect for successful treatment the diagnosis gives. The reward that Chantal and Ingrid received for accepting the diagnosis was a successful treatment for their problems.

A number of participants do not fully identify with the medical discourse, although they do use it as a cultural repertoire in their explanatory bricolages. Erik and Emily are examples of such ambiguous acceptance of the illness label. Emily explains that she is in the process of accepting that she has schizophrenia. However, she finds it difficult to accept:

Yes I know that it's schizophrenia, but I'm hesitant to accept the disease. [...] I really do n't like that it has happened to me... I actually just don't accept it. (Emily)

This citation indicates that accepting the disease label can occur on different levels: *knowing* that one has the disease apparently is not the same as accepting the disease. Although Emily cognitively accepts the disease label, she has not been able to do so emotionally. Erik's narrative reveals another ambiguity; although he does not accept the illness label, he does acknowledge that he has *symptoms* of schizophrenia. His comment that psychiatry does not even know what schizophrenia is, is backed up by critics of the biopsychiatric discourse (Bentall 2001, Read et al. 2004) At another point Erik mentions that he might have schizophrenia, but that this is not related to the voices:

So when they say, Erik, you have a schizophrenia gene, I will say: the genetic material you found shows my problems. They are mine. I have collected them in the course of my incarnations and I have become the way I am because of myself. But I will say: those voices, they have nothing to do with it.

This illustrates that participants who use biomedical terminology in their explanations, such as genes and schizophrenia, do not necessarily adopt the illness model and therefore do not per definition identify with the biomedical discourse.

7.2 Cultural relativism and rejection of the biomedical discourse

The majority of participants used normalizing statements and explicit rejections of psychiatric diagnoses for hearing voices. A remarkable recurring theme in these normalizing statements is cultural relativism; as if *they* are the anthropologists, participants often place the phenomenon of hearing voices in a cross-cultural

framework. Nicolas, for example, explains that he regards hearing voices as a human characteristic *'which is of all times and all places, and the explanations for which depend on the culture'*. He does not agree with the medical tendency to think in diagnoses, and does not find such categories helpful; he prefers to think in terms of people with experiences. Lilly also refers to other cultures: *'there are cultures where it's totally, completely normal, where they don't immediately bring you pills. [...] In some cultures you can just say, I hear voices. I have African friends – and there it's not crazy at all.'*

Another reason why participants question the biomedical discourse is its relationship to commercial stakeholders. Nicolas explains that *'another problem is that the brain disorder explanation is the basis for all psychopharmacology; many companies are making an awful lot of money with it.'* The biomedical emphasis on pharmacological treatment – not only for voices, but for all mental afflictions – was explicitly criticized by participants, and has also been questioned by academics. (Dehue 2008, Read et al. 2004, Bentall 2009) Richard Bentall, for example, comments that *'the pharmaceutical industry has spent enormous sums on persuading mental health professionals, lay people and politicians that patients suffering from chemical imbalances in the brain can only be cured by medication'* (Bentall 2009:275).

Not only the biomedical discourse was rejected for labelling the voices as a symptom of disease; the entire western culture, of which the biomedical discourse is a product, was often the subject of critique. Lilly expresses her discontent with *'western thinking'* for *'putting people in a box'* and for regarding voicehearers as *'crazy, as not normal [...] and as sick.'* In her rejection of the biomedical discourse, Irene refers to *'a societal issue in which western cultures are very much into quick fixes for any kind of emotional/spiritual/mental crisis'*, to which she adds that according to her, this *'just isn't possible.'* This critique of the cultural assumptions on which the medical discourse is based is reflected in Alice's account:

Fundamentally I think that the art of healing in western society has gone completely off course. Thinking of and treating living organisms as if they are dead machines... No matter if we talk normal medicine or psychiatry... We base our lives in the belief that "illness", pain, old age and death are all wrong, something to fix, get rid of or avoid. The medical world is based on these beliefs of what is "well" and "right". That we must not feel pain or deteriorate in any way and that we must stay alive at any price (Alice).

In their critique of the biomedical discourse, participants questioned the philosophical premises on which biomedical science is based, in a way that is reminiscent of the *'Mindful Body'* article by Scheper-Hughes and Lock (1987). These authors also suggest

that 'at least one source of body alienation in advanced industrial societies is the symbolic equation of humans and machines' (ibid.: 22). Moreover, they point to Cartesian Dualism as the basis of 'radically materialist thinking [which is] characteristic of clinical biomedicine':

A singular premise guiding Western science and clinical medicine (and one, we hasten to add, that is responsible for its awesome efficacy) is its commitment to a fundamental opposition between spirit and matter, mind and body, and (underlying this) real and unreal. (Scheper-Hughes & Lock 1987: 8)

This citation beautifully captures the essence of many participants' rejection of the biomedical discourse: its underlying materialist basis does not allow any other explanation for hearing voices than a brain based pathology. There is an important difference between using biological terminology - or expressing an interest in brain research - and accepting the materialist paradigm. Peter explicitly points to this difference: *'I do not refute [Dick] Swaab⁴² - I only refute his philosophical claim. What he has discovered about the brain is all very interesting.'*

7.3 Intervoice and agency

Instead of referring to a psychiatric illness label, or to the umbrella category of mental illness, participants who support the Intervoice movement identify themselves on the basis of their experience of hearing voices. They refer to themselves as *voicehearers*. Not self-identifying with medical diagnoses can itself be seen as a form of passive-resistance against the body politic. However, participants also actively engage in biopolitics. This section illustrates how the Intervoice participants exercise agency and it analyses the role that Intervoice plays for participants in dealing with the body politic.

On the level of the lived experience of voicehearers, the concepts of power and resistance apply to the individual's relationship to the voices. Those participants who are in control of the voices exercise agency by restricting the power that the voices have over their lives. As has been described in chapter 5, this can be done in several ways; from channelling or expressing emotions to learning to understand the voices and making agreements with them. On the contrary, a lack of agency can result in obeying the voices, believing their threats, intense anxiety or even escalation into psychosis. Deducing from the narratives of my participants, the strength of the Intervoice approach is that it

⁴² The neuroscientist who was mentioned in chapter 2.2, author of the bestseller 'We are our Brain'.

teaches voicehearers how to become in control of the voices and to establish a better relationship with them. On this level, the voicehearer is literally empowered – in relation to the voices.

I do what I want. But because I learned how to talk with them and how to make agreements with them... I choose what I do. And they accept that. I have to do it. They help, but if I don't listen it's my own responsibility. (Tamara, emphasis hers)

According to the Intervoice discourse, the voicehearer can learn to live with the voices through an active process of learning to listen and understand them. Instead of waiting for the voices to go away by taking antipsychotic medication, the voicehearer is actively involved in his/her recovery. Although this recovery process can be emotionally difficult, participants like Natalie and Irene prefer it over a strictly medical treatment. They emphasize that the voicehearer should play an active role in recovery; according to these participants, this idea is lacking in the medical approach.

I think anybody that's told they have to live their whole life "medicated" loses a certain sense of hope and power. They are being told their experience is wrong and should be stopped. To me it's not about shutting out voices or symptoms, for you have to feel and deal with them to get through to the other side at some point. (Natalie)

The dominant perspective is a very medical one which puts a person in a very passive role. "Here take this tablet, sit back and wait for it to work". Whereas actually, I think that a journey of healing and self-discovery is actually one that involves a lot of active participation in the process. (Irene)

On the level of the social body – which deals with cultural interpretations and representations of hearing voices – Intervoice does not restrict the explanatory model for hearing voices to a materialist paradigm. As has been discussed in section 6.5, this leaves the voicehearer free to interpret the nature of the voices in his/her own way and it emancipates the voicehearer from a (materialist) worldview that does not resonate with his or her experiences. Irene, for example, explains most voices from a psychological perspective, but also hears who she believes to be ‘a guardian angel’ and she also has ‘a part that tells me she is a spirit – once a living person and I believe her on that’. Agency, on this level, can be ascribed to those participants who resist the dominant representation of voices and who stick to their own interpretation because it is more meaningful to them.

Resistance against the medical discourse involves changing the societal norms on hearing voices. Many participants contribute to this process by raising awareness and fighting stigma. This agency is directed at the voicehearers’ immediate environments

and at society at large; the public discourse on hearing voices is the target of action. Individuals who are not involved with Intervoice also engage in this form of agency; even those who accept the illness label strive to normalize the experience of hearing voices by changing public opinion. For them, the aim is not to remove hearing voices from the medical discourse, but to change the perceptions and attitudes about it in society and to lessen the stigma. Most of my participants have experienced some form of stigmatization or discrimination. The following citation will illustrate the pain that this can inflict:

Some still will not accept and will not realize the truth: that I am a human like them, that I am not dangerous, just have a little more to fight with at times and that I am a great guy...I hate ignorant people just blindly believing, I hate the medias sending out lies, and I hate the psychiatrists who exclaim that they are experts but say the complete opposite of the truth. (George)

As Emma explains and other participants' accounts also reveal: '*the perceived link between violence and voices is very pervasive*'. The media is partly seen as responsible for perpetuating this prejudice; examples of such media representations have been given in chapter 2.2. The stereotype of negative and dangerous voices is harmful to voicehearers in another way, as Alice explains: '*It is a self-fulfilling prophecy because anyone who then experiences hearing voices will get scared – of themselves and the experience and that will start off a vicious circle*.' Generally, participants want to create more understanding for hearing voices and they try to raise awareness by openly talking about their experiences. Emma, who runs Hearing Voices Groups for teenagers and who is an active member of Intervoice, explains how she uses humour as a tool in fighting prejudice:

At college, after keeping my voice-hearing quiet for a year, a good natured reaction to my disclosure was 'do they tell you to kill people?' Nothing bad was intended, but the perceived link between violence and voices is very pervasive. The way I've learnt to deal with these good natured, but ill informed, comments is in using humour. I often joke that I've left my axe at home (or that it's in my other bag). I then do a bit of awareness raising (which people are often quite interested in). (Emma)

For most participants, the motivation to participate in this research should also be seen in the light of raising awareness. People often regarded my thesis as a potential vehicle to change the perception on hearing voices; my research was perceived as a way of influencing the social body and the cultural norms about hearing voices. Participation in research such as this, can therefore in itself be regarded as an act of agency – and for many also an act of resistance against the social body.

Not all participants who sympathize with the Intervoice movement also actively engage in its emancipatory struggle. Judging from their accounts, the peer-support function of the movement is perhaps as important as its emancipatory task, and is greatly facilitated by the internet. In the areas where Hearing Voices Groups are organized, people can also connect to others offline; these self-help groups also serve the purpose of peer support. By creating a community where other norms apply and where conformation to the psychiatric cultural norms is not demanded, voicehearers can experience a (temporary) relief from the body politic. The Intervoice community is valuable to participants, because it is a safe environment where they feel respected and understood and in which they are exempt from the stigmatization that they encounter in society at large. Emma's citation is illustrative of the relief from the body-politic that voicehearers can experience through peer-support:

I found solace from other people's perceptions of my experiences by joining a Hearing Voices Group and other survivor organisations. We created a community where, for the most part, others beliefs didn't matter quite so much. For a while, my social circle was completely people from these groups. I felt no stigma at all. (Emma)

Apart from reaching inward by giving peer-support, the Intervoice movement community also reaches outward. By trying to influence the dominant discourse on hearing voices, Intervoice attempts to emancipate the experience and to remove it from the domain of biopsychiatry. A number of participants contribute to this process: they are active members of the movement. Through their work as experts-by-experience, they educate mental healthcare professionals and medical students by giving workshops and lectures. Lilly explains how her motivation to give lectures to medical students is fuelled by her positive experiences with the Intervoice approach as well as by her negative experiences with the medical model: *'[it makes me]more agitated and more resolute... wanting to dedicate myself even more. And that's why I'm so happy that I can reach all those students.'*

The biomedical discourse is essentially a system of knowledge, which is both maintained and recreated through the education of medical students and medical professionals. Therefore, the practice of targeting this population by organizing lectures, in which an alternative perspective on hearing voices is introduced, can be regarded as a constructive effort to influence the dominant discourse. In promoting the Intervoice discourse, not only voicehearers are actors in a process of cultural change; their voices

too can engage in this process. Together with his voicehearer Irene, Master Ace recently gave a presentation at the International Intervoice Conference in Cardiff and explains:

I'm spending my time on changing how people see us voices. Right now I'm constructing a website with Troublesome Companion and Angie (more of Irene's voices) that will support voices in their journey to living harmoniously with their voice hearer. (Master Ace)

In the UK, where Intervoice is most active, the efforts of the movement are beginning to influence mainstream mental healthcare. On a government website of the British National Health Service about 'hallucinations and hearing voices', the advice is given to 'talk to other voice hearers' and to 'try the Hearing Voices Network', which is followed by a link to the Intervoice website.⁴³ In the Netherlands, a symposium about the Intervoice vision was recently organized at a large mental healthcare institution near Amsterdam. This sold out event was received with enthusiasm and interest by the attending healthcare professionals. It is through events like these that the Hearing Voices Movement attempts to influence and reshape the dominant discourse on voices. Being able to contribute to this process of cultural change is regarded as empowering by participants; their experiences with hearing voices become *experienced based knowledge*, which they employ to help others.

This section has demonstrated the ways in which the Intervoice approach to hearing voices stimulates the agency of voicehearers. Although my focus in this section has been on Intervoice participants, I would like to briefly emphasize that agency is not their prerogative; the narratives of other participants also point to agency and empowerment. One example is choosing to take antipsychotic medication. For Sara, Tim and Gaby, taking medication is the prime method of dealing with the voices and all three of them express that they are helped by it. Furthermore, Tim and Sara state that – in spite of having schizophrenia and taking medication – they have a good life and they do not present themselves as victims of the medical discourse. Tim is very optimistic and very active in giving meaning to his experiences:

You are the director of your own life. Everybody encounters setbacks. That's the art of life; to overcome those setbacks. [...] You know, life doesn't end when you hear voices. Of course, it can be very tough. Of course. I will not deny that. But you know, you have to give it a positive spin. Do something with it. Start writing, painting, or help other people who suffer from it. (Tim)

⁴³ Source: <http://www.nhs.uk/conditions/hallucinations/Pages/Introduction.aspx>

Therefore, to equate the medical discourse with oppression while ascribing empowerment to Intervoice would be too simplistic – although some participants have expressed that they feel it this way.

8. Conclusion and personal reflection

The first section (8.1) of this concluding chapter will recapture the core findings and analysis that have been discussed in this Master thesis. The final section of this thesis (8.2) will present some of my personal reflections on the outcome of this research and its possible implications.

8.1 Conclusion

The main objective of this thesis was to give insight into the lived experience of hearing voices, and to illustrate the discrepancies that exist between such lived experiences and the dominant medical model. The narratives of my participants – most of whom have a history as recipients of psychiatric care – were studied from three analytical angles. In the chapter on the phenomenological experience – the *individual body* – of hearing voices I demonstrated that the term ‘voicehearer’ is ambiguous, that the experience cannot easily be generalized and that it is too complex to fit simplistic dichotomies such as negative/positive. Even the premise that voices express themselves verbally was refuted. Although the participants in this research identified themselves as voicehearers, they often reported other non-ordinary perceptions such as visions or tactile sensations. I argued that the answer to the first research question, ‘what is it like to hear voices’ cannot easily be captured. The diversity in phenomenological variables to the experience seems endless. Therefore, the only conclusion that can be drawn from this part of my research is that hearing voices is a highly individual and complex experience that cannot be generalized easily.

One aspect about the experience of hearing voices is that it is dynamic; familiar voices can disappear, new voices can arrive at the scene, positive voices can turn into negative ones, and threatening voices can become benign. The answers to the questions ‘when does hearing voices become problematic’ and ‘how do people overcome these problems’ are related to the dynamic character of the experience. I illustrated that voices

can be perceived as problematic for several reasons. Although a lack of concentration and fatigue brought about by the voices are common complaints, this is not the reason why people end up seeking help. Participants usually end up in psychiatric care after having yielded to the threats and commands of abusive voices; in these situations, the voices were in control of the individual. By examining several case-studies of participants who have undergone (or who are currently undergoing) a process of transformation, I have highlighted some common factors that are involved in overcoming problematic voices. The participants in these *narratives of transformation* all engaged in a process of learning to deal with past trauma and emotions. Furthermore, instead of ignoring the voices, they listened to what they had to say and they learned how to establish a better relationship with them, in which the voices are no longer in control. These narratives suggest that, for these participants, psychotherapy is a viable alternative to pharmacological treatment in dealing with concerning voices.

The analytic level of the *social body* was used to illustrate how participants make use of a diversity of cultural repertoires while engaging in a process of theory-building. I have demonstrated that their explanatory models are mostly *bricolages* that combine externalising and internalising explanations for what the voices are and why they present themselves. Although some participants adapt some biological elements in their bricolage – by referring to brain activity, genetic disposition or medical diagnoses – none of the participants use the medical model as their only explanatory model. This suggests that the biological model is not sufficient to explain the full experience of hearing voices. Other cultural repertoires from which participants have drawn explanations are the psychodynamic paradigm, the para-psychological paradigm and a diversity of spiritual and religious paradigms. I have suggested that in making these *bricolages*, my participants are rational actors. They adapt and dismiss explanatory models through a process of trial and error; different models are assessed pragmatically, philosophically and phenomenologically.

From the narratives of my participants, limitations of the biomedical model could be distilled. These limitations were highlighted through the case-studies of two participants who presented *research narratives*; these participants not only experience but are also aware of a clash between the materialist scientific paradigm and the spiritual paradigm. Other participants also lament the biomedical denial of spirituality. I have argued that the Intervoice discourse is an appealing cultural repertoire for

voicehearers, because it does not explicitly deny the spiritual dimension to hearing voices. By focussing on the 'why' and 'how' questions and largely ignoring the 'what' question, the Intervoice approach is more flexible and therefore more accessible to voicehearers who identify their voices as spiritual or metaphysical beings. In contrast, the biomedical model is more restrictive. Another appealing factor about the Intervoice discourse is its mission to normalize the voice-hearing experience.

Furthermore, the analytical angle of the *body politic* was used to examine how participants engage in biopolitics and to assess on which levels they exercise agency. I demonstrated that some participants (partially) identify with the dominant discourse, while others explicitly reject it. I have argued that in relating to the biomedical discourse, participants are also rational actors; they are involved in a dynamic process of negotiation, in which the benefits and disadvantages of accepting the disease label are weighed out. Participants who explicitly reject the biomedical discourse often adopt a cultural relativistic attitude; these participants recognize psychiatry as a cultural product of western societies. The discrepancy between their lived experience of hearing voices and the medical model can be summarized as a clash between cultural paradigms.

Finally, I illustrated how voicehearers engage in biopolitics by actively working on sociocultural change through their work as experts-by-experience. On the level of the individual body, participants exercise agency by becoming empowered over their voices. The Intervoice method is valued by participants for its focus on establishing a better relationship with the voices and thereby stimulating peaceful co-existence. By some participants, agency is exercised by taking anti-psychotic medication, although this approach focuses on suppression and elimination of the voices instead of coexistence and understanding. On the level of the social body, participants exercise agency by actively fighting stigma and creating awareness. This agency is directed at changing sociocultural values. On a more individual level, the process of giving meaning to one's experiences – by using an explanatory model that is either in accordance or in opposition to the cultural norms – can also be regarded as agency. Finally, seeking peer-support in self-help groups or in Intervoice community is also an act of agency, through which participants find (temporary) relief from the stigmatizing body politic.

8.2 Personal reflection

The narratives of my participants struck a chord with me on several levels. Not only did they stimulate my academic thinking and reinforce my motivation as a healthcare worker, but they also triggered a desire to be involved in their struggle for change. This research made me sensitive to the gap between the lived experience of voicehearers and the perspective of the mental healthcare professionals that try to help them. I realize that my research population was a specific one and that my research may not represent voicehearers who do not experience such a gap between their life-world and the medical perspective. With these biases in mind, I would like to briefly discuss some therapeutic recommendations, ethical implications and suggestions for further research that follow from my analysis.

My first recommendation to mental healthcare concerns the main complaint that participants voiced about psychiatry; they did not feel that their experiences were taken seriously. Taking the explanatory model of the voicehearer seriously would benefit the therapeutic relationship between doctor and patient. In my opinion, psychiatry would do well to look beyond the boundaries of the discipline and to cooperate with other healthcare professionals. One of the mayor psychiatric institutions in Amsterdam is currently offering specialized Winti⁴⁴ treatment to psychiatric patients with a Surinamese background. While acknowledging the influence of culture on the experiences of ethnic minorities, psychiatry ignores the role that culture can play on the experiences of native Dutch⁴⁵ people. For them, spirituality can be equally important, and it is often reinforced by the experience of hearing voices. In commenting on the concept of cultural competence, Kleinman and Benson (2006) suggest that the clinical interview should ideally resemble a 'mini-ethnography', in which the clinician elicits the explanatory model of the patient. By listening to the illness narrative of the patient, the clinician can learn what is at stake for the person, and take this into account during treatment. I would recommend psychiatrists to adopt such an approach in dealing with all clients – not just ethnic minorities. The participants in this research have illustrated

⁴⁴ "An Afro American religion, within which the belief in personified supernatural beings occupies a central position. These personified supernatural beings can take possession of a human person, switch off their consciousness, as it were, and thereby reveal things concerning the past, present and future as well as cause and/or heal illnesses of a supernatural nature." (Wooding 1972)

⁴⁵ Or Danish, British, Australian, etc.

what is often at stake; the rejection of profound personal experiences by reducing them to a disorder of the brain.

Another recommendation for mental healthcare that I would like to suggest revolves around the use of experts-by-experience. Several participants have emphasized the importance of experts-by-experience when dealing with overwhelming non-ordinary perceptions. Some even said that their first psychosis could have been prevented, if only they had had someone 'like them' to talk to. Joseph Campbell has suggested that 'The psychotic drowns in the same waters in which the mystic swims with delight'.⁴⁶ This metaphor can also be used to indicate the difference between healthy voicehearers and people for whom the voices are problematic. Instead of denying people the potential delight of the water, perhaps all that is needed is teaching them how to swim.⁴⁷ I want to argue that experts-by-experience are an essential element in transforming the negative voice-hearing experience; whereas someone on the shore can only give directions, someone in the water is a direct example and a source of hope and inspiration; he proves that it can be done. The role of 'swimming teacher' could also be assumed by a spiritual teacher who knows how to navigate in these realms of consciousness because of his/her own experiences with non-ordinary states. This has also been suggested by a number of participants.⁴⁸

Additionally, I would like to point out an ethical issue raised by my research that pertains to the freedom of religion. In western societies, freedom of religion is considered a universal human right; people are free to believe in whichever higher power they want and should be respected in their belief systems by others. However, if voicehearers explain their experiences in spiritual or religious terms, they are often considered delusional. Because the voices cause trouble, they are denied any metaphysical reality and are instead explained as symptoms of a mental illness. Is it ethically right to deny the perceived spiritual nature of 'psychotic' symptoms? Why does the human right to freedom of religion not seem to apply to psychiatric patients? Why is there such a taboo on non-ordinary states of consciousness in western societies and how

⁴⁶ Cited in Grof 2010: 137.

⁴⁷ To build upon this metaphor: an expert-by-experience who talked at the 2012 conference of Stichting Weerklank (Stemmen Horen Congres - Castricum) introduced her lecture with the words 'You *cannot* stop the waves. But you *can* learn how to surf.'

⁴⁸ Such interventions would challenge biomedical authority - by handing over biopower to experts of experience or alternative healers - and therefore it is debatable whether they are feasible in the near future. However, the rapid proliferation of Complementary and Alternative Medicine in our society indicates that - at least for physical ailments - people increasingly resort to medical pluralism (Bode 2011, Coulter & Willis 2004).

does this rhyme with the freedom of religion? These are some of the ethical and philosophical questions that were triggered by my research and in my opinion deserve further exploration.

These final words will be dedicated to the concept of hope – which to me personally, represents the essence of what my research was *really* about. Arthur Kleinman writes that ‘chronicity arises in part by telling dead or static stories, situating the individual in a wasteland, a denervated place, robbed of its fertility and potential’ (Kleinman, 1988: 180). For many of my participants the diagnosis of schizophrenia represents exactly that; a wasteland, robbed of potential. The possibility that belief in an incurable brain disease can actually *make* the experience of hearing voices negative and chronic, while believing that voices can be negotiated with and carry meaningful messages might actually *create* a more positive outcome, deserves more attention. This touches on the notion of symbolic healing, of which the placebo effect is a - biomedically acknowledged- example. As a researcher, I think that the relationship between hope, agency and recovery from severe mental distress deserves more extensive social scientific and psycho-cultural investigation. Perhaps mental healthcare could benefit by shifting its emphasis: from treating the brain as a potential enemy, to treating the mind as a potential ally. After all, hope does not foster in genes or synapses, but comes to expression in the mind. As a caregiver, I have found enough hope in the narratives of my participants. May their resilience, creativity and perseverance in dealing with voices be an inspiration to others – professionals, voicehearers and voices alike.

I completely understand why they were being so abusive towards me and that they were having just a hard a time as me. All they were trying to do was help me and flag up that I needed to start working on various things. But they are the reason I am here today and if they hadn't arrived then there is no way I would be who I am today. They are the reason I managed to survive difficult circumstances. So really what they did for me completely outweighs the nasty things they said... We have all made things difficult for each other in our own ways, but we were just doing the best we could, given our circumstances. We have all apologized and shown remorse but we focus on our relationship now and it's a great one! (Irene)

References

Artwork on title page: Edvard Munch - The Scream of Nature (Der Schrei der Natur) - 1895

Al-Issa, Ihsan

1995 The illusion of Reality or the Reality of Illusion. Hallucinations and Culture. *British Journal of Psychiatry* 166: 368-373.

Allsop, J.K. Jones and R. Baggot

2004 Health consumer groups in the UK: A new social movement. *Sociology of Health and Illness* 26, no. 6: 737-56.

American Psychiatric Association

2000 *Diagnostic and Statistical Manual of Mental Disorders IV-TR*. Fourth edition, text revised. Washington, DC.

American Psychiatric Association

1994 *Diagnostic and Statistical Manual IV*. Washington, DC.

Aschebroc, Yasmin & Nicola Gavey, Tim McCreanor and Lynette Tippett

2003 Is the content of delusions and hallucinations important? *Australasian Psychiatry* 11(3): 306-311.

Joanna R. Atkinson, Kate Gleeson, Jim Cromwell & Sue O'Rourke

2007 Exploring the perceptual characteristics of voice-hallucinations in deaf people. *Cognitive Neuropsychiatry*, 12: 4, 339-361.

Beavan, Vanessa & John Read

2010 Hearing Voices and Listening to What They Say: The Importance of Voice Content in Understanding and Working With Distressing Voices. *Journal of Nervous and Mental Disease* 198 (3): 201 -205.

Bentall, Richard P.

2003 *Madness Explained: Psychosis and Human Nature*. London: Allen Lane.

Bentall, Richard P.

2009 *Doctoring the Mind. Why psychiatric treatments fail*. London: Allen Lane.

Bentall, Richard P.

2011 The Point Is to Change Things. *Philosophy, Psychiatry, & Psychology* 18 (2): 167-169.

Betty, Stafford

2005 The Growing Evidence for 'Demonic Possession': What should Psychiatry's Response be? *Journal of Religion and Health*, vol. 44(1): p. 13-30.

Blume, Stuart

2000 Land of Hope and Glory: Exploring Cochlear Implantation in the Netherlands. *Science, Technology, & Human Values*, 2000, Vol.25 (2), pp.139-166 .

Bode M.

2011 The transformations of disease in expert and lay medical cultures. *J. Ayurveda Integr. Med* vol. 2(1):14-20.

Brown, P. and S. Zavestovski

2004 Social movements in health: An introduction. *Sociology of Health and Illness* 26, no. 6: 679-94.

Bury M.

1982 Chronic illness as biographical disruption. *Sociol Health Illn.* Jul;4(2):167-82.

Butin, D.W.

- 2001 If this is resistance I would hate to see domination: Retrieving Foucault's notion of resistance within educational research. *Educational Studies* 32 (2):157-176.
- Carpenter-Song, Elizabeth, E. Chu, R.E. Drake, M. Ritsema, B. Smith & H. Alverson
2010 Ethno-cultural variations in the experience and meaning of mental illness and treatment: implications for access and utilization. *Transcultural Psychiatry* vol. 47(2): 224-225.
- Castillo, Richard J.
2003 Trance, Functional Psychosis, and Culture. *Psychiatry* 66(1): 9-21.
- Choong C, Hunter MD, Woodruff PW.
2007 Auditory hallucinations in those populations that do not suffer from schizophrenia. *Curr Psychiatry Rep.* 9(3):206-12.
- Cohen, Alex & V. Patel, R. Thara, O. Gureje
2008 Questioning an axiom: better prognosis for schizophrenia in the developing world? *Schizophrenia Bulletin* vol. 34(2): 229-244.
- Conrad, Peter
1992 Medicalization and Social Control. *Annual Review of Sociology*, Vol. 18: 209-232.
- Csordas, Thomas J. (ed.)
1994 *Embodiment and Experience: The Existential Ground of Culture and Self*. Cambridge: Cambridge University Press.
- Csordas, Thomas J.
1994 *The sacred self: A cultural phenomenology of charismatic healing*. Berkeley: University of California Press.
- Coulter, D. and E. Willis
2004. The rise and rise of complementary and alternative medicine: A sociological perspective. *The Medical Journal of Australia* 180, no. 11: 587-89.
- Critchley E.M., Denmark J.C, Warren F, & Wilson K.A.
1981 Hallucinatory experiences of prelingually profoundly deaf schizophrenics. *British Journal of Psychiatry* 138: 30-2.
- Davis, J.E.
2009 Medicalization, social control and the relief of suffering. In: Cockerham WC (ed.) *The New Blackwell Companion to Medical Sociology*. Malden, MA: Blackwell Publishers, 211-241.
- Desjarlais, Robert & C. Jason Throop
2011 Phenomenological Approaches in Anthropology. *Annual Review of Anthropology* vol. 40 : 87-102.
- Dehue, T.
2008 De depressie-epidemie: over de plicht het lot in eigen hand te nemen. Amsterdam: Augustus.
- Dongen, Els van
1994 *Zwervers, knutselaars, strategen. Gesprekken met psychotische mensen*. Amsterdam: Thesis Publisher.
- Dongen, Els van
1998 'I wish for a happy end'. Hope in the lives of chronic schizophrenic patients. *Anthropology & Medicine* 5(2): 169-192.
- Dongen, Els van
2002 *Walking stories. An oddnography of mad people's work with culture*. Amsterdam: Rozenberg Publishers.
- Estroff, Sue & W. Lachicotte, L.C. Illingworth, A. Johnston
1991 Everybody's Got a Little Mental Illness: Accounts of Illness and Self among People with Severe, Persistent Mental Illness. *Medical Anthropology Quarterly, New Series*, vol. 5 (4): p. 331-369.

- Foucault, Michel
2001 [1954] *Madness. The Invention of an Idea*. Presses Universitaires de France/
Harper Collins Books: New York.
- Foucault, Michel
1964 *Madness and Civilization*. New York: Vintage Books
- Foucault, Michel
1973 *The Birth of the Clinic: An Archaeology of Medical Perception*. New York: Pantheon Books.
- Foucault, Michel
1975 *Discipline and Punish: The Birth of the Prison*. New York: Vintage Books
- Foucault, Michel
1991 Governmentality. In Burchell G, Gordon C and Miller P (eds) *The Foucault Effect: Studies in Governmentality*. London: Harvester Wheatsheaf, 87–104.
- Friedner, Michele
2010 Biopower, Biosociality, and Community Formation: How Biopower Is Constitutive of the Deaf Community. *Sign Language Studies* Vol. 10 (3): 336-347.
- Gaventa, John
2003 *Power after Lukes: a review of the literature*. Brighton: Institute of Development Studies.
- Gagg, Sue
2002 The Reality of Voices: 'Auditory Hallucinations'. *Australian & New Zealand Journal of Family Therapy* 23(3): 159-165.
- Good, Byron
1994 *Medicine, Rationality, and Experience: An Anthropological Perspective*. Cambridge: Cambridge University Press.
- Giddens, Anthony
1991 *Modernity and Self Identity: Self and Society in the Late Modern Age*. Oxford: Polity Press.
- Green, Judith & Nicki Thorogood
2004 *Qualitative methods for health research*. London: Sage Publications.
- Grof, Stanislav
2000 *Psychology of the Future: Lessons from Modern Consciousness Research*. Albany, NY: State University of New York Press.
- Halfmann, Drew
2011 Recognizing medicalization and demedicalization: Discourses, practices, and identities. *Health (London)* 16: 186.
- Hanegraaff, Wouter J.
1999 New Age Spiritualities as Secular Religion: a Historian's Perspective. *Social Compass* 46(2): 145- 160.
- Hanegraaff, Wouter J,
2003 How magic survived the disenchantment of the world. *Religion* 33 : 357 - 380.
- Harrison G. et al.
2001 Recovery from psychotic illness: a 15- and 25-year international follow-up study." *British Journal of Psychiatry* 178: 506-17.
- Helman, Cecil G.
(2001 [1984]) *Culture, Health and Illness* (fourth edition). London: Arnold Publishers.
- Hess, D.
2004 Medical modernisation, scientific research fields and the epistemic politics of health social movements. *Sociology of Health and Illness* 26, no. 6: 695–709.
- Houtman, Dick & Peter Mascini

- 2002 Why Do Churches Become Empty, While New Age Grows? Secularization and Religious Change in the Netherlands. *Journal for the Scientific Study of Religion* 41(3): 455-473.
- Houtman, Dick & Stef Aupers
2003 Oriental Religion in the Secular West: Globalization, New Age, and the Reenchantment of the World. *Journal of National Development*, Vol. 16, No. 1 & 2, p.67-86.
- Hughes, Bill
2009 Disability activism: social model stalwarts and biological citizens. *Disability & Society*, 24: 6, 677-688.
- Jaarsma P & Welin S.
2012 Autism as a natural human variation: reflections on the claims of the neurodiversity movement. *Health Care Anal.* 20(1):20-30.
- Jablensky, A. & N. Sartorius, G. Ernberg et al.
1992 *Schizophrenia: manifestations, incidence and course in different cultures: a World Health Organization ten-country study*. Psychological Medicine, Monograph Supplement 20. Cambridge: Cambridge University Press.
- Jablensky, Assen
2000 Epidemiology of schizophrenia: the global burden of disease and disability. *Eur Arch Psychiatry Clinical Neuroscience* 250: 274-285.
- Jenkins, Janis H. & Elizabeth Carpenter-Song
2005 The new paradigm of recovery from schizophrenia: cultural conundrums of improvement without cure. *Culture, Medicine and Psychiatry* 29: 379-413.
- Jenness V. & Broad K.L.
1994 Antiviolence activism and the (in)visibility of gender in the gay/lesbian and women's movements. *Gend. Soc.* 8: 402-23.
- Jobe, Thomas H. & Martin Harrow
2010 Schizophrenia Course, Long-term Outcome, Recovery and Prognosis. *Current Directions in Psychological Science* 19: 220-225.
- Johnston, Hank & Bert Klandermans (eds.)
1995 *Culture and Social Movements*, Minneapolis: University of Minnesota Press.
- Kleinman, Arthur
1978 Concepts and a model for the comparison of medical systems as cultural systems. *Social Science and Medicine* 12(2B): 85-95.
- Kleinman, Arthur
1987 Anthropology and psychiatry. The role of culture in cross-cultural research on illness." *British Journal of Psychiatry* 151: 447-454.
- Kleinman, Arthur
1991 [1988] *Rethinking Psychiatry*. New York: Basic Books.
- Kleinman, Arthur & P. Benson
2006 Anthropology in the clinic: the problem of cultural competency and how to fix it. *PLoS Med.* 3(10): e294.
- Kvigne, K. & E. Gjengedal, M. Kirkevold
2002 Gaining access to the life-world of women suffering from stroke: methodological issues in empirical phenomenological studies. *Journal of Advanced Nursing* 40(1), 61-68.
- Kyziridis, T.C.
2005 Notes on the History of Schizophrenia. *German Journal of Psychiatry* (8): 42-48.
- Larsen, John A.
2004 Finding Meaning in First Episode Psychosis: Experience, Agency, and the Cultural Repertoire. *Medical Anthropology Quarterly, New Series*, vol. 18 (4): 447-471.

- Lindseth, Anders & Astrid Norberg
2004 A phenomenological hermeneutical method for researching lived experience. *Scand J Caring Sci*; 18: 145–153.
- Luhrmann T.M.
2000 *Of Two Minds: The Growing Disorder in American Psychiatry*. New York City, Alfred A. Knopf.
- Meho, Lokman I.
2006 E-Mail Interviewing in Qualitative Research: A Methodological Discussion. *Journal of the American Society for Information Science and Technology* 57 (10): 1284–1295.
- Merleau-Ponty, Maurice
1962 *Phenomenology of Perception*. Trans. James Edie. Evanston, IL: Northwestern University Press.
- Mosher, Loren R. & Richard Gosden, Sharon Beder
2004 Drug companies and schizophrenia. Unbridled capitalism meets madness. In: Read et al. 2004, *Models of Madness. Psychological, social and biological approaches to schizophrenia*. Hove, East Sussex: Routledge: 115-130.
- Nichter, Mark
2008 *Global Health. Why Cultural Perceptions, Social Representations and Biopolitics Matter*. Tuscon: The University of Arizona Press.
- Nicolson, Stephen E & Helen S. Mayberg, Page B. Pennell, Charles B. Nemeroff
2006 Persistent Auditory Hallucinations That Are Unresponsive to Antipsychotic Drugs. *American Journal of Psychiatry* 163(7): 1153-1159.
- Noonan, R.K.
1995 Women against the state: political opportunities and collective action frames in Chile's transition to democracy. *Sociol. Forum* 10: 81-111.
- Ortega, F.
2009 The cerebral subject and the challenge of neurodiversity. *Biosciences*, 4 : 425–445.
- Racine, Eric & Sarah Waldman, Jarett Rosenberg, Judy Illes
2010 Contemporary neuroscience in the media. *Social Science & Medicine* 71: 725-733.
- Read, John, Loren R. Mosher & Richard P. Bentall
2004 *Models of Madness. Psychological, social and biological approaches to schizophrenia*. Hove, East Sussex: Routledge.
- Romme M. & M. Morris
2007 The harmful concept of schizophrenia. *Mental Health Nursing* 27: 7-11.
- Romme, M.A.J., Honig, A., Noorthoorn, O., Escher, A.D.M.A.C.
1991 Coping with voices: an emancipatory approach. *British Journal of Psychiatry* 161: 99-103.
- Rose, N.S.
2006 *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty- First Century*. Princeton, NJ: Princeton University Press.
- Saravanan, B & K.S. Jacob, S. Johnson, M. Prince, D. Bhugra, A.S. David.
2007 Belief models in first episode schizophrenia in South India. *Soc. Psychiatry Psychiatr. Epidemiol.* 42: 446-451.
- Scheper-Hughes, N. and Lock, M. M.
1987 The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology. *Medical Anthropology Quarterly*, 1: 6–41.
- Silverman, Hugh J.

- 1980 Phenomenology. *Social Research*, vol. 47 (4): 704-720.
- Sismondo, S.
2008 Pharmaceutical company funding and its consequences: a qualitative systematic review. *Contemporary Clinical Trials* 29 : 109–113.
- Snow, David A. & Leon Anderson
1987 Identity Work Among the Homeless: The Verbal Construction and Avowal of Personal Identities. *American Journal of Sociology* 92(6): 1336-1371.
- Swaab, Dick
2010 *Wij zijn ons brein. Van baarmoeder tot Alzheimer*. Amsterdam: Contact.
- Taylor, V & N. Whittier
1995 Analytical Approaches to Social Movement Culture: The Culture of the Women's Movement. In: Johnston, Hank & Bert Klandermans (eds.) *Culture and Social Movements*, Minneapolis: University of Minnesota Press. Chapter 9: 163 -187.
- Tilly, Charles
2004 *Social Movements, 1768–2004*. Boulder, Colorado, USA: Paradigm Publishers.
- Verdoux H. and van Os J.
2002 Psychotic symptoms in non-clinical populations and the continuum of psychosis. *Schizophrenia Research*; 54(1-2): 59-65.
- Waters, Flavie
2010 Auditory Hallucinations in Psychiatric Illness. *Psychiatric Times*; Vol. 27(3).
- Weber, Max
1918 *Science as a Vocation*. Published as "Wissenschaft als Beruf," *Gesammelte Aufsätze zur Wissenschaftslehre* (Tubingen, 1922), pp. 524-55. Originally a speech at Munich University, 1918, published in 1919 by Duncker & Humblodt, Munich. From H.H. Gerth and C. Wright Mills (Translated and edited), *From Max Weber: Essays in Sociology*, pp. 129-156, New York: Oxford University Press, 1946.
- Westermeyer, Joseph
1979 Folk concepts of mental disorder among the Lao: continuities with similar concepts in other cultures and in psychiatry. *Culture, Medicine and Psychiatry* 3: 301-317.
- Wilson, Samuel M. and Leighton C. Peterson
2002 The Anthropology of Online Communities. *Annual Review of Anthropology*, Vol. 31: 449-467.
- Whitaker, Robert
2004 The case against antipsychotic drugs: a 50-year record of doing more harm than good. *Medical Hypotheses* 62: 5–13.
- World Health Organization
1979 *Schizophrenia: An International Follow-up Study*. Chichester, UK: John Wiley and Sons.
- Wooding, Charles J.
1972 The Winti-Cult in the Para-District. *Caribbean Studies*, Vol. 12 (1): 51-78.
- Wooding, Charles J,
1972 *Winti: Een Afroamerikaanse Godsdienst in Suriname*. Meppel, Holland: Krips Reprint.
- Young, Allan
1967 Internalizing and externalizing medical belief systems: An Ethiopian example, *Social Science & Medicine*; Vol.10 (3–4): 147-156.

Appendix 1: Call for participants (in Dutch)

Ik ben Dorien en ik studeer medische antropologie aan de UvA. Mijn afstudeeronderzoek gaat over

STEMMEN HOREN.

Als antropoloog ben ik geïnteresseerd in de **subjectieve ervaring** van mensen. Ik wil graag onderzoeken **hoe het is** voor mensen om stemmen te horen, **hoe ze er mee om gaan**, en **hoe ze er zelf over denken**. Dit wil ik doen door middel van open interviews, waarin mensen de ruimte krijgen om te vertellen over hoe zij het horen van stemmen beleven.

Belangrijk om te vermelden: iedereen die meewerkt aan mijn onderzoek zal **volstrekt anoniem** blijven; in mijn scriptie zal ik met gefingeerde namen werken in plaats van met echte namen. De interviews zullen worden opgenomen met een voicerecorder maar ze worden weer gewist nadat ik het interview heb uitgewerkt. Ik ga in mei van start met mijn onderzoek en het zal een aantal maanden duren.

Hoor jij stemmen en wil je je ervaringen en gedachten hierover met me delen in een interview?

Neem dan contact met me op! Ook als je vragen hebt over het onderzoek kan je me mailen:

onderzoek.stemmenhoren@gmail.com

Alvast bedankt, Dorien

Appendix 2: Interview topic-list (in Dutch)

- Kort over afstudeeronderzoek en het doel van het interview.
- Benadruk anonimiteit, uitleg over opnemen van interview
- Benadruk dat het welzijn van de deelnemers belangrijker is dan het interview: we kunnen te allen tijde het interview pauzeren of helemaal stoppen
- Er zijn geen foute antwoorden, geef aan als je ergens niet over wil praten
- Geef ook aan als de stemmen vervelend worden tijdens het interview.

Achtergrond info

- Wil je jezelf kort introduceren en wat achtergrond informatie met me delen? (werk, leefsituatie, culturele achtergrond, geloof, hobbies, etc.)
- Hoe ziet een normale week er uit voor je, wat doe je zoal?
- Mag ik vragen hoe oud je bent?

Jouw ervaring van het stemmen horen

- Zou je iets kunnen vertellen over de stemmen die je hoort, en over je geschiedenis met de stemmen? Wanneer hoorde je ze voor het eerst, en hoe was dat?
- Kan je de ervaring van het stemmen horen proberen te beschrijven?
- Mag ik vragen wat de stemmen precies zeggen?

Jouw ideeën over het stemmen horen

- Hoe denk je dat de stemmen veroorzaakt worden, waar ze vandaan komen? Wat betekenen de stemmen voor je?
- Wat vind je van het idee dat stemmen horen een symptoom is van een psychische ziekte?
- Hoe denk je over de inhoud van de stemmen, is het belangrijk wat ze zeggen?

Over hoe je om gaat met het stemmen horen

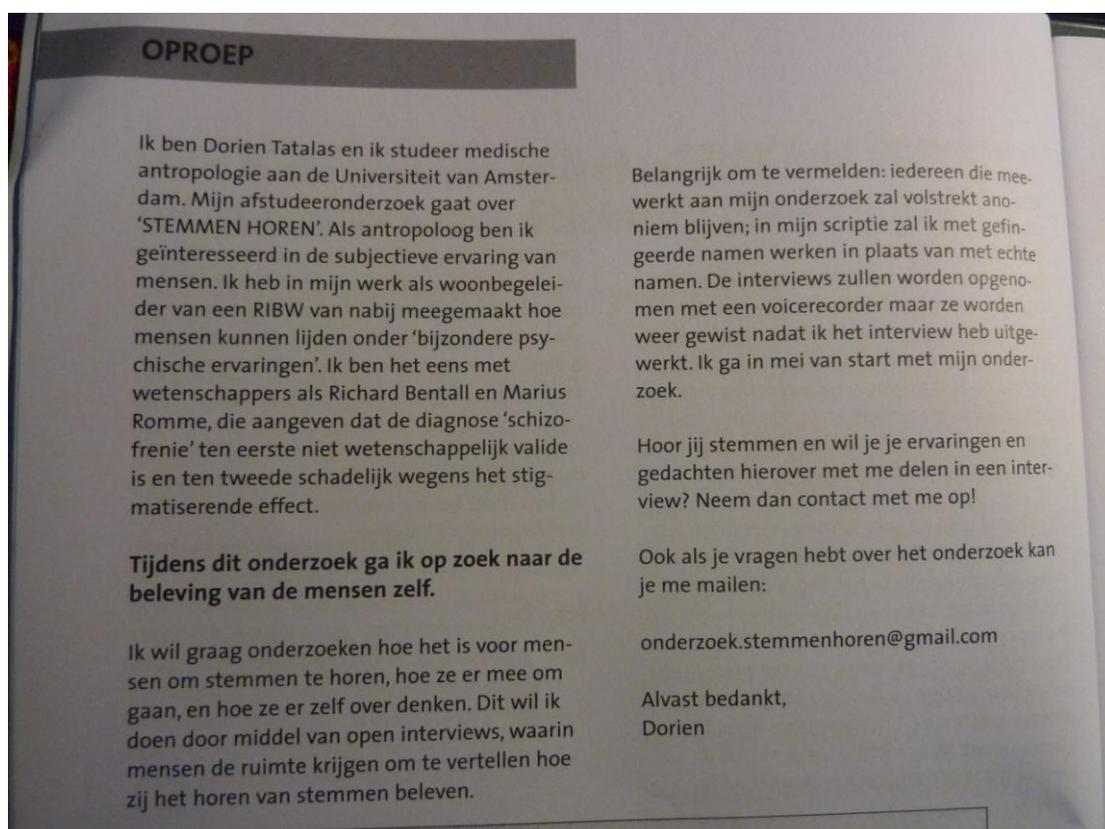
- Kan je beschrijven hoe je om gaat met de stemmen?
- Hoe effectief vind je jouw manier van er mee om gaan? Ben je tevreden met de resultaten en waarom / waarom niet?
- Vertel je andere mensen dat je stemmen hoort? Waarom wel of niet?

Totslot

- Als je een postbus 51 spotje zou mogen maken om andere mensen te informeren over stemmen horen, wat zou daar dan in komen? Wat vindt jij belangrijk dat andere mensen erover weten?
- Is er nog iets dat je zou willen toevoegen aan dit interview? Heb je zelf nog vragen?

Appendix 3: Call for participants in *Klankspiegel* (in Dutch)

“Gisteren is de redactie van de *Klankspiegel* bijeen geweest. De vraag is of je je oproep zou kunnen uitbreiden met een korte beschrijving van jouw stellingname ten opzichte van stemmenhoren. Hoe zie jij dat verschijnsel? We gaan namelijk niet zo graag in zee met mensen die dit direct zien als een teken van zware stoornis. Zou je er iets hierover aan toe kunnen voegen?”



Appendix 4: Terms-of-participation for Facebook group

Please read the following information carefully:

- The purpose of this group is to help me, Dorien Tatalas, with the research for my Master's Thesis (in Medical Anthropology and Sociology). After my Thesis is completed, this group will be removed from facebook.
- This group is for people who hear voices or have done so in the past. Their voices are also welcome to contribute, as long as they make clear who they are and which person they accompany.
- The information that you post in this group can be used in my Thesis. Your contributions may be paraphrased (summarized in my own words) or cited in my Thesis.
- You will remain completely anonymous. Your real name will not appear in my thesis or anywhere else. Other details that can be connected to your identity (names of other people, exact locations, etc.) will also be replaced with pseudonyms.
- The most important 'rule' for participating in this group is: **your wellbeing is more important than my research**. So, if you notice that the voices give you a hard time when you are contributing to this group, or if my research threatens your well-being in any other way, please consider to stop or pause your participation.
- Don't feel obliged to reply to my posts. Participation in this group must always be voluntary. You may choose to stop participating in my research at any moment. Please let me know by sending me a message, and I will not use your posts in my research.
- Don't worry about spelling or grammar. As long as I understand what you write, spelling mistakes really don't matter.
- Unfortunately I cannot offer you any financial compensation for your time and effort. What I can offer you, besides my gratitude, is taking your experiences and ideas seriously and to use them in this social-scientific research. Once my thesis is finished (in the beginning of 2013), you will receive a digital copy.
- Please be respectful towards other members of this group, and please respect their privacy.

Appendix 5: Online interview questionnaire

SECTION 1: Background information

For this section, please keep your answers short.

- 1) **How old are you?**
- 2) **Where do you live? (Country & city)**
- 3) **What are your daily activities?** (School / work / voluntary work / hobbies)
- 4) **What is your main source of income?** (Work / welfare / pension / family)
- 5) **What is your family/ living situation?** (Single, married, divorced, widowed / living independently, with family or in a assisted living facility, etc.)
- 6) **What is your cultural background and/or religion (if relevant for you)**

SECTION 2: Your experiences with hearing voices

The questions in the following sections are all open questions. In some cases I have given some examples of the things I'm interested in. However, these are just examples. I'm especially interested in what YOU think is important to tell me. Try to give extensive answers: one paragraph rather than one line. BUT: try not to write too much either. (Keep in mind that I have to read many interviews!) So let's say: **please write a maximum of 1 page per question, and a minimum of a few sentences per answer.**

And a reminder: spelling does not matter. You don't have to run a spell check for me.

- 1) **Can you tell me something about your history with the voices?** (For example: when did it start? How old were you then? How was it? How did you respond?)
- 2) **Can you try to describe what it is like for you to hear voices?** (for example: How many different voices you hear / How often you hear them / When do you hear them / are they male or female voices / Do they have a name or identity? / Do you hear them inside or outside of your head? / Are they positive or negative / loud or soft?)
- 3) **Can you tell me about the content of the voices: what do they say to you?**
- 4) **Do the voices bother / disturb you?**
If yes: in what ways do they influence your daily life?
If not: has this always been the case, or was it different in the past?

SECTION 3: Your explanations for hearing voices

- 1) **Where do the voices come from, according to you? What/who are they?**
- 2) **What do you think about the content of the voices – is it important WHAT they say?**
- 3) **What do you think about the idea that hearing voices is a symptom of a disease?** (such as is often said in mainstream psychiatry)

SECTION 4: Your way(s) of dealing with the voices

- 1) **Can you try to describe how you deal with the voices?** (For example: Do you ignore them / listen to them / talk to them / discuss with them? Do they listen to you? Can you send them away? Do you use medication / are you in therapy or in a self-help group?)
- 2) **How effective do you think your way of dealing with them is? Are you satisfied with the results and why (not)?**
- 3) **Do you tell other people that you hear voices? Why (not)?**

SECTION 5: Concluding questions

- 1) **Imagine that you are asked to develop an information campaign about hearing voices. You can shoot an infomercial that will be broadcast on national television. What do you want people in your country to know about hearing voices? What should be in this infomercial?**
- 2) **Is there anything that you would like to add to this interview? Something that you think is important but which hasn't been asked?**

Thank you VERY much for taking the time and effort to share your experiences with me. It is greatly appreciated.

Appendix 6: Instructions for email interview

Please read the following information carefully.

- The information that you will provide me will be used for my Master's Thesis (in Medical Anthropology and Sociology) about hearing voices.
- You will remain completely anonymous. Your real name will not appear in my thesis or anywhere else. Other details that can be connected to your identity (names of other people, exact locations, etc.) will also be replaced with pseudonyms.
- If the voices bother you more than usual during the answering of my questions, or if my research threatens your well-being in any other way, please don't hesitate to stop or pause. Do not feel obliged to finish answering the questions. **YOUR WELL- BEING IS MORE IMPORTANT THAN MY RESEARCH!**
- You may choose to stop participating in my research at any moment. You can let me know this by sending me an email.
- There are no wrong answers. I'm interested in how YOU experience, explain and deal with the voices. If there are questions that you would rather not answer: this is no problem. In such cases, please state: I don't want to answer this question.
- Don't worry about spelling or grammar. As long as I understand what you write, spelling mistakes really don't matter!
- I estimate that you will need between one hour and several hours to complete the interview (depending on how much you like to write, and on how much you want to share with me). The advantage of this online interview is that you don't have to write down everything at once but that you can work on it in different sessions. **As long as you send your answers back before august 25^h, you will still be in time to let your interview be included in my analysis.**
- After receiving your answers, I might email you again with some further questions. This is only in case I don't understand your initial answer, or if something is still unclear to me. I will, however, try to keep the number of email-exchanges to a minimum.
- Unfortunately I cannot offer you any financial compensation for your time and effort. What I can offer you, besides eternal gratitude, is taking your experiences and ideas seriously and to use them in this social-scientific research. Once my thesis is finished (in the beginning of 2013), you will receive a digital copy. (It will be written in English)

If you agree with all of the above and still want to participate in my research, please reply to this email that you agree. I will then send you the questions.

If you have any questions regarding the above, please don't hesitate to ask! Thank you for your time, Dorien Tatalas.

Appendix 7: Coding scheme

Background info			23
	Social life / relationships		10
	Biographical context / narrative		63
		Suicide thoughts / attempts	5
		Interest in spirituality / religion / mysticism	16
		Trauma (descriptions)	22
	Hobbies / day activities		16
	Future plans / ambitions		13
	Religious background		6
	Work		
		Paid work	8
		Voluntary work	12
	Education		16
Coping			
	Voice hearing community		
		Expert by Experience	36
		Self-help group / patient group	11
	Working on oneself		
		Transformation process	20
		Autonomy / control over voices & own life	13
		Dealing with emotions	10
		Psychotherapy	18
		Self-development / strengthening identity	13
	Working WITH voices		
		Finding an explanation / more info	21
		Ignoring / not taking them seriously	6
		Maastricht Interview / Intervice / Romme	9
		Dialogue with voices	14
		Learning to understand the voices / the experience	15
	Acceptance		
		Accepting the disease label	5
		Accepting that they are there	4
	Activities		
		Spiritual practice / spiritual community / praying	14
		Talking about it with other people	16
		Distraction through work / hobbies	13
		Writing / keeping a diary	4
	Other coping		21
	Voices disappeared / lessened because		8
	Unsuccessful coping		14
Effect voices have on daily life			12
	Associations / delusions / paranoia		6
	Suicide attempts		6
	Lack of energy / tired		10
	Physical restrictions		6
	Other effects		13
	Lack of concentration / distracted / busy head		15
	Grief / anger		7

	Self stigma / shame			11
	Social restrictions / social isolation			11
	Positive effects / results			43
	Assignments / self-harm			22
	Fear / anxiety			23
Experience				
	Identity of voices			10
		Fixed identity / character		30
		Mix of familiar and unfamiliar		5
	Interaction with voices			
		Interaction possible		11
		No interaction		5
	Phenomenological details (number, tone, frequency, etc.)			61
	Other non-ordinary experiences			
		Unusual thoughts & beliefs		19
		Voices taking over consciousness / Dissociation		12
		Dreams		8
		Sensitivity / intuition		10
		Physical sensations / feeling voices in the body		11
		Other		5
		Visions		40
	First experience			24
	Content			12
		Symbolic / religious		8
		Predicting future events		8
		Meaningful / related to biography		15
		Judging / commenting		21
		Tone / intention / experience		
			Threats	14
			Random / incoherent	12
			Ambiguous	27
			Negative (no direct threats)	24
			Positive	9
Explanations				
	Interpretations / reflections			
		Rationality / spirituality / (non)materialism		24
		Anthropological / reference to culture		54
		Normalizing statements		29
		Relativizing		17
		Transpersonal / collective consciousness / Jung		13
	WHY / HOW			
		Use of Marihuana / other substances		8
		Biological explanation - DNA, Family		4
		Ambiguous		6
		Related to biography / psychological explanation		25
			Survival mechanism	11
			Stress	8
			Trauma	15
		Spiritual explanation - helpers / guidance / intuition		14
		Paranormal explanation - 'witchcraft', telepathy		17

WHAT - Explanatory Models			
		Unknown / ambiguous / several	28
		External	
			Paranormal / Other person / External info 14
			Metaphysical / Non-human entities 8
			Spirits/ Deceased people 8
			Religious 11
		Internal	
			Mental illness / disease 7
			My head / brain 7
			My mind/ psyche 21
			Imagination / own creation 12
Medical Model / Psychiatry			
	Diagnosis		
		Negative effects of diagnosis	18
		Rejection of psychiatric diagnosis	16
		Acceptance - positive about diagnosis	4
	Medication - attitudes & experiences		7
		Negative / critical	16
		Ambiguous	25
		Positive	10
		Doesn't take medication	6
	Psychiatric treatment - attitudes & experiences		
		Ambiguous	12
		Positive	17
		Negative / critical	42
	Psychiatric terminology (used by participant)		
		Borderline	5
		Conversion disorder	1
		Depression	9
		PTSD	2
		Addiction	2
		Hallucination	3
		Dissociation	3
		Biological / neurological terminology	9
		Schizophrenia	24
		Delusions	14
		Psychosis	42
Miscellaneous			
	KEY QUOTES		200
	Interaction VOICES during interview		11
	Participation motivation		17
	Mention of Weerklank		11
	Ambiguity / grey areas		56
Relation with Society			
	Telling others		
		No	19
		Yes	19
	Advice for other people		15
	Negative social experiences		9
	Mention of stigma / taboo / prejudice		37