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Listening to Those Who Hear Voices: Ethnography

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Z á s a d y p r o v y p r a c o v á n í :

Fenomén slyšení hlasů je často spjato s duševní nemocí nebo šílenstvím. Moderní medicína a psychiatrie se dívají na tento fenomén jako na hlavní symptom duševní nemoci jako je schizofrenie. Existují i další přístupy v psychiatrii a v psychologii, které se dívají na fenomén slyšení hlasů jako na běžnou zkušenost u člověka, která sama o sobě není problémem či nemocí. Tyto přístupy vidí smysl a význam u fenoménu slyšení hlasu, který můžeme spojit s osobní historií člověka. Jak v západní společnosti, tak i mimo ní, existují různé náhledy na fenomén slyšení hlasů. U některých kultur je tento fenomén vítán a je běžným jevem, který je součástí jejich mýtu, náboženství atd. Můj výzkum se zabývá lidmi, kteří slyší hlasy a kteří mají diagnózu schizofrenie. Ve formě případových studií jsem provedl etnografickou práci, abych zjistil jak každý zažívá fenomén slyšení hlasů, jak se objeví, jaký význam má nebo nemá pro tohoto člověka. Jaký model používá, aby si vysvětlil fenomén slyšení hlasu a jak jsou hlasy zapojené do jeho osobního života.

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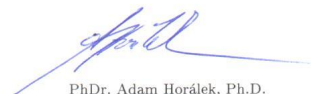
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Annotation

Listening to Those Who Hear Voices: Ethnography

Phenomenon of the hearing voices is considered to be one of the major symptoms of schizophrenia and that it is divorced from the life context of the person. I argue that this phenomenon is not per se a problem or part of the mental health issues, but that can be understood in the context of the life narrative of the person and their intersubjective experience. This research looks into narratives of the three people that have diagnosis of schizophrenia that hears voices as well. Hearing voices phenomenon can be understood as meaningful even in the extreme experiences like psychosis. Informers presented here experienced hearing voices in the different way because phenomenology of their experience is different. They also have different explanatory models that they are using in understanding this experience that is connected with their intersubjective experience and social dynamics. Hearing voices, and psychosis, are a life changing experiences that has a great impact on person's identity as well.

Key words: hearing voices, schizophrenia, meaning, case study, narrative, ethnography, intersubjectivity.

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1. Introduction to the Topic

1.1. Overview

The main goal of this thesis is answering three questions about informers who hears voices:

1. How do they experience hearing voices (and psychosis)?
2. How do they construct the meaning of this experience? Has the meaning changed over time?
3. What kind of influence voice hearing experience has on their everyday life?

In order to do that I have structured this thesis into five major parts/chapters. Every part has it's own subparts as well.

The first part of the thesis is Introduction to the topic. Here we have presented subchapter about my personal motivation to do this research, theoretical introduction to the topics of hearing voices, schizophrenia and collaboration between anthropology and medicine (psychiatry). Last two subchapters in this first part are dealing with the history of the understanding of hearing voices phenomenon in the Western world and different cultures as well.

Second part of the thesis is about different theoretical and philosophical influences that are presented in this research. Main focus is on intersubjectivity, narrative and concept of meaning. Those concepts will be presented in the context of

anthropology, culture, psychology, psychiatry and International Hearing Voices Movement.

Third part is about methodology, methods and techniques that were used during this thesis. Visual ethnography is also presented, as a part of this thesis, as I had reordered a film with one of the informers. As I consider visual part of the thesis as separate part, Visual ethnography is only mentioned without detailed elaboration.

Forth part are three case studies of the informers. I have spent 8 months with informers conducting the interviews and participant observation. Their life histories will be presented in the form of personal narrative, where intersubjective reality and social dynamics will be investigated. Every case study has different parts or themes that are important in the context of the informer's life.

In the last part we will have discussion about hearing voices experience, psychotic experience and identity. How someone sees himself influence the explanatory model that he uses, and in the end influence recovery of that person as well. This part also contains subchapters about consequences of the ethnography and ethical considerations. Thesis ends with bibliography.

1.2.A Personal Account and Motivation: Nothing Human is Alien to Me

When dealing with the topics regarding the mental health and psychiatry, usually the first questions are: "*Why* are you interested in this topic?", "Do you have a *personal experience* with mental health problems?", "Do you have this experience *in your family*?" etc.

The assumption is that you have some personal motivation to go into this “political minefield” (Whitaker 2010: ix), otherwise, why bother, why stir the pot? Personally, I do not have any experiences with mental health issues, I do not have experience of being a patient or a user of mental health services, and I do not have, as far as I know, anyone in my family in the last few generations who had experience with serious mental health problems. So why bother?

While growing up I was always curious about the world and people, especially if something or someone was "different" and "unusual" in some way. I tried to understand different positions, different worldviews and different worlds within people. Now, when I turn and look back on that young's boy experience, the best way to define that curiosity is by the famous maxim “Nihil humani a me alienum puto” (“nothing human is alien to me”), (Fromm 2011: 257 in Roberts 2015: 51). Question of normality - what is acceptable and what is defined as abnormal always fascinated me. How come that it was *normal* that neighbours, of different religions, ethnicity and worldviews were best friends in former Yugoslavia, who shared all the best moments of each other's lives (childbirth, new jobs, birthdays, weddings) and all the bad things (divorces, deaths and losses of their favourite football teams)? How come that it was *normal* that those same people and neighbours, shot each other and forced each other to leave their homes?

I was 6,5 when the war started in Bosnia and Herzegovina and that taught me that normality and abnormality are relative, socially and contextually defined. Maybe because of this extreme experience I started to be more interested in unusual states of mind, unusual experiences such as hearing voices, seeing visions and madness in general. I believe that every aspect of us, no matter how incomprehensible at first, has to do something with our lives, our experience and biographical history context.

I don't hear voices personally, so I was thinking about the roots of my motivation to explore and understand phenomenon such as “psychosis” and hearing voices. I came to the conclusion that the common thread I have with the people labelled as “psychotic”, “mad”, “schizophrenic” etc., is different worldview and different experience than the majority of people. Because of the war, my family and I moved a lot. We lived in different cities in Bosnia and Herzegovina, and different countries. Neither of those cities I felt like my own. In some way, I have been always a minority, person with different background and experience. Being on this margin helped me to see things that others do not, and to have experiences that others don't have. This is something that is affecting and influencing my motivation and interest in the topic of mental health.

I also believe that everything personal is political at the same time. What I am experiencing and thinking, feeling and saying is always filtered through the norms, rules and laws of the society. Homosexuality, for example, was officially treated as a mental disorder by psychiatry until the year of 1973. It was removed from the list of disorders by voting of the psychiatrists on the board of DSM¹ manual (American variant of classification of mental disorders), (Burton 2015). So, everything that homosexual person feels, says or does is political, not just personal. The same applies for people experiencing mental health difficulties and unusual experiences such as hearing voices. There is a social tendency to control people's experiences (from outside² or inside³), behaviours and feelings and to define it up front (what you should

¹ After removing homosexuality as a disorder from DSM, the term “sexual orientation disturbance” was replacing it. “Not until 1988 did homosexuality completely fall out of the DSM” (Burton 2015).

² Via total institutions (in Erving Goffman see “Asylum: Essays on the Social Situation of Mental Patients and Other Inmates” 1961), also see Michele Foucault (“Madness and Civilization: A History of Insanity in the Age of Reason”, 1988 and “Discipline and Punish: The Birth of the Prison” 1979).

³ From within ourselves that we monitor and control ourselves by integrating social norms of behaviour.

or should not experience). If you experience something that is not usual in the society at that time, it doesn't mean that you are mad, ill or dangerous *per se*.

Anthropologist Renato Rosaldo said that you get to know your own culture when you encounter the foreign one (Rosaldo 1989 in Seikkulla & Arnkil 2013: 46). So, in a way, I wanted to understand myself better encountering unusual experiences. At the same time, I wanted to get closer to the unusual experiences in order to understand them and to make space for them in my own context and society. This was my motivation to study psychology, to explore the cosmos within us, to understand people, to connect and to hear their personal life stories.

I thought that psychology is a humanistic science, searching for meaning in experiences and trying to understand different aspects of people's lives. But I was wrong. Nowadays psychology is more oriented in helping capitalist society to manipulate people, consumers to buy more, helping the military to find better torture means for the enemy, and of course to put people in categories (psychiatric diagnosis) and numbers (statistical research), (Roberts 2015). I wanted to quit psychology studies when I was in my third year. Then I discovered a book that "saved my life". It was a book called "*The Divided Self*", by Scottish psychiatrist and psychoanalyst Ronald David Laing. This book was about a "study of schizoid and schizophrenic persons; its basic purpose is to make madness, and the process of going mad, comprehensible." (Laing 1981: 9). Understanding human suffering in this book has opened a completely different window for me, a window into a subjective world of human experience. From that point onwards, I was inspired mostly by existential thinkers like Martin Buber, Jean-Paul Sartre, Kierkegaard, Heidegger, and existential psychotherapists like Ronald David Laing, Rollo May, Victor Frankl and others. The *search for meaning* was the most important aspect of my interest. While I was

exploring the meaning in lived experiences like hearing voices or "psychosis", I came upon *the International Hearing Voices Movement (IHVM)*. This movement is gathering mental health professionals and people who hear voices in order to explore their experience and to help them overcome the problems they are facing. Main goals of the Movement (on the social level) is to normalize voice hearing experience and emancipate people who hear voices⁴.

Also, I decided to go into a five-year process of becoming a Gestalt therapist. Gestalt therapy is a psychotherapy approach influenced by psychoanalysis, Gestalt psychology, existentialism (mainly Buber and his I-Thou philosophy) and Zen Buddhism. Gestalt therapy has three main foundations: Field Theory (everything is explored in a person's context), Phenomenology (researching what is obvious and present, not analyzed and interpreted) and Dialogue and existentialism (I-Thou, Martin Buber, contact between people, what is happening between people, authenticity of contact), (Mann 2010: 4). These concepts and this philosophy are very close to me and I tried to implement them in my own personal and professional life. They motivated the basic assumptions of this work.

Another important concept is *self-disclosure and self-reflection*. In order to get close to and understand some experience or everyday life of people, you need to explore and reflect on your own life as well. By being present in someone's life you are changing that person and the person changes you as well. We all get affected by mental health issues in life. We all experience partially or "in full" states of mind like fear, despair, depression etc. I presented my soul searching process on the 10th World Hearing Voices Congress that was held in the Hague in September of 2018

⁴ More about International Hearing Voices Movement, it's values and characteristics will be described in one of the following chapters.

(Intervoice 2018: 36-37). In exploring my life narrative I came to realize that my life story is shaped by one more general unusual life experience and two personally linked unusual experiences (one of them culturally influenced). The first experience happened when I was 8. The war was still going on in Bosnia and we fled from my hometown to a different city where it was “less dangerous”. In this city, I had a best friend. When he moved from our neighbourhood (city and country), I've missed him so much. One day, when it was sunset, I saw him in front of his former home a few seconds. He was just looking at me in the grey sweater that he was wearing all the time. He was there in front of me, but at the same time long gone.

The second experience I had is more culturally related. In my culture food is sacred. I was raised not to play with the food (especially not during the war). You need to respect the food served at your table. Once, while we were playing in the neighbourhood, we have found a spilt bag of beans on the street. Playfully, we started to jump on the beans. Immediately as I did it, I had a feeling that "something is wrong". I went home and found out that my grandfather had died, approximately at the same time that I was “playing with the food”.

The third experience is again related to the war in Bosnia and Herzegovina. My family moved so many times during the war. We lived in six different cities and three counties (Bosnia and Herzegovina, Croatia and Austria). Every city meant a new beginning. For me, this brought the feelings of not belonging. The most difficult experience for me during the war, except moving around, was the absence of my father. This was happening on and off for four years due to his military duties on the front line. After the war, we settled in Sarajevo, where I finished high school and University. Parents were working and trying to get back to normal routine life.

After I've finished psychology studies and psychotherapy training, I started being engaged in my community. I was promoting Hearing Voices approach and organizing peer⁵ support groups for people with lived experience of hearing voices. The response of people in my local community was immediate. People who hear voices, who were usually part of a psychiatric system, didn't have the opportunity to talk with anybody about how voice hearing experience influence their everyday life. In the context of psychiatry, people are only asked about hearing voices only as part of an interview that establishes a diagnosis. Personal experience is not investigated nor considered as important.

On the other hand, the response from my senior colleagues, most of my peers and colleagues from University, was not that positive. Most of them didn't welcome this idea. They even thought that it is dangerous to explore voices and personal experience of people who hear voices because it was considered to be pathology that needs to go away.

After some time, I started getting calls from people from different countries of former Yugoslavia (Serbia, Croatia and Slovenia). They were asking me to do something similar regarding the Hearing Voices approach in their countries. Values of Hearing Voices approach connected mental health professionals and voices hearers from the countries that were on different sides in the war, not long ago. After creating Hearing Voices Approach Network for Western Balkan (www.nasglas.org), we continued with work in our local communities. We promoted different psychosocial approaches, talked in public about mental health issues and worked on the regional level as a Western Balkan Network.

⁵ Peer support, in this context, means that members of these groups were people with (same) or similar experience like hearing voices or "psychosis".

After being granted a scholarship by the Czech Government in 2016, I have decided to move to Prague and I've left Western Balkan Network to my friends and colleagues that worked with me. However, I am still a member of this Network and I provide help and support when needed.

When I came to Prague, once again I was a minority. My work in the NGO sector with people who have mental health issues helped me to be more integrated. Even though I was still learning the language, cultural habits and values, people who are in the NGO sector called "clients" or "users of services" welcomed me. I started to meet people with hearing voices experiences and realized that nobody talked with them about it. I gathered my colleagues from different NGOs or Centers for Mental Health (where I work at the moment) and we started the first Hearing Voices group in Prague. The group exists since May of 2018, and since then we have many people coming (between 8-16 per meeting, every week). Meanwhile, we started with another Hearing Voices group in Psychiatric hospital Bohnice on "Pavilon 19". On 14th of February 2019, we had first Hearing Voices Network meeting for the whole Czech Republic. The meeting was organized in Prague, in order to gather a network of organizations and individuals, who works according to Hearing Voices values. So far Hearing Voices Network for Czech Republic functions as "self-support" group of organizations and individuals, voice hearers and professionals from mental health and social services.

This part brings me to a last personal influence and motivation that will be visible in this research. That is my education and training in Open Dialogue (method for first episode "psychosis") and my interest in Postmodernist psychotherapies, especially Narrative Therapy. Therefore concepts like search and constitution of

meaning, phenomenology (social phenomenology), social constructivism and narrative will be present throughout this paper.

My personal path, including the content of this research, helped me, to paraphrase Rosaldo (Rosaldo 1989), to know myself better when encountering differences, and at the same time helped me to become familiar with the differences in other people by crossing the border between Us and Them.

1.3.Hallucinations: An Introduction

The word hallucination comes from Latin verb *alucinari* or *hallucinari* (“to wonder in mind, to talk idly, to rave”), (McCarthy-Jones 2012: 22), and it was used by Cicero and Seneca (Rojcewicz & Rojcewicz 1997 in McCarthy-Jones, 2012: 22). The term, as we know it, was coined and defined by French psychiatrist Jean-Etienne Esquirol in the 1830s (Sacks 2012: ix). The phenomenon of what is generally known as hallucination is old, but in the last few decades our understanding “greatly increased” (Sacks 2012: xi). It's important, in the beginning, to distinguish differences between perception, hallucinations, and images and sounds that we produce in our mind. Hallucinations can be “defined as percepts arising in the absence of any external reality-seeing things or hearing things that are not there” (Sacks 2012: ix). On the other hand, perceptions are “sharable” (Sacks 2012: ix) in some way, meaning that two or more people can see or hear the more or less same thing that other is seeing or hearing. Hallucinations are not sharable with others, but still, they are the reality for the person experiencing them. Hallucinations are similar to the voices or images that we are producing voluntarily in our mind, but hallucinations differ from those sounds

and images because they are not “self-invited and person is in a passive and sometimes helpless position, which can produce difficult emotions of, for example, fear of confusion” (Sacks 2012: x). Hallucinations are seen as creative, dream-like states, even though they share some elements of dreams, imaginations and creativity they are “unique and special category of consciousness and mental life” (Sacks 2012: xiii). Type of hallucinations are connected to senses, so they can "occur in any sensory modality, whether visual, auditory, olfactory, gustatory, tactile or kinesthetic" (La Barre 1975: 10).

1.3.1. Hearing Voices: Definition and Explanation

Hearing Voices or Auditory Verbal Hallucinations, as “mind sciences” (McCarthy-Jones 2012: 1) are defining it, are mainly connected in the eyes of the society (and very often in the eyes of mental health professionals) with “madness”, “insanity”, “unreason” and “schizophrenia” or “psychosis” (Baker 2015: 27). Medicine defines this phenomenon as “hearing speech in the absence of corresponding external stimulation of the ear, with a sufficient sense of reality to resemble a veridical perception, over which subject does not feel s/he has direct and voluntary control, and which occurs in the awake state” (McCarthy-Jones 2012: 1). This clinical definition is somewhat “technical” because it does not describe the whole spectrum of voice hearing experience. This can be understood in terms that modern medicine and clinical psychology considers hearing voices⁶ or auditory verbal hallucinations as “hallucinations” and symptoms (or one of the symptoms) of the “mental illness”, usually schizophrenia and therefore clinicians do not investigate the differences in phenomenology of the experience (Luhmann et al. 2015: 648). In the

⁶ From this point on, in the research term hearing voices or voice hearing will be used.

psychiatric context, voices are only relevant to diagnosis (Luhmann et al. 2015: 655) not for the exploration of the experience. This lack of involvement from clinicians in exploring hearing voices has a foundation in the belief that talking about voices will make a psychological state of that person worse (McCarthy-Jones 2017: 293). However, if we don't ask voice hearers about their experience, we promote silence about what happened to them and powerlessness in those people (McCarthy-Jones 2017: 293). Hallucinations and voices can be seen as a continuum “with ‘normality’ and that any and every intermediate gradation of the experience is possible” (Watkins 2008: 131) from our own thoughts to externally experienced voices.

Psychiatrists divide hallucinations to *real* and *pseudo-hallucinations* so they can distinguish the nature of the hallucinations. The first term means that these voices are coming from the outside of a person's head, which are *real* hallucinations and more relevant to the diagnosis. Second term means that they come from inside the person and are more *thought-like*, meaning that they are less relevant for psychiatric diagnosis.⁷ *Pseudo-hallucinations* have same “hallmarks as (real) hallucinations”, that they are “uncontrollable” and “involuntary” (Sacks 2012: x). This division has origins in belief that real hallucinations are connected with Schneider's First rank symptom of schizophrenia, a belief that if a person hears voices coming from the outside, that comments on his behaviour, or if he hears two or more voices talking, that is enough to be diagnosed as "schizophrenic". There was a belief that some forms of voices are specific for the diagnosis of schizophrenia, but "there is no validity to this" (McCarthy-Jones, 2017- 87). Schneider' s notion of First rank symptom of

⁷ Historically this definition comes from Augustine of Hippo (354-430) and was later “transmuted into psychiatric orthodoxy” (McCarthy-Jones 2017: 87). Voices that come from the outside of the head (externally located) were linked with major psychiatric conditions like psychosis and schizophrenia but “there is no validity to this” (McCarthy-Jones 2017: 87). “The voices heard by people diagnosed with BPD (Borderline Personality Disorder) are not notably different to these heard by people diagnosed with Schizophrenia” (McCarthy-Jones 2017: 87). One of the possible reasons is that maybe all mayor psychiatric diagnosis could maybe be “subtly different reaction to trauma” (McCarthy-Jones 2017: 87).

schizophrenia is abandoned in the newest DSM-V manual (McCarthy-Jones & Longden 2015). Now we know that all forms, contents and phenomenological traits of hearing voices could be present in the clinical population, general population and as a part of different psychiatric diagnosis, besides diagnosis of schizophrenia.

Hearing voices, as well as other forms of unusual experiences like seeing visions or having a sense that someone is following you, has to be seen as a part of “often profoundly altered inner life and life circumstances” (Sacks 2012: xiii), when talking about people labelled with the diagnosis of schizophrenia. If we consider the uniqueness of the inner world of each one person labelled with the diagnosis of schizophrenia, we can understand these experiences, we can see meaning in these “altered worlds”, and we can also see a reflection of social and personal circumstances and events that moulded them. But more importantly, we need to find a place for these unusual experiences in our commonly agreed reality, build awareness in our societies so that “two worlds” come closer in understanding and living through intersubjective negotiation of the experience.

Phenomenology of voice hearing experience is heterogeneous, different in expression and content. Voices can be male, female, without gender, voices of children, robots, nonhuman (Baker 2015: 15) etc. A person can hear one or many voices, sounds, music, orchestra or group of people murmuring. Voice can be experienced inside of the head, coming from the outside, or from the part of the body (Baker 2015: 15), coming from the neighbours, God etc. Voice hearing experience can be found in the general population of people without psychiatric diagnosis and in the population of people with a different psychiatric diagnosis. There are different data's, from different researchers about the percentage of people in the general

population who hear voices. Reasons for this can be because of the researcher's question⁸ or target group⁹ that answers questions. It is believed that somewhere between 4% and 25% of general population (Johns, Nazroo, Babbington & Kuipers, 2002; Slade & Bentall, 1988; Tien 1991) heard voices at least ones, while in student population 39% heard their thoughts aloud (Barret & Etheridge 1992; Posey & Losch 1983) .The first major research about hallucinations happened n 1894 by Society for Psychical Research (England), and they found out that 10% of the researched population had some sort of hallucination, and “more than a third heard voices” (Sacks 2015: 57). Interesting information that supports the notion that hearing voices is more common experience then we think, is that only 1 out of 3 people who hear voices ask for some psychological help (Baker 2015: 27). There are more people in the general population who hear voices than people who hear voices and have some psychiatric diagnosis (McCarthy-Jones 2017: 112). Oliver Sacks is saying a similar thing: “In the popular imagination, though, hallucinatory voices are almost synonymous with schizophrenia - a great misconception, for most people who do hear voices are not schizophrenic” (Sacks 2015: 56). In trans-diagnostic comparison about nature of voices in different diagnostic categories (Moskowitz et al. 2017) it was concluded that hearing voices is “common in schizophrenia and posttraumatic disorders, and are not significantly differently manifested in these disorders” (Moskowitz et al. 2017: 37). Voice hearing can be found in different psychiatric diagnosis: Dissociative Identity Disorder (70-90%), Schizophrenia (70%), Posttraumatic Stress Disorder (50%), Borderline Personality Disorder (32%), Bipolar Disorder (7%) etc. (McCarthy-Jones 2012). Richard Bentall wrote (Bentall 2003: 96-

⁸For example, research questions could be focused on different frequencies of the experience (how many times a day or week or month do you hear voices?) therefore we will have different answers and outcomes.

⁹ Known fact is that the student population is very sensitive to different mental health problems because this period is stressful and formative.

98) that in most countries in the world around 1% of the population has diagnosis of schizophrenia, around 10 % experiences hallucinations and from that 3-4% hears voices. From this, we can see that only a small percentage of people who hear voices have a diagnosis of schizophrenia or psychosis and still this phenomenon is closely connected with *madness*. Potential explanation can be that, generally speaking, people who are labelled with diagnosis of schizophrenia have difficulties to cope with distressing voices, and in their case the content of the voices is usually more negative or frightening (abusive, threatening or critical) when compared to other diagnosis, they hear voices more frequently than other people (Nayani & David 1996).

Experiences of hearing voices in people who have the label of schizophrenia can be more “accusing, threatening, commanding, jeering and persecuting” (Sacks 2015: 58), perhaps due to a lack of good coping strategies and fear of the voices. However, it was not found that there are specific forms or “schizophrenic” voices. All forms (outside or inside of the head, in the body etc.), content (positive or negative, pleasant or critical) and frequency (how often they occur) of voice hearing could be found in different psychiatric diagnosis and outside the psychiatric system (in general population). Saeed Wahass and Gerry Kent (Wahass & Kent 1977 in Jenkins, 2014: 39) found that “the form of the hallucinations experienced by both patients and nonpatients subjects is similar, “irrespective of diagnosis” (Wahass & Kent 1977 in Jenkins 2004: 39). Some differences between different diagnostic groups and patient and nonpatient groups can be seen in content, emotions that voices bring and level of control that someone has over them. Voice hearing can be a distressing experience, and someone who hear voices can get a psychiatric diagnosis if he cannot cope with the experience, if he hears emotionally negative content, if voices are more frequent and if he started to hear them in later onset in life (McCarthy-Jones 2017: 103).

1.4. The Schizophrenia Question: View from Psychiatry and Anthropology

At the official web page of the most influential Psychiatric Association in the world, American Psychiatric Association (APA), we can see explicitly that “Schizophrenia is a chronic brain disorder” (APA 2019) and it “can include delusions, hallucinations, trouble with thinking and concentration, and lack of motivation” (APA 2019).

In modern medicine and psychiatry schizophrenia is defined as an illness with genetic and biological foundation. Altered chemical processes in the brain are considered to be the main cause of this illness and the only form of treatment are psychotropic drugs (Luhmann & Marrow 2016: 2). Dominant narrative in the society when someone speaks about schizophrenia is “broken brain” (Jenkins & Barrett 2004: xv), where emphasis is on the biology and genetics even though “there is still no biological marker in everyday clinical practice that can be used to diagnose and follow the course of the disorder” (Jenkins & Barrett 2004: iv). This is the reason why “schizophrenia is *the* defining problem for psychiatry” (Jenkins & Barrett 2004: XV).

Psychiatry defines schizophrenia as combination of several symptoms, which are divided in several general groups: *positive symptoms* (delusions, hallucinations and incoherent speech), *negative symptoms* (emotional withdrawal, unexpressive face, tone), “*mismatched emotion-cognitive symptoms*” (e.g. smiling on the funeral etc.) and *symptoms of cognitive dysfunctions* (difficulties in personal life and at work for a longer period of time), (Luhmann & Marrow 2016: 2). Schizophrenia is best looked at as “more likely a number of disorders that are, for the time being, classified under

one rubric” (Jenkins & Barrett 2004: 2), because it “has no unique symptoms” (Luhmann & Marrow, 2016:1) that are not found in other psychiatric categories. In modern medical anthropology, there is a distinction between understanding the term *disease* and *illness*. The disease is a biomedical term, something that we can measure, while illness a way that the person understands and experiencing it (Plessy 2018: 10). Anthropologists are mainly focused on the *illness* aspect of the experience.

For a long time socio-cultural elements and influences regarding schizophrenia, psychosis or mental illness in general, were in the background of scientific focus. Thanks to the growing interest of anthropologists in mental health issues, the question of schizophrenia (and hearing voices) is not dominantly seen through the glasses of “bio-bio-bio” model (Luhmann & Marrow 2016: 2).

In the book “*Our Most Troubling Madness*” (Luhmann & Marrow 2016) there is question “how this madness is shaped by its social context: how life is lived with this madness in different setting” (Luhmann & Marrow 2016: 2) and how different contexts and life circumstances are shaping schizophrenia and voice hearing. This means that schizophrenia (and voice hearing) is becoming less biological and more culturally informed (Luhmann & Marrow 2016:3). There is evidence that people have more chance to have mental health issues in some social contexts than in other, because “something about social world gets under the skin” (Luhmann 2016: 3). Great example of this is ethnography of Nancy Scheper-Hughes in Western Ireland (Scheper- Hughes 2001), where “madness can be seen as projection of cultural themes” (Scheper-Hughes 2001: 176) such as “social stresses, social isolation, social disintegration and depopulation” (Scheper-Hughes 2001: 226).

In 1973 World Health Organization (WHO) provided big research project, called “International Pilot Study of Schizophrenia” (Luhmann & Marrow 2016: 21) showing that “patients looked better in Africa and India...”, they had better recovery rates “, then in the West (Luhmann & Marrow 2016: 21). This research was redone in ten countries in the world, and the conclusion was that “patients in the developed countries experienced significantly longer periods of unimpaired functioning and clinical remission was far more common” (Luhmann & Marrow 2016: 21). In 2001, both studies were reanalyzed with the anthropologist Kim Hooper and in the 2007 results were published to conclude that “roughly 50 percent more people do well after a diagnosis of schizophrenia in developing¹⁰ world then they do in the developed world” (Luhmann & Marrow 2016: 22).

One of the possible explanations is that “it may be more acceptable to respond to stress with psychotic hallucinations outside of a Western setting” (Luhmann & Marrow 2016: 23), because dominant thinking about psychotic experience in the West is the disease one, that cause is looked in genetics and biology, therefore person can't do much but be a passive recipient of the cure. The way the Western world approaches mental health issues could be a way of making the people chronic while supporting, what is called “social defeat” (Luhmann & Marrow 2016: 25) and “repeatedly creating the conditions for demoralizing and despair” (Luhmann & Marrow 2016: 25).

Thanks to the anthropological and ethnographical insights we know that “social disintegration generates personality disintegration” (Scheper-Hughes 2011: 300) and that the way children are raised (Scheper-Hughes 2001: 60) can influence mental health issues. We also know that some groups of people are in higher risk to

¹⁰ India had the best results among 10 countries, especially Chandigarh and the Chennai in India.

have mental health issues like immigrants, children raised in poor families, people with lower socioeconomic status, people living in the cities, ethnical minorities and people abused during the childhood (Luhrmann & Marrow 2016: 21). All of this is important in changing the views about genetic being the main factor in mental health issues. Ethnographical insight is valuable for clinicians and social change (how mental health issues are treated). These notions Recovery Movement had incorporated in their approach which is “that serious psychotic disorder is not a chronic condition, but that people can return to productive, functioning lives” (Luhrmann & Marrow 2016: 19). Their core philosophy is “that the way we imagine and understand mental illness shapes the way those who are ill respond to their condition” (Luhrmann 2016: 19).

Experiences from different cultures about approaching mental health issues and schizophrenia can help us to better understand schizophrenia and to plan recovery with better outcomes. Some of the main aspects of living that can shape understanding, meaning and recovery process of schizophrenia and people hearing voices are defined in the book “*Our Most Troubling Madness*” (Luhrmann & Marrow 2016). Those aspects are: understanding of madness, whether the person can work, involvement of family members, general social conditions and the experience of the illness itself (Luhrmann & Marrow 2016: 204-216). This means when a person understands his experience as a pathology caused by genetics, doesn't have a job or support of family members and experience these problems as a primarily negative experience, he has a smaller chance for recovery.

1.5. Medicine, Anthropology and Psychiatry

Anthropologist's interest in people that are different in some respect in their own society, people with mental health issues or marginalized people is understandable, partly because anthropologists were the outsiders or minorities in the foreign cultures they were exploring (Lindholm 2010: 298).

More systemic collaboration between medicine and anthropology started in 1960s (Bernard & Spencer 2002: 540) with the very exciting sub-discipline of medical anthropology, which is “generally understood to refer to the study of social and cultural dimensions of health, ill health and medicine“ (Bernard & Spencer 2002: 540). Interest in the anthropology of mental health is growing very fast in the last few decades and discipline of “medical anthropology is the fastest growing specialist area within anthropology, in both North America and Europe” (Jenkins & Barrett 2004: 4).

Psychiatry, both as a science and as an institution, is a “part of western cultural and social history” (Mihanović et al. 2005: 747) while anthropology as science started researching “others” in non-Western cultures. This combination is a starting point of early research work and interests in mental health in non-Westerners (usually in colonized states). Interest in mental health issues, outside of the Western world, can be traced back to the beginning of 18th century when mental health professionals noticed “existence of ethnic differences in mental illness” (Mihanović et al. 2005: 747) which lead to clinical researches in non-Western world and development of “cultural psychiatry” (Mihanović et al. 2005: 747) concerned with cultural aspects of psychopathology and treatment. The first doctors and psychiatrists who came from the West to the colonies, very soon found out that symptoms of local non-Western people are different than symptoms of mental health patients back home. They defined this as

a “culture-bound syndromes” (Mihanović et al., 2005: 747) which were defined as a “locally recognized patterns which recalled mental illness but could not easily be fitted into Western nosologies” (Bernard & Spencer 2002: 304) and “which represented a society’s character” (Bernard & Spencer 2002: 304). Some of the now well-known culture-bound symptoms are: *koro* (fear of penis withdrawal in East Asia), *latah* (imitation compulsion in Malaysia), *windigo psychosis* (person is possessed with cannibalistic demon in Ojibwa tribe), (Lindholm 2010: 306), *dhat* (preoccupation with purity in Hindu), *pibloktoq* (known as Arctic hysteria), (Bernard & Spencer 200: 304) and many others. Culture-bound syndromes are present in the Western world as well, in a form of Multiple personality disorder that “responds to present-day social fragmentation and to the erosion of family ties” (Lindholm 2010: 307), PTSD (post-traumatic stress disorder) or even alcoholism (Lindholm 2010: 310).

The beginning of a collaboration between psychiatry and anthropology goes back to 1898 when psychiatrist W.H.R.Rivers went with his colleagues to Torres Straits Expedition where he “combined a medical and an ethnographical approach” (Mihanović et al. 2005: 747). He thought that local healing practices and medicine could be approached and studied as “a social institution employing the same principles and methods that are used to study other social and cultural phenomena” (Bernard & Spencer 2002: 540). Other famous anthropologists like Victor Turner or Evans-Pritchard, were also interested in local aspects of medicine, mental health and illness, and they “have discussed aspects of illness and healing in the course of describing mechanisms of social regulation, religious systems or aspects of cosmology in particular cultures” (Bernard & Spencer 2002: 541).

After River's expedition, in 1904 psychiatrist Emil Kraepelin went for a trip in Java, Mexico and the United States describing differences in symptoms of local people (Mihanović et al. 2005: 747). His trip to the psychiatric institutions of Singapore and Java is considered to be a beginning of "transcultural psychiatry" (Jenkins & Barrett 2004: iv). Soon after, there was another significant historical moment in bridging psychiatry and anthropology. It was a Psychology Conference, organized by Clark University at Worcester, in September of 1909. Participants on that conference were Franz Boas and Sigmund Freud, amongst other famous people of that time (Mihanović et al. 2005: 747).

In the first part of the 20th century, most of the now well-known anthropologists were interested in the mental health of Native people. Malinowski used Freud's ideas of the Oedipus complex in his matrilineal research. Margaret Mead researched child upbringing and adolescence in different cultures, while G. Róheim (anthropologist and psychoanalyst) was interested in neuroses in natives in Australia (Mihanović et al. 2005: 747). In the 1930s psychoanalysis was heavily involved in psychiatric definitions of schizophrenia and other mental health problems, and psychoanalyst defined schizophrenia as a "reaction to social experiences - not a disease" (Luhrmann & Marrow 2016: 9). Anthropologist's interest in personality and culture, introduced concepts such as "cultural configurations" (Mihanović et al. 2005: 747) by Benedict or "basic personality structure" (Mihanović et al. 2005: 747) by Kardiner or "modal personality" (Mihanović et al. 2005: 747) by C. du Bois. This is the beginning of the anthropology of "Culture and Personality" or "beginning of Psychological anthropology". After the First World war until 1950s anthropologist mainly researched topics of mental health problems in the context of Culture and Personality school (Bernard & Spencer 2002: 304). Benedict and Mead wrote about

people, which were considered in some way different in their own culture as “temperamentally unsuited to the world they were born into” (Lindholm 2010: 298). These configurationist’s assumptions defined deviance as relative - what was normal in one society was extraordinary in another (Lindholm 2010: 298). Every culture has individuals considered to be different or deviant but the “labels” given to them are very different from culture to culture.

In that time, abnormal was defined as an opposition to normality, which was considered to be social and relative (Luhrman & Marrow 2016: 9). In her famous article “Anthropology of the Abnormal” (1934), Ruth Benedict argued that people hearing voices in Western cultures could normally function and “thrive in a less modern setting as shaman” (Luhrman & Marrow 2016: 9). That was a period of a belief that “ ‘our’ schizophrenia is ‘their’ shamanism” (Luhrman & Marrow 2016: 9). But shamanism and schizophrenic experience are considered to be different, mainly because shamans are behaving in context of cultural expectations and their states of mind are “willed” (Luhrman & Marrow 2016: 9). Schizophrenic state of mind is usually not under the control and it is not culturally expected. Nowadays shamanism is understood as a dissociative process not as a psychotic experience even though in the last decade there is more intensive evidence which suggests that psychotic experiences and hearing voices are connected with the dissociative process as well (Moskowitz & Corstens 2008; McEnteggart et al. 2017).

Nancy Scheper-Hughes also wrote “every culture has its own normality threshold” and that “society reveals itself most clearly in the phenomena they reject, exclude and confine” (Scheper-Hughes 2001: 73). During this period in the history of social and cultural anthropology, there was a belief that Western society and the way of life causes mental health problems and that primitive cultures “do not have this

kind of problems” (Scheper-Hughes 2001: 154). Claude Levi-Strauss wrote that Amazonian people are free, unlike people in the West (Luhmann & Marrow 2016: 6) and C.G. Seligman thought that mental illness does not exist in New Guinea (Luhmann & Marrow 2016: 6).

Durkheim, who had big influence on anthropologist in this period, wrote that people in the West are killing themselves because of the “anomie”, in places where “social cohesion is loosened” (Luhmann & Marrow 2016: 5-6), while non-Western people may kill themselves but not because they are hurting, but for “altruistic reasons” (Luhmann & Marrow 2016: 5-6). He also believed that every society has to have deviant people, because “normality *requires* abnormality for its definition” (Lindholm 2010: 299). This idea was later developed in Labeling theory, which said that the source of deviance is not a person but the society (Lindholm 2010: 300).

George Devereux, ethnologist and psychoanalyst, had a series of researches amongst Aboriginal people in North America during the 1950s. His most famous ethnography was amongst Mohave Indians, and it popularized term ethno- psychiatry “that refers to the local presentation of psychiatric illness” (Bernard & Spencer 2002: 305). He was especially interested in the etic and emic perspective and normal and abnormal distinctions in North American Aboriginals (Bernard & Spencer 2002: 305). During the first encounters on the North American soil with Aboriginal people, psychiatrists and anthropologists defined mental health of Aboriginal people as “immature mental development, especially existence of spirits and animated objects within their world views” (Waldram 2004: 109). Mental health problems in North American Aboriginals were later presented as a question of acculturation and acculturative stress (Waldram 2004: 118-124), where stress due to acculturation was seen on a cultural and individual level. This stress can construct a feeling that

someone is “between two worlds” - traditional and modern, which can bring a sense of not belonging, a crisis of identity, apathy and other mental health problems.

During the 1960s, Gregory Bateson and his Palo Alto group were highly involved in researching schizophrenia. He was mainly exploring communication and relationships between members of the family that had a child labelled as a schizophrenic. He came up with a concept called “double-bind” (Luhmann & Marrow 2016: 11). In the communication with his mother, child is usually put in a “no-win” situation, because whatever he does it is not good enough. That form of communication goes something like “hug me, don't touch me” (Luhmann & Marrow 2016: 11) and this “double-bind” situation is “emotionally impossible” (Luhmann & Marrow 2016: 9) which can lead to the schizophrenic experience.

Contemporary anthropologist changed the way they think about deviance and being different, mainly under the influence of social constructivism, postmodernism and influence of Russian literary critic Mikhail Bakhtin. Anthropologists used Bakhtin's terms of heteroglossia and they had “portrayed cultures as complex and multiple texts, made up of countless individual voices” (Lindholm 2010: 298). In this way polyphony is present and because “there are so many individual variations in any culture that the very notion of the exceptional or unusual is an error” (Lindholm 2010: 299). Nowadays the majority of anthropologists believe that mental illness (as psychiatric diagnosis) is a social construct, but still, they are having a consensus that “certain near universal categories of abnormal behaviour do exist” (Scheper-Hughes 2001: 254). Anthropologists “long term field work” (Luhmann & Marrow 2016: 7) changed their mind that madness is only specific to the Western world. For example, ethnographer M.J. Field was researching schizophrenia and depression in Ghana, and

in her book *“Search for Security”* (Field 1960) she came to a conclusion about psychotic-like states that “the basic rates are same as in Britain” (Luhmann & Marrow 2016: 7). Another ethnographer Jane Murphy, in her article *“Labeling”* (Murphy, 1973) presented her fieldwork amongst Yupik speaking Eskimos (Bering sea) and Egba Yoruba (West Africa), using “labelling theory” and concluded that patterns of madness and “losing one's mind” existed almost everywhere.

While modern-day medicine and psychiatry are investigating neurobiological factors of schizophrenia, psychosis and other mental health issues, we now know that “manifestation, causation, treatment and outcome are equally powerfully affected by interpretation and context” (Lindholm 2010: 310). Looking back in the recent history we can say that anthropology influenced psychiatry (and mental health in general) in many aspects mainly in criticizing biomedical model of illness for disregarding cultural factors, context and applying Euro-American categories to culturally specific states like trans (Mihanović et al. 2005: 750). Ethnographers also showed that the person is not isolated from the community and they “depict processes of interpersonal communication, of negotiations and placement into a context which is a generator of every kind of experience in the local community: (Mihanović et al. 2005: 750). Anthropologists define this as “social course of an illness” (Mihanović et al. 2005: 750), emphasizing the importance of the social environment in shaping experience and understanding of illness and recovery. Thanks to recent ethnographic research, we know that cultural factors such as immigration, ethnical minority, socioeconomic status etc. contribute to the mental health issues (Luhmann & Marrow 2016: 21). Relationship between anthropologists researching mental health issues and mental health professionals has changed in the last hundred years, and as T.M.Luhrman

(Luhmann & Marrow 2016) wrote, relationship has changed from having very “sceptical, even dismissive approach to the clinicians to a more clinically engaged research process” (Luhmann & Marrow 2016: 5).

1.5.1. DSM and Culture

Psychiatry has a positivist understanding that hearing voices is a symptom of mental health problems, mainly schizophrenia and psychosis and they are searching for problems in the individual. In the last two editions of the DSM manuals, in the DSM IV (1994) and DSM V (2013), there have been some improvements regarding the cultural understanding of mental health symptoms, including hearing voices.

DSM IV was the first diagnostic tool in psychiatry that included culture. DSM IV “includes a brief cultural section on each category and a glossary of culture-bound syndromes written by ethno-psychiatrists” (Bernard & Spencer 2002: 305). In the Annex I of that manual, it is mentioned that it "contains a list of key parameters by which a psychiatric patient can be described in terms of the culture to which he belongs: 1. cultural identity of the person, 2. explanation of illness in terms of culture, 3. cultural factors related to psychosocial environment, 4. cultural elements in patient-doctor relationship (Mihanović et al. 2005: 750). On the official web page of American Psychiatric Association it is written that they want to have more “cultural sensitivity” (Cummings 2013) and that “DSM-5 updates criteria to reflect cross-cultural variations in presentations, gives more detailed and structured information about cultural concepts of distress and includes a clinical interview tool to facilitate comprehensive, person-centered assessments” (Cummings 2013). Appendix of the DSM IV manual is named “Glossary of Cultural Concepts of Distress” (Cummings

2013), which gives more cultural sensitivity. Maybe the most important contribution for including culture in DSM is criticism of psychiatric nosology, that problems come from (within) the individual, and to open the possibility to see problems in a social world and in interpersonal relations as well (Cummings 2013). Some improvement has been made in order to include culture as an important aspect of mental health issues, but still DSM manuals are socially constructed in the Western World and they can not be applied to the rest of the world because this “fails to recognize that individuals are active participants within their culture, which has its own historical and conceptual views about mental illness” (McCann 2016: 7).

1.6. Anthropology, Culture and Hearing Voices

Social and cultural anthropologists, as well as some psychotherapy approaches (existential and humanistic) and critical psychiatry are very sceptical about bio-medical view regarding psychiatric diagnosis. However, in the broader scientific world, there is a consensus that what we know as *madness* exists in almost every part of the world, in every society and group of people. Nancy Scheper-Hughes said that “madness exists throughout the world, its content and expression may be culturally specific” (Scheper-Hughes 2001:155). In contemporary psychiatry, hearing voices is seen as “primary symptom” (Luhmann & Marrow 2016: 1) of psychosis and schizophrenia, but it is influenced by the culture and local context in many ways. Hearing voices phenomenon exists across the world and it is believed that hallucinations are “pathoplastic”, meaning that they are shaped by local expectation and meaning” (Scheper-Hughes 2001: 216). Influence of culture on voice hearing is

present on every level of the experience, not just in the content and form of the voices (Larøi et.al, 2014: 216), but also "culture shapes hallucinations in all dimensions of the phenomena: in identification, in experience, in content, in frequency, in meaning, in the distress they elicit, and in the way in which others respond" (Larøi et al. 2014: 218). Culture has an influence on how hallucinations are defined in one society. This is directly connected with the understanding of the reality in one culture (Larøi et al. 2014: 213). Here we can see that hallucinations and voice hearing phenomenon are socially constructed.

Anthropologists were always interested in the hallucination-like phenomenon in non-Western cultures. They have been interested especially in states of mind that a shaman goes through in different rituals while experiencing hallucinations (including voice hearing) under the influence of psychoactive drugs (La Barre 1975: 9-53). They have found that the most common motifs in those altered states of hallucinations (visual, audio or others) are loneliness and social deprivation, and they are explained as possession of the spirits (La Barre 1975: 15). La Barre goes even further by saying that "much of the culture is hallucinated" (La Barre 1975: 16), stating that the content of hallucinations is "manlike because they have been made of men's own psychic stuff" (La Barre 1975:16). Anthropologists interested in these kinds of experiences described above, especially ones influenced by psychoanalysis, defined hallucination-like experiences as a form of dissociation. In religious societies hearing voice of God is seen as dissociation "that the subjects have trained their attention in culturally prescribed ways, so that the shaman or possessed person who regularly hears spirits talking is best understood as going into frequent trance" (Larøi et al 2014: 215). This could be something like "cultural conditioning" (Larøi et al. 2014: 216) of

hallucination experience. Every religion has its own stories when it is acceptable to hear voices or have visions.

This also applies in Western religious contexts. In her book "*When Gods Talk Back*" (2012), T.M. Luhrmann described ethnographic work in the group of evangelical Christians in the USA who heard the voice of God. She found out that evangelical Christians have series of "spiritual exercises" (Sacks 2012: 249) when praying, those techniques "are often focused on attention to sensory details" (Sacks 2012: 249). When they practice praying, there is a connection between imagination and sensory aspect of those imaginations (how something looks like, smells like, sounds like etc.). As a consequence "what they are able to imagine becomes more real to them" (Luhrmann 2012 in Sacks 2012: 250), where "one day mind leaps from imagination to hallucination" (Sacks 2012: 250). Here we see the concept of contextual expectation as the main factor in hearing voices. Contextual circumstances can change over time, and even people from the same society in different historical periods can have different voice hearing experience. A great example of that was provided by Michell and Vierkant (Michell & Vierkant 1989) in their research where they are comparing the voice hearing content and phenomenology using hospital documents of patients in East Texas hospital from two different decades. They compared documents from admitted patients in 1930s and 1980s and found that voices reflected different social elements or "subcultural milieu" (Michell & Vierkant 1989) that were important in a particular time. In 1930s voices reflected a longing for material stuff, possession, and they had more positive but intrusive commands (for example "be good"). The social context of that time in the USA was an economic crisis and people did not have enough money. In 1980s voices reflected technological innovations and more

negative destructive commands were present (like “kill others”). Also, we know that the social context of this time was rising of the capitalist way of thinking and post-Vietnam war period. This example shows that the voice hearing experience is under the strong influence of social and personal context.

Distribution of what we call madness (psychosis or schizophrenia) is not equal across the world, neither is voice hearing experience, because “culture or subculture you live in influence if you will hear voices” (McCarthy-Jones 2017: 110). Nancy Scheper-Hughes in her famous ethnography about rural Ireland and schizophrenia “*Saints, Scholars and Schizophrenics*” (2001) wrote that “societies will differ markedly in the attention they give to some symptoms and disregard of others” (Scheper-Hughes 2001: 155). This also goes for aspects of the same experiences (symptoms). In cross-cultural studies of voices hearing experience, in different cultures¹¹ it was shown that participants with a diagnosis of schizophrenia had a different experience of voice hearing and that experience was influenced by cultural expectations. Participants from USA saw their voices as “intrusive unreal thoughts” (Luhmann et al. 2015: 646), participants from India as something that is “providing useful guidance” (Luhmann et al. 2015: 646) and participants from Ghana described voices as “morally good and causally powerful” (Luhmann et al. 2015: 646). Luhmann introduced term “social kindling”¹², which she uses to explain why people from different cultures are thinking differently about their voice hearing experience. She said that it could be because there are “variations in ways of thinking about minds, persons, spirits and so forth” (Luhmann et al. 2015: 646) and because people

¹¹ Groups of people that have a diagnosis of schizophrenia from India, Ghana and USA (“Hearing Voices in Different Cultures: A Social Kindling Hypothesis” 2015).

¹² “We describe this process as “social kindling” (Cassaniti & Luhmann 2014) that the implicit and explicit ways in which a local social world gives significance and meaning to sensation (such as a hallucination) will alter not only the way those sensations are interpreted but the likelihood and the quality of the sensation itself.” (Luhman et al. 2015: 658).

from different cultures are selective of the voices in a different way. In other words, there is a different cultural significance and meaning of “cultural invitations”, what to hear and what not to hear (Luhrmann et al. 2015: 648).

People from different cultures have “cognitive bias” (Luhrmann et al. 2015: 648) on how they experience, define, respond and remember voices (Luhrman net al. 2015: 648). Participants in this research heard both negative and positive voices, but they had selective attention what to hear and what not to hear, which played important role in defining voices as primarily good or bad (Luhrmann et al. 2015: 650) and defining the meaning of the experience. Participants from the USA heard primarily negative voices defined them as bad and they usually thought about voices in a more pathological way (Luhrmann et al. 2015: 653). Participants from Ghana and India heard more positive voices and they connected voices in a more “socio-centric” way (Luhrmann et al. 2015: 657) with kin in India or spirits in Ghana (Luhrman et al. 2015: 653). This gives important insight about cultural elements which are playing important role in constitution and perception of mental health problems and unusual phenomenon because “...there are social norms about what people perceive, feel, and hold in the mind” (Cassaniti & Luhrmann 2011: 50).

The most important insight from this research is that people in the non-Western world report more benign or positive voices or they have better relationships with the voices than people in Western World (Luhrmann et al. 2015: 655-6). This has been also confirmed in a more recently published ethnographies and cross-cultural case studies of people hearing voices. In the case of a young Indian lady named Sita (Luhrmann & Padmavati 2016: 99-112), anthropologists have found some of the cultural reasons why she is not bothered with her voices. She considers her voices as culturally normal and not as a symptom of schizophrenia. Voices had god-like or

human-like form, they were part of her social life. She talked to them and did not emphasize or focused on negative and distressing voices (Luhrmann & Padmavati 2016: 99-112).

Recent anthropological research about the influence of culture on senses that we use (as dominant), can give us some clues about why Western people who hear voices are more focused on negative aspects of that experience and why they define their voices as less benign. In this particular cross-cultural comparison between supernatural experiences (including hearing voices) in USA and Thailand, participants from different cultures were focused on different senses of the experience.

Participants from Thailand were more focused on tactile senses (because in their Buddhist culture they can feel ghosts on their skin), while American participants were more focused on sight and sound (Cassaniti & Luhrmann 2011: 47). It has been said that culture and society influence how we understand, accept, interpret and define (unusual) experiences, so it is no surprise that “culturally shaped patterns of attention seem actually to shape the auditory experiences themselves” (Luhrman et al. 2015: 658).

Expectations in a culture about voice hearing (and other experiences) are connected with the collective stories, myths and individual authentic experiences that have some foundation to the original story or myth. If hearing voices is not culturally expected or present in some cultural scripts or myths, then it could be sign of the madness as it is in the West (Larøi et al. 2014: 215).

Another factor that could play a role in understanding the voice hearing experience (and other psychiatric and unusual experiences) is that individuals labelled as mentally ill in the non-Western world are less anxious and afraid because their culture

better tolerate a different range of behaviours. Also, they have concepts (e.g. spirits and possession), which offer a better understanding of what is happening with the person (Estroff 1981: 209). Other authors like Sacks offer similar understanding, where “behind the personal attitude are the attitudes of society” (Sacks 2015: 59). This social attitude is different “profoundly in different time and spaces” (Sacks 2015: 59).

Culture also influences the meaning of recovery and coping strategies of voice hearer's. Coping strategies are different in Saudi and British people with a diagnosis of schizophrenia (Wahass & Kent 1977 in Jenkins & Barrett 2004). Saudi voice hearers explained their experience in a religious context and coping strategies had a religious foundation, while British voice hearers found some techniques for distraction or that are physiologically self-stimulating (Jenkins & Barrett, 2004: 40). Western man is afraid of everything that can contribute to losing control and self-control, which is very important for the individualistic society. Hearing voices is one phenomenon that comes from nowhere and it is hard to control. If society does not welcome such experience people will continue to be afraid and consider it as pathology. On the other hand, if voices (and other unusual experiences) are “given credibility” (Scheper-Hughes 2001: 302) in the society if people who hear voices are equal members of the society that can result in “natural remission of the symptoms” (Scheper-Hughes 2001: 302). That remission of the symptoms is usually present in the cases of people who explore their own experiences with hearing voices, explore their own personal biography and narrative in search of the meaning, and people who have better relationship with the voices (Romme et al. 2009:104-319)¹³. Anthropological ethnographies in transcultural research of hearing voices showed that

¹³ See 50 stories of recovery, of people hearing voices, from all over the world.

the way we approach this phenomenon has a direct influence on what kind of relationship we will have with the voices. Ethnographies that explore mental health topics, including hearing voices, have potential clinical consideration that can change the psychiatric approach in dealing with a phenomenon like hearing voices. A great example comes from New Zealand where in Maōri Mental Health Services, where we can find a cultural therapist (Bush & NiaNia 2012), that understands and treats hearing voices, and other experiences, in the context of Maōri tradition and not in the context of psychiatric diagnosis. Bush and NiaNia (Bush & NiaNia 2012) presented the case of a young Maōri man who heard distressing voices. The cultural therapist explained voices as “unresolved intergenerational issue” (Bush & NiaNia 2012: 349) that had a negative impact on their family and relationship within the family. After that, he and his family had a ritual called “whakawetewete” (Bush & NiaNia 2012: 350), where they wrote a list of people that they maybe have hurt in any way and then they burned this list. In Maōri tradition it is expected to communicate with the dead by hearing voices or having visions (Bush & NiaNia 2012: 350) and that is the reason why it is not considered as pathology.

Focusing on (inter) subjective experience of schizophrenia, Jenkins (Jenkins & Barrett 2004) is arguing that this experience is a “paradigm case for understanding fundamental human processes” (Jenkins 2004: 11) and we can say that “hearing voices is undeniably a fundamental self-process that is thoroughly infused with cultural meaning” (Larøi et al 2014: 216).

1.7. History of the Hearing Voices Phenomenon in the Western World

1.7.1. Ancient times

History of hearing voices is not a history of madness per se, but still, we can see how “experience is understood, how it became synonymous with madness, and how people have tried to liberate it from madness” (McCarthy-Jones 2012: 10).

When we look at the history of hearing voices, we can see that there was always one major power at a particular time in history that defined this phenomenon according to their needs. That is why personal narratives and views are important because they bring us a different perspective on the phenomenon and power shift. McCarthy-Jones uses the term “histories” to stress the importance of this aspect and how we need to incorporate different understandings and views on the subject. This means that there is more than one true history (McCarthy-Jones 2012: 3).

Throughout the history of the Western civilization, we can see that there was, at least, medical-pathological and spiritual-meaningful perspective on voice hearing. “These discourses have been used as tools at the various times by various people to achieve invariant aims... control and power... Church trying to discipline its flock...” or “...voice-hearer trying to regain control and power over the meaning of their own experience” (McCarthy-Jones 2012: 5).

The first written text in our civilization came from Mesopotamia (cca. 3000 BC), (McCarthy-Jones 2012: 11) and hearing voices was connected to the “reality of ghosts (dead spirits) and demons” (McCarthy-Jones 2012: 12). In this period, hearing voices was seen as a “bad sign” that “something is very wrong with the patient”

(McCarthy-Jones, 2012: 11). In Ancient Egypt in medical papyri, “mental illness” is described as “disease of the heart” (McCarthy-Jones, 2012:14).

In order to explain the historical period between 9000 BC and 1000 BC, American psychologist Julian Jaynes presented a very controversial theory about voice hearing. He said that in that period all people heard voices (Jaynes 2000). In his book "*The origin of consciousness in the break down of the bicameral mind*" (2000) he argued that in this period the human brain had two parts (two-chambers, bicameral mind). One was responsible for “human speech” and the other one for “language of the gods”. “Anything that could not be dealt with on the basis of habit, any conflict between work and fatigue, between attack and flight, any choice between whom to obey or what to do, anything that required any decision at all was sufficient to cause an auditory hallucination [i.e. hearing voices]”, (Jaynes 2000 in McCarthy-Jones 2012: 14). This period, according to Jaynes, came to an end when people started writing, with overpopulation and social disintegration that “self-consciousness arose and the voices of the gods were replaced by the verbal inner speech we have today” (McCarthy-Jones 2012: 15).

In Ancient Greece and Rome, people wrote more about the hearing voices experience. It's said that in Ancient Greece, the most common type of hallucination was “vision of a god or hearing a divine voice which commands or forbids the performance of certain acts” (McCarthy-Jones 2012: 17). In Classical Greece, philosophers like Aristotle and Plato had their own theories about voice hearing. Aristotle (384-322 BC) thought that hearing voices occurs because people are mistaking internal voices for external voices or they saw them as “phantasms” which are “traces of perception” left behind from seeing the original object (McCarthy-Jones 2012: 17-8). Socrates (469-399 BC) heard the voices giving him commands or telling

him what not to do. In his time it was common that gods communicate with humans (“polytheistic society”), (McCarthy-Jones 2012:19). The problem was that his voices were not “licensed by the state” (McCarthy-Jones 2012:19). His experience brought problems for the state and, they had to do something. In the end, he was executed.

During the Ancient Rome, Neo-Platonists were influential and believed “that the experience of hallucinations was implacably real at the time” (O’Brien 1924 in McCarthy-Jones 2012: 21) when spirits of the dead people were present, and they were good or bad spirits. In this case, there was a “socially acceptable framework for people hearing voices in which to frame their experiences” (McCarthy-Jones 2012: 21). The medical approach came to focus with the Hippocrates (brain as a cause), (460-370 BC) and Galen (typology of four humours) (129-199 AD), (McCarthy-Jones 2012: 21).

1.7.2. Religious tradition

In the Old Testament voices were seen as a divine experience, “a way that God could contact humanity” usually through prophets¹⁴ (McCarthy-Jones 2012: 22-3). It was written that “He would reveal Himself to human beings through visions and voices” (Watkins 2008: 36). In the New Testament, hearing voices is present as “supernatural communications” (McCarthy-Jones 2012: 23) “in which an individual hears supernatural voices” (Watkins 2008: 36), like it was written in many personal accounts of holy people (e.g. Jesus, Zechariah, Mary Magdalene etc.). In ascetic Desert Fathers, Christians who went outside of the cities to pray had voice hearing experiences “in the ranging silence of the desert under the condition of fasting and introspection” (McCarthy-Jones 2012: 24). This is interesting because one of the

¹⁴ Moses and Ezekiel (heard commanding voices), Isaiah, Jeremiah etc.

theories about voice hearing says that people hear voices because of sensory deprivation. Voices in this period were not seen as an illness. St. Augustine (354-450), one of the most influential thinkers at that time, defined types of visions, which can be also translated to voices. He knew *Corporeal locutions* experienced through the body, *Imaginative locutions* were interior and *Spiritual/Intellectual locutions* where voices were heard without the sound (McCarthy-Jones 2012: 25). Church preferred voices (and visions) that came from the inside, while those from the outside were treated with suspicion (McCarthy-Jones 2012: 25).

Concept of possession changed in the 12th century from bodily to spiritual and causes of voices were seen in spiritual/demonic possession as we can see in the example of mystic Hildegard of Bingen, whose voices (and visions) were accepted by the Church as true (Watkins 2208: 43). St. Thomas Aquinas (1225-1274) was well-renowned thinker of his time and he thought that voices can occur “due to pure natural reason and spontaneous physiological changes”. He also thought that one way of “receiving such divine revelation” is by hearing voices (McCarthy-Jones 2012: 28).

At the beginning of the 14th century we can see that mystics, especially women¹⁵ mystics, appear as scholars who used their emotions and introspections as the main focus of their faith. The debate about the origins of Joan of Arc's voice is still active, but the majority of women mystics were approved by the Church at some point. In the 15th century Church was losing power and Pope Innocent VII and two monks started their witch hunt. He wanted to explore the phenomenon of witches by writing a book that we know as “*Malleus Maleficarum*” (lat.) or “The Hammer of Witches”. In this book, there was a specific part describing voice hearing

¹⁵ St. Birgitta of Sweden (1303-73), Hildegard of Bingen, Joan of Arc, Julian of Norwich (1342-1416) and Margery Kempe (1373-1438), it is considered that she wrote first-person perspective experience about voice hearing in English (McCarthy-Jones 2012: 34). Women mystics were “treat to the authority of the hierarchical male society” (McCarthy-Jones 2012: 34).

phenomenon in the context of "how the devil talked to witches" (McCarthy-Jones 2012: 35). Both external and internal voices are mentioned. It is important to say that the Church did not automatically define voices as divine. There were specific classifications about how to recognize demonic or divine voices.

When the Church lost its power, we entered the historical turn in the conception of the self. People were focusing more on the inside, differentiating between outside and inner "I" (McCarthy-Jones 2012: 38). People "were more able to see themselves from the distance" (McCarthy-Jones, 2012: 38). This turn meant the birth of the Western values, as we know them today, primarily "self-control" and "control over circumstance" (McCarthy-Jones 2012: 38). People are more afraid of what comes from the outside or from the inside that they can't control.

Martin Luther, the beginning of the Reformation, and Gutenberg's printing machine influenced different view on hearing voices. Luther thought that people can hear the voice of God and that it is true only in relation to the Scripture (McCarthy-Jones 2012: 40). He fought against the medicalization of the voice hearing saying that cause of voices and visions are "not melancholy dreams that have no bearing on reality" (McCarthy-Jones, 2012: 41).

There were several mystics writing on such experience in Spain at that time. Two well-known individuals were St. Teresa of Avila (1515-82) and St. John of the Cross (1542-1591), who had personal experiences of hearing voices from contemplative meditation (McCarthy-Jones 2012: 43). St. John¹⁶ and St. Teresa¹⁷ had their own classifications of this phenomenon. St. Teresa was the one who embraced

¹⁶ Successive locutions (while meditating), Formal locution (outside of the meditative state, "it just comes to you") and Substantive locutions (has a great impact on a person, like when you are talking to your self), (McCarthy-Jones 2012: 44-5).

¹⁷ St. Teresa defined what constitutes "genuine divine communications" as "heard clearly, comes unexpectedly, it is about thing people did not think about, meaning, more than what words are saying and you cannot ignore them (McCarthy-Jones 2012: 46).

medical explanation as well, saying that the person can hear voices because of melancholy (McCarthy-Jones 2012: 47).

Medical explanations regarding spiritual hearing voices co-existed but they “co-existed uneasily” (McCarthy-Jones 2012: 47). In England, Anglican Church moved from the concept of exorcisms as a spiritual possession and brought medicine to explain this experience. In this way, Anglican Church could have control over this phenomenon. Voice hearing was seen as an experience that had roots in human nature and “key diagnoses for voice-hearers were epilepsy, hysteria or melancholy” (McCarthy-Jones 2012: 41). This is a clear example of medicalization of experience that was before seen as spiritual. Anglican Church wanted to control individuals who claimed to talk directly to God, like George Fox (founder of Quakers) to whom doctors said that he is “melancholic” and “mentally sick” (McCarthy-Jones 2012: 51). Ruling authority of the Church at that time did not like having groups of people claiming to be in direct contact to the divine or God without their approval. That is a reason why Anglican Church employed medicine to discredit those people (they were called “enthusiasts”) by saying that this enthusiasm is “a sign of illness, with both old humeral physiological explanations...” and “...as well as newer neurological explanations“ (McCarthy-Jones 2012: 51).

From that point, the dominant view on hearing voices phenomenon is the secular one. For example, Descartes also gave a neurological explanation “that any activation in the brain in the pathways between the ear and the center of consciousness could result in hearing voices that were not there” (McCarthy-Jones, 2012: 53). Physicians such as William Battie said that voices “resulted from factors such as gluttony and idleness” (McCarthy-Jones 2012: 57). Consequently, due to the

medicalization of the hearing voices phenomenon, meaning of this experience was lost.

1.7.3. Dawn of psychiatry

Birth of psychiatry (and psychology) is connected with the birth of capitalism, industrial and technical revolution and social control (Roberts 2015). All of this had a great impact in understanding the voice hearing phenomenon, especially in the context of “reformation of character” (McCarthy-Jones 2012: 58). This meant that people needed to integrate self-discipline and “control had to come from the inside” (McCarthy-Jones 2012: 58). People were understood as machines and voices were not welcomed because voices hearers, mad people and others who could not work were seen as “defective human mechanisms” (McCarthy-Jones 2012: 58). Society was mainly focused on productivity and labour, so people who could not work had to be somewhere else. This is how psychiatric asylums and psychiatrist¹⁸ as professional were born (McCarthy-Jones 2012: 58). “Broken” people were put together and observed by “professionals”, who provided the treatments in order to fix them so they could go back to work. Medical secular, biological and neurological explanations about voice hearing but the treatment was lacking. So, by the end of 18th century new approach to mental distress was created by William Tuke (McCarthy-Jones 2012: 59) and called *Moral treatment*. Famous York retreat was center of this “Moral treatment” where people were in their own clothes, working, having different activities and where they were treated with respect and kindness. In the eyes of psychiatry, the problem was that Tuke and others in York Retreat were “layman claiming authority to treat the ‘mentally ill’” (McCarthy-Jones 2012: 60).

¹⁸ Johann Christian Reil coined term psychiatrist in 1808, meaning *Psyche* (soul/mind) and *iatry* (physician). Now we have a clear understanding that “mentally ill” and voice hearers should be treated by the new expert called psychiatrist (McCarthy-Jones 2012: 58-9).

An important year for hearing voices is 1817 when Jean-Étienne Dominique Esquirol (French psychiatrist) defined all sensory experiences, such as hearing voices and having visions, as hallucinations. This “firmly moved hearing voices from being an experience that may tell us something about the world (i.e. potentially with theological/spiritual value) to being medical symptoms” (Berrios, 1990 in McCarthy-Jones 2012: 60). Esquirol also thought that people could hear voices and not have any problems, which led to the debate in French society about meaning of the voices, where for example hallucinations could be part of reason and not just insanity (“hallucination compatible with reason”), (Berrios 2002: 36 in McCarthy-Jones, 2012: 65). As we can see even today, there is always a *need* to have one and only *right* way to interpret this phenomenon. An interesting method called “*me´decine retrospective*” (Littre 1860: 103, in McCarthy-Jones 2012: 66) appeared in the 19th century. It had a tendency to interpret experiences of famous voice hearers like saints, philosophers etc. using the medical arguments available at that time. The second half of the 19th century defined that “lunatics” are the responsibility of doctors (physicians) and that the main approach to voices and insanity is neurological¹⁹. It was said that “hearing voices resulted from irritation (spontaneous activity) in cortical centres where auditory sensory impressions became perceptions” (McCarthy-Jones 2012: 69). This started the search of the causes of hearing voices in the brain.

¹⁹ Mainly influenced by work of an Italian psychiatrist Tamburini (McCarthy-Jones 2012: 69).

1.7.4. Contemporary time, broken brain and coming back to the meaning

Contemporary time in the context of voice hearing experience starts with the end of 19th and beginning of the 20th century. In the first half of the 20th century, institutional psychiatry was quickly developing throughout Western World. Colonial powers, like England, spread this approach to mental health in their colonies as well (Scull 2015: 322). This period is also significant because the concept of schizophrenia was born. This concept had a great impact on the history of humanity in general and particularly in the world of mental health. In 1896, German psychiatrist, Emil Kraepelin defined voices as “symptom peculiarly characteristic of dementia praecox²⁰” (McCarthy-Jones 2012: 71) that had its cause “in the temporal lobe” (McCarthy-Jones 2012: 73). In 1911, Eugene Bleuler (Swiss psychiatrist) introduced term schizophrenia (as split personality) and positioned hearing voices as “a secondary or accessory symptom of schizophrenia” that “resulted from psychological changes occurring in response to the primary symptoms directly caused by the illness” (McCarthy-Jones 2012: 74). This introduced the possibility that content of the voices could be understood psychologically, not only neurologically. Psychological explanations regarding hearing voices were present after the First World War, because it was clear by that time that mental health problems could be also influenced by environmental factors (e.g. war). Freud²¹, a father of psychoanalysis, at first believed “that hallucinations resulted from forgotten traumatic experiences from childhood which returned and forced themselves into consciousness” (McCarthy-Jones 2012: 76). In this way Freud, at least partly, reintroduced meaning in occurrence of this experience. However, if the voice hearer wanted to explain his experience, he had to

²⁰ Dementia praecox is one of three forms of psychosis that Kraepelin defined: dementia praecox, manic depression and mania (McCarthy-Jones 2012: 71).

²¹ He had experiences of hearing voices as well (McCarthy-Jones 2012: 75).

learn many complex psychoanalytic words, which meant that he could not own his experience by explaining it with his own words. Freud's pupil and colleague, Carl Gustav Jung²² was one of the first people to focus on the content of the voices saying that “hallucinations contain a germ of meaning”. Jung also connected this experience with the personal life context where “a personality, a life history, a pattern of hopes and desires lie behind such experiences”. There were other psychiatrists and psychologists that thought that hearing voices can be meaningful. One of them was Karl Jaspers, philosopher and psychiatrist, who said that voices can be meaningful if they come from person's life history (McCarthy-Jones 2012: 78). Infamous psychiatrist and psychoanalyst Ronald David Laing believed that experiences such as hearing voices and psychosis are “much more socially intelligible than has come to be supposed by most psychiatrists” (Laing & Esterson 1964:13 in McCarthy-Jones 2002: 87).

1.7.5. The dark side of the society and hearing voices

Genetic oriented approach to voice hearing and insanity was mainstream in the 20th century and some psychiatrists like Franz Kallman thought that schizophrenia is dangerous for public health and that people with schizophrenia are illness carriers (McCarthy-Jones 2012: 82). This was used by Heinrich Himmler in Nazi Germany and he conducted “compulsory sterilization of psychiatric patients (Bentall 2003: 76). This led to what McCarthy-Jones calls “greatest criminal act in the history of psychiatry” (McCarthy-Jones 2012: 82) where Nazis “have killed between 100,000 and 137,500 patients with schizophrenia, based on the idea that it was an inherited genetic disease (Fuller-Torrey & Yolken, 2010 in McCarthy-Jones 2012: 82).

²² Also had hearing voices experience (Jung C.G. 1963)

Amongst these people, there were about 50,000 voice hearers (McCarthy-Jones 2012: 82)

1.7.6. DSM, Psychiatric “revolution” and the Big Pharma

After World War II, soldiers experienced a variety of psychological problems which psychiatric community did not have experience with. The need for some sort of scientific classification occurred in order to describe and understand what was going on with the individual. First edition of the psychiatric classification manual was published in 1952, and it was called DSM-I²³ (Diagnostical and Statistical Manual, first edition). In this edition, voices were not mentioned per se, but they were mentioned as a part of “hallucinations” in diagnosis such as “‘schizophrenic reaction', ‘psychotic depressive reaction', organic brain syndromes and alcoholic hallucinosis” (McCarthy-Jones 2012: 83). The second edition was published in 1968, and voice hearing experience was mentioned just once in the context of “other alcoholic hallucinosis” where a person could hear voices (McCarthy-Jones 2012: 83-4). Despite this, hearing voices experience was primarily connected with the state of psychosis and schizophrenia²⁴. The third edition of the DSM, (DSM-III), published in 1980, was a turning point in the approach of psychiatry and diagnosis, and this approach is still present today. In this edition, voice hearing was for the first time mentioned and related directly “to the psychotic disorders (schizophrenia and affective disorder)”, (McCarthy-Jones,2012: 84). Generally speaking, this edition was focused more on defining diagnosis with more details. It was said that hallucinations are characteristically connected with the schizophrenic disorders and voice hearing is the

²³ Published by the American Psychiatric Association (APA). World Health Organization (WHO), published a similar Manual called ICD (International Classification of Diseases). This manual, unlike DSM, includes all physical and mental diseases. The current edition is ICD-11.

²⁴ See Rosenhan experiments about pseudo-patients from 1973.

“most common” (McCarthy-Jones 2012: 84). Also, the new thing was that the content and the form of the voices started to be diagnostically significant. For example, if the voices had the same mood as a person who hears them, then it could be diagnosed as “mood disorder”. If the voices are saying that the person is being followed that could be a symptom of “paranoid schizophrenia” etc. (McCarthy-Jones 2012: 85). Two types of voices were important as symptoms for schizophrenia²⁵: voices that comment on what the person is doing or thinking and if the person hears two voices talking to each other (McCarthy-Jones 2012: 84). Fourth edition, DSM-IV (2000), mentioned hearing voices primarily in the context of schizophrenia and Kurt Schneider's First Rank symptom criteria. If the person is going to be diagnosed with schizophrenia, the sufficient symptoms could be that the person hears voices that comment on his behaviour or voices talking to each other along with “social/occupational problems” that are present over some period of time, or that the person hears voices alongside with other symptoms such as delusions etc. (McCarthy-Jones 2012: 86). Another important new thing in this edition is consideration that voices have a different cultural context. For example, in some religions voice hearing experience is common. In the last edition the DSM V (2013), “the idea that certain types of voices are indicative of schizophrenia has been quietly dropped” (McCarthy-Jones 2016: 73). In the recent years, many kinds of research are focused to find out is there “specific trait” or kind of voices that appears only in cases of schizophrenia and other psychiatric diagnoses, comparing to non-clinical voice hearers. Research from 2016 confirmed that “the results showed that there is no single hallucination feature or characteristic uniquely indicated a diagnosis of schizophrenia” (Flavie & Fernyhough 2016: 32). This means that the same types of voices, with similar characteristics, can be found in

²⁵ In psychiatry, this is known as First Rank Symptom criteria for schizophrenia, defined by psychiatrist Kurt Schneider (Schneider & Hamilton 1959 in Baker 2015: 27).

different psychiatric diagnosis, in medically related voice hearing (e.g. drugs, alcohol or surgery) and in non-clinical groups (people that do not have psychiatric diagnosis and hear voices), (Flavie & Fernyhough 2016: 32-43).

From this historical overview on hearing voices phenomenon, we could see how voices were understood in different parts of the Western World and during different times, kingdoms and civilizations.

There are some important conclusions:

1. There was always some institution (state, church or psychiatry) that had power over this phenomenon;
2. Who had the power defined the phenomenon and used it for political, social or economic purposes;
3. There were always several outlooks on hearing voices phenomenon, outside of the mainstream and dominant approach.

In the last 30 years, for the first time in human history, we have a situation that person who hears voices defines that experience for himself. We will look that in more details in the chapter about the International Hearing Voices Movement.

2. Theoretical and Philosophical Influences: Searching for Meaning

2.1. (Social) Phenomenology

Phenomenology is a study of experience. Phenomenology as a theory was born with Edmund Husserl on the turn of the 20th century, under the influence of philosopher Franz Brentano's notion of intentionality, or directedness to object of our attention. At the University in Freiburg, Husserl appointed as his successor Martin Heidegger who continued to develop the theory of phenomenology. Heidegger said, “human beings cannot be understood independently of the world in which it is experientially and practically engaged” (Overgaard & Zahavi 2009: 2). A human being is “being-in-the-world”. Husserl and Heidegger influenced new generations of scientists and philosophers interested in phenomenology like Emmanuel Levinas, Jean-Paul Sartre and Maurice Merleau-Ponty. Besides philosophy as its cradle, phenomenology influenced other disciplines such as psychology, law, political science, psychotherapy etc.

2.1.1. Social Phenomenology and Intersubjectivity

Sociology combines two extremely different terms like society (collective) and I (individual) into term social phenomenology. Social phenomenologists are investigating the importance of everyday life or “life-world” (Overgaard & Zahavi 2009: 1). Life-world is “experientially given world that

we are familiar with” (Overgaard & Zahavi 2009: 4). This experience of everydayness can offer us meaningful insights and information about the reality of individual(s). According to the social phenomenologists, the reality is not something objective, that can be found, revealed. They think that social reality is a “product of human activity” (Overgaard & Zahavi 2009: 1), where “through the process of ‘typification’, we ‘constitute’ a meaningful social world around us” (Overgaard & Zahavi 2009: 1). Social reality is constituted between people. This phenomenology does not deny the importance of science, however, they are against objectification and scientism (that reality is what is told by science) of natural sciences that has “exclusive claim to reality” (Overgaard & Zahavi 2009: 6). Life-world is a construction, our product, and the way we respond to the things in the outside world.

Main protagonists of phenomenological sociology are Alfred Schutz, Peter L. Berger, Thomas Luckmann and Harold Garfinkel. Alfred Schutz, inspired by Max Weber and Husserl, tried to examine the constitution of social meaning. Schutz thought that every aspect of life (e.g. dreams, children's play, religion etc.) has its meaning and its logic. Central position in his understanding and research of the world's meaning is *life-world*, that “constitutes the frame and stage of social relations and actions” (Overgaard & Zahavi 2009: 8). This theory tried to “describe and analyze the essential structures of the life-world” (Overgaard & Zahavi 2009: 8). He explains how subjective experience "is involved in the construction of social meaning, social action and situations" (Overgaard & Zahavi 2009: 8). A person is an agent in his or her life. People as agents construct their everyday world by giving meaning to the everydayness. Schutz also thought that intersubjectivism, how one person experiences the other and create the space between them, is very important (Schutz,

1972: 97-99 as in Overgaard & Zahavi 2009: 9). For him, the main objective of sociology is not institutions but people and their (inter) experience of their life and others.

Schutz's ideas influenced many people and theories, including Peter L. Berger and Thomas Luckmann's "*The Social Construction of Reality: A Treatise in the Sociology of Knowledge*". They also did not see the world as an objective entity but said: "social order exists *only* as a product of human activity" (Berger & Luckmann 1991: 70). They were interested in how subjective or intersubjective worlds that people share become a so-called objective reality that is socially controlled via institutions.

Schutz's social phenomenology also influenced Harold Garfinkel and his ethnomethodology which investigated "how social agents structure their social environment in a meaningful way" (Overgaard & Zahavi 2009: 17). Garfinkel also thought that social reality is constructed in the interaction between people and that "we are all busy constructing the world in which we feel at home" (Overgaard & Zahavi 2009: 17).

2.2. Anthropology, Psychology and the Meaning: Inter (Subjective) Experience of Schizophrenia and Hearing Voices

Phenomenology of human experience is usually named as "lived experience" (Cassaniti & Luhrmann 2011: 38). In the context of people hearing voices or having a diagnosis of schizophrenia, it means "specific phenomenology" (Cassaniti & Luhrmann 2011: 38) where "a personal history of the schizophrenic reveals individual's unique interpretation of his disease" (Scheper-Hughes 2001: 298). This

experiential aspect of lived experience comes from Merleau-Ponty, who said that “embodied experience is the starting point for analyzing human participation in a cultural world” (Csordas 2002: 242 in Larsen 2004: 449). Here cultural phenomenology is interested in the way how cultures shape experience and how that experience is understood in intersubjective action (Larsen 2004: 449).

Psychologists and anthropologists have a long history of interest in phenomenology as a way of understanding human being. Edward Sapir, an anthropologist, and Harry Stack Sullivan, a psychiatrist, were both interested in social interaction. Sullivan considered “psychiatry to be a study of interpersonal relations” (Jenkins 2004: 32), while Sapir thought that culture is created when people are in process of social interactions (Jenkins 2004: 32). Sapir also thought that schizophrenia “was a productive route for anthropological theorizing about the subjective experience” (Jenkins 2004: 32). This kind of researching and writing influenced this paper which tries to present and describe “context of local worlds shaping the experience of sufferers, family members and professional” (Jenkins & Barrett 2004: xvi) and, at the same time, to “challenge the core pathogenetic/pathoplastic ideology of psychiatry and psychology” (Jenkins & Barrett 2004: xvii). In my research, I would like to present “inner life and intersubjective connections” (Jenkins & Barrett, 2004: xvi) which constitutes and negotiate meaning-making process of voice hearing in people diagnosed with schizophrenia.

By exploring intersubjectivity of people hearing voices with diagnosis of schizophrenia in cultural context of Czech Republic, I had definition of culture as “shared symbols and meanings that people create in the process of social interaction” (Jenkins & Barrett 2004: 4) which is a “process including the production and

reification of knowledge, the transformation of practice and the reproduction of values” (Jenkins & Barrett 2004: 4). Cultural research is not focused on nation-state but on “specific domain of interaction” (Jenkins & Barrett 2004: 4) like family, identity, ethnicity etc., or in this case a group of people with hearing voices experience and a label of schizophrenia. In this way, emphasizing the experiential and existential aspect of anthropology “perspective directs attention to the mentally ill as individual agents and the ways in which they try to make sense of their experiences and their personal lives” (Larsen 2004: 466). I was guided by three presumptions presented in the book “*Schizophrenia, Culture and Subjectivity*” (Jenkins & Barrett 2014: 7-8):

1. *The primacy of lived experience over analytic categories.* Geertz presents definitions of “experience distant” where someone who is a specialist (psychiatrist) analyses experiences of others (etic perspective) and “experience-near” where someone “effortlessly use to define what he or his fellows see, feel, think, imagine, and so on, and which he would readily understand when similarly applied by others” (Geertz 1984:1 24 in Jenkins & Barrett 2014: 8). In anthropology, this is known as a “person-centered ethnographies” (Jenkins & Barrett 2014: 8), where subjectivity is a central and focal point (emic perspective).
2. *The active engagement of subjects in the process of cultural construction.* This means that elements of agency and intentionality are present, how a person from his point of view “‘enacts’, ‘resists’, or ‘negotiate’ the world as given and in so doing, ‘make’ the world” (Jenkins & Barrett 2014: 9).

3. *The irrepressibility of subjectivity as embedded in intersubjectively created realms of meaning and significance, it can be seen as a connection between social reality and personal experience.* Arthur Kleinman, anthropologist and psychiatrist said that “experience is thoroughly *intersubjective*. It involves practices, and contestations among others with whom we are connected. It is a medium in which collective and subjective processes interfuse” (Jenkins & Barrett 2014: 9).

Jenkins said (Jenkins & Barrett 2014: 22) that exploring people with the label of schizophrenia is a journey between usual (some would say normal) and extraordinary, unique experience. Both experiences are meaningful to their agents.

2.2.1. Hearing Voices and Meaning of Lived Experience in Culture

Does the voice hearing experience have meaning, usually depends on the way that we perceive the cause of this phenomenon. Voices carry meaning, but maybe not all (Sacks 2015: 64). Voice-hearing phenomenon is heterogeneous, different explanations “may apply in different circumstances” (Sacks 2015: 63). Modern psychiatry knows organic and functional mental disorders (Watkins 2008: 62). For organic mental disorders, physical cause of the disorder is known. People can hear voices that come from the known physical causes like in organic psychosis, delirium, drug intoxication and alcohol withdrawal (Watkins 2008: 62-64). Functional mental disorders are known usually as psychiatric diagnoses of schizophrenia, bipolar disorder, depression etc., there is no “identifiable physical cause” (Watkins 2008: 62) and other factors (psychological, social or spiritual) play an important role. For some

voice hearing experience causes are known and physical (Sacks, 2013) and for others that are more psychosocially based there are several explanations (for a more detailed overview of the theories on origins of voice hearing experience (Watkins 2008: 130-163). A biomedical model tries to find evidence in functional and structural changes in the brain of a person hearing voices. There is some evidence of changes in the structure of the brain of voice hearer, but also it is known that “persons' s subjective experiences can result in neurochemical and neuroanatomical changes in their brain” (Watkins 2008: 160), especially during traumatic events (McCarthy Jones 2017: 47). Neuroimaging confirmed that in people hearing voices “areas of the brain involved in speech perception increases their activity” (McCarthy-Jones 2017: 46), so voices are a real experience.

Another approach explaining the causes and origins of the voices is a trauma-informed approach. This approach sees the origins of voices coming from traumatic life events like bullying, emotional neglect or sexual child abuse. Psychological process which happens is disassociation from the original traumatic events where “may be an instant distancing or dissociation when the life-threatening situation occurs” (Sacks 2012: 241), and all the parts of the experience “get locked away in a separate subterranean chamber of the mind” (Sacks 2012: 242). Part of this hypothesis and theory is also memory, what happened during the trauma is connected to what voices are saying (McCarthy-Jones 2017: 139). A traumatic experience is not well connected to the whole autobiography and “autobiographic memories” (Sacks 2012: 242). Instead, it is isolated (Sacks 2012:443) and it can come in the form of the “atmosphere” that can resemble the original traumatic event (McCarthy-Jones 2017: 140).

In the book *“Living with Voices: 50 Stories of Recovery”* (2009), people shared their personal stories of recovery and the majority of them connected their voices with some traumatic life events. Most of them (18) connected voices with sexual abuse, emotional neglect (11), adolescent problems (6), high level of stress (4), bullying (2), physical abuse (2). Only 7 of them were not sure about the connection between voices and life events. Generally, it is shown that trauma is present in between 70% and 90% (Baker 2015:15; Corstens & Longden 2013) in the stories of people having a diagnosis of schizophrenia. There is strong evidence that all voices across the diagnostic categories in psychiatry are dissociative in nature (Moskowitz et al. 2017: 37) and that voices in people experiencing psychosis should be considered as dissociative as well (Moskowitz & Corstens 2008). A trauma-informed approach can be summed up by this sentence by John Read: ”Bad things happening, often enough, early enough or sufficiently severely, can drive us mad with or without a genetic predisposition” (John Read et al. 2016 in McCarthy-Jones 2017: 152).

Other explanations about the origins of the voices can be connected with religious or spiritual experiences, parapsychology, metaphysical experiences (Romme & Escher 2000). Whatever the explanation is, it is important to work with the theory of voice hearer not our own and to use person narrative. In medical anthropology, this is known as “explanatory models” (Kleinman 1980:104–118, 1988a: 155–157 in Larsen 2004: 449), which talks about how this experience is understood “demonstrating how psychiatric patients' descriptions represent different understandings of the nature, cause, and course of mental illness” (Larsen 2004: 449). The actual explanatory model that a person uses is connected to the actual narrative situation in his life (Larsen 2004: 451). It was shown that people who were

hospitalized for the first time have a more flexible understanding of their experience, while people who are hospitalized several times usually accept a biomedical explanation of illness (Larsen 2004: 449). Here intersubjectivity is very important. If a person is connected only, or most of the time, with mental health services and professionals, there is a great possibility that he will accept the biomedical model of his experience. In this way, we can consider hospitalization as a constructed reality, where a person becomes a psychiatric patient.

There is a more general explanation of the meaning-making process in psychotic experience proposed in “systems of explanation” (Larsen 2004). That approach sees unusual experiences, like voice hearing “interpreted and negotiated as meaningful by the individual acting as a creative and meaning-generating agent constrained and empowered by the available social institutions and cultural resources.” (Larsen 2004: 448). A different explanatory model can exist simultaneously in the life of an individual, even though they are incompatible to each other (Larsen 2004: 456). Those models can exist simultaneously in the same institution, like on the psychiatric ward that works under the biomedical approach, but other explanatory models are forbidden because, “generally it is regarded as good psychiatric practice for staff not to encourage such explanations when talk” (Larsen 2004: 456).

Individuals are inspired, indoctrinated or limited by the explanations that are represented to them, but they are also “drawing on a range of cultural conceptualizations and engaging in innovative, meaning-creating activity” (Larsen 2004: 448), which involves agency of a person. Meaning of the experience like psychosis or hearing voices depends on the cultural repertoire that is available to that

person, through contact with other people, institutions or cultures. These kinds of experiences are “interpreted and negotiated as meaningful by the individual acting as a creative and meaning-generating agent constrained and empowered by the available social institutions and cultural resources” (Larsen 2004: 448). In this approach, a person who is experiencing psychosis or hears voices is seen as a constantly active agent that uses different explanations in order to construct his own explanation and meaning of his experience. These explanations are unique, and maybe sometimes unusual but "what 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” (Larsen 2004: 462).

Another concept that is used in explaining unusual experiences is illness narrative where “the reflexivity and talk of individuals are the focus in studies of individuals' discourses or narratives” (Becker 1997; Hyde´n 1997; Kleinman 1988b n Larsen, 449). The narrative is seen as entrance into individuals meaning-making process of his experience, and narrative as a concept is crucially important for an understanding of voice hearing phenomenon in this paper. Narrative of the person with the psychiatric diagnosis of schizophrenia can be seen as “disruptive change” (Becker, 1997: 4) and living with the voices (at least in the beginning) as a “disrupted life” (Becker, 1997). In the West, life is seen as linearity, and when something happens to disrupt this linearity people are trying to recreate it by connecting past with the present life. People who hear voices and have a diagnosis of schizophrenia are on the quest to make sense of their own life by constructing a meaningful narrative. This has been seen in different context when medical nurses are working with the narrative of voice hearers (Place et al 2011) and psychologists and

psychiatrist are (Thomas & Longden 2015; Longden et al. 2011) using biography and personal narrative as a way of recovery and construction of the meaningful experience. Discursive way to approach personal narrative of the voice hearer is seen as meaningful demonstration “of agency and intentionality of the auditory hallucinating self” (Jenkins 2004: 39). One example of that is research by Lucy P. Goldsmith (2011), where she has found that several modes of talking about voice hearing experience. Those modes includes “‘many selves', ‘taking-the-lead-in-your-own-recovery', ‘voices-as-an-imagined-world” and “‘voices-as-a-coping-strategy-for-dealing-with-trauma” (Goldsmith, 2011: 235). By defining their voices people can “create a subjectivity from which vantage point the experience holds meaning and value and can be integrated into life experiences” (Goldsmith 2011: 235).

Anthropological perspective also says that hallucinations are often culturally meaningful and that culture affects the meaning and characteristics of hallucinations associated with psychosis (Larøi et al. 2014). The social meaning of the symptoms such as hearing voices depends on the "social world" (Luhrmann 2016: 202). If a voice hearer has an opportunity to choose different models of explanations in his social world (Luhrmann 2016: 203), there is a greater chance for recovery and meaningful understanding of his experiences.

Hearing voices or other unusual experiences can be sometimes difficult to understand but “psychotic-related symptoms and processes are not so distinctly and categorically different from the fundamental and ordinary processes of everyday life” (Jenkins & Barrett 2004: 34).

2.3. Narrative turn in social sciences

The narrative is a way to “create cosmos out of the chaos” (Barusch 2012: 2). People are meaning-making animals or as Fisher said: “homo narrans” (Fisher 1984 as in Barusch 2012: 2). The narrative approach is highly connected with the postmodern world (Barusch 2012). Ronald Barthes saw the importance of the narrative as an omnipresent phenomenon in human history in different human artefacts, myths, written and spoken language amongst all human groups and kinds (Czarniawska 2004: 3). Interest in the narrative is not new but "narrative turn" that happened in the 1970s comes from the hermeneutics of the holy text like Koran, Bible and Talmud. Introduction of the narrative approach to social sciences happened especially because of the English translation of Vladimir Propp's book “*Morphology of the folktale*” in 1968 (Czarniawska 2004: 3). Authors that have influenced narrative turn (e.g. Mikhail Bakhtin or Ferdinand de Saussure) were interested “in texts as such, not in the authors’ intentions or the circumstances of the texts’ production” (Czarniawska 2004: 2). Interest in narrative spread beyond the literary theory into psychology, economics, political sciences and sociology (Czarniawska 2004: 3).

Narratives can be individual and social (collective). Both narratives are connected to each other. Narrative of individual history is a process of understanding our own lives or lives of the others (Czarniawska 2004: 5). The individual is not constructing its own narrative alone, because others have an influence on it as well. Individual, personal narratives are connected with social narratives. In order to "understand a society or some part of a society, it is important to discover its repertoire of legitimate stories and find out how it evolved" (Czarniawska 2004: 5).

There are four perspectives in narrative research:

1. Narrative as a genre;
2. Foucaultian discourse/narrative of power dynamics, between dominant narrative and narratives on the margins;
3. "Narrative way of knowing" (Barusch 2012: 4) of Jerome Bruner where the narrative has intentionality;
4. Focusing on the elements of the narrative like plots, events, actions, context and setting (Barusch 2012: 4).

2.3.1. The narrative in psychology and anthropology

In anthropology, there is a notion of Narrative anthropology as a way to understand other human beings. In the context of medical anthropology, narratives of illness are "not merely accounts of symptoms but the mechanism through which people become aware of and make sense of their experiences" (Kaplan-Myrth 2007). Making sense of the lived experiences happens when the lived part is interpreted in the context of narrative biography. In that way process of "narrativization" therefore acts as a reflexive, therapeutic, and even a transformative mechanism for people who have experienced illness" (Kaplan-Myrth 2007). In this way, as a researcher, a participant in the lives of informers in my ethnographic work, I became a part of their narrative, their meaning-making process and recovery journey. In psychiatry context, the narrative of illness and symptoms is told as the main narrative. In the context of recovery movement or IHVM, people are encouraged to explore and tell their own narrative. Kaplan-Myrth wrote (Kaplan-Myrth 2007) that it is important how stories are told (e.g. with or without the consent of the client), by whom (by doctor or patient) and the form of the story (e.g. language that was used).

Focusing on the personal narrative brings not just the meaning to the experience, but it also confirms the agency of that person, because a person can be expert of his own experience (Place et al. 2011). In psychology, there is a long tradition of theories focusing on the narrative and meaning. We have already seen a position of the IHVM, but in contemporary psychology and psychotherapy, we can also mention the importance of Narrative therapy and Open Dialogue approach. Narrative therapy is a postmodern approach to therapy where the main goal is to create a comprehensive personal narrative (White & Epston 1990). This approach uses a person's narrative to find “ways to find meaning, and a pathway to a better understanding of ourselves” (Positive Psychology Program 2018). Narrative therapy emphasizes and respects the agency of the person where that person is seen as an expert. Main foundations in Narrative psychotherapy come from postmodernism - the reality is socially constructed (Positive Psychology Program 2018) and we influence reality through language.

Another example is a Finnish approach called Open Dialogue. This is a network-based, language approach (Seikkula & Olsen 2003: 403) that includes a social system of the individual when dealing with the crisis. Open Dialogue was developed from Systemic family therapy (Lakeman 2014: 26) as a need-adapted approach to psychosis (Lakeman 2014: 26). This approach has the best outcomes for the first psychotic episode recovery because it prevents psychotic symptoms to become chronic and prevents hospitalization (Seikkula & Olson 2003: 403). This is done with minimal use of or without psychotropic medication at all (Lakeman 2014: 26). Open Dialogue approach is very close to Narrative therapy in realizing that the reality is socially constructed. They differ in a way that they approach the narrative. In

Narrative therapy, the client usually changes narratives of his experience, the content or language of the original narrative in a way that becomes meaningful. In Open Dialogue, there is no predefined narrative, because the client “constructs a new language through which they can express difficulties in their lives” (Lakeman 2014: 26). Open Dialogue is influenced by communication researches of Gregory Bateson (double-bind) and dialogism of philosopher Mikhail Bakhtin. Foundation of Open Dialogue is the use of dialogism as a “communicative process through reality is socially constructed” (Lakeman 2014: 29). Dialogism that is part of the Open Dialogue was meant to be “relational, dynamic and produces new descriptions of the world and is considered a process that enables meaning to be generated” (Lakeman 2014: 29). In dialogism, people are always renegotiating the meaning of the experience. Person experiencing unusual experiences and hearing voices “has not found a way to be in dialogue with the self or others” (Lakeman 2014: 29) and therefore they “do not yet have any other words than those of hallucinations and delusions” (Seikkula 2002: 265 in Lakerman 2014: 29). Hallucinations or hearing voices are understood “as one voice amongst others” (Lakeman 2014: 29) in finding the way to construct the experience. Open Dialogue is happening in the social context of a person in crisis (with family members and friends) and the important aspect is to find a way that all people involved construct the present reality through dialogue. If during that dialogue we discover some experiences which are not understandable for others (such as voices, visions or paranoid thoughts) we should pay special attention to them. Open Dialogue, like IHVM, thinks that trauma can be a reason why a person develops hallucinations and hearing voices as hallucinations “can contain traumatic events in the metaphorical form” (Seikkula & Arnkil 2013: 113). Hearing voices and other unusual experiences are considered as traumatic life events that don't have

verbal expression. It is important to listen to a person experiencing hallucinations or voices in order to “find together the language that can name experiences that are not said before” (Seikkula & Arnkil 2013: 113). In this way, a “symptom” that others don't understand, can have a meaning in the social context (family).

2.3.2. *Recovery, Schizophrenia, Hearing Voices and Narrative*

Recovery from mental health issues is defined differently in different contexts. In psychiatry, recovery means not to have symptoms. In the Recovery Movement or IHVM, recovery can be defined as living your life despite the symptoms. In literature, we can find two different approaches to recovery. One is “turning away” approach (McCarthy-Jones 2017: 263) or “sealing over” approach (Larsen 2004: 458) where a person usually takes medication, accepts voices as a symptom of illness. Another approach is known as “turning towards” (McCarthy-Jones 2017: 266) or “integration” (Larsen 2004: 458) where a person wants to explore his or her experiences and try to find meaning. In this approach, if a person talks about voices their personal narrative becomes a part of “non-pathologized identity” (McCarthy-Jones 2017: 267).

Personal lived experience can be seen as a disrupted narrative or a “part of the chaos narrative” (Frank 1995 in Thomas & Longden: 187), where “recovery from madness becomes possible once the person is able to organize her experiences within a narrative framework” (Thomas & Longden: 187). A narrative can be a powerful tool to bring order into the broken personal narrative because “it assists us in our search for meaning and our attempts to understand our experiences” (Thomas & Longden: 188). In order to start the recovery journey in making sense of a lived experience,

sometimes a simple question can be enough. For Eleanor Longden, a voice hearer who has a PhD in psychology, the starting point was questioning by her psychiatrist “Can you tell me a bit about yourself?” (Longden 2013). This question is a perfect example of how we can start exploring the lived experience of people who hear voices.

2.4. International Hearing Voices Movement (IHVM)

International Hearing Voices Movement (IHVM for short) is “about dialogue, normalizing the experience and accepting the reality of voice hearing” (McCarthy-Jones 2017: 59) and it respects the diversity of opinions because for IHVM “empowerment comes before ideology” (McCarthy-Jones 2017: 62).

Beginning of the IHVM started by pure coincidence in the city of Maastricht, Holland and it is connected with the story of Patsy Hague. In 1986 she was hearing 20 different voices. She was hearing voices during her high school but she managed to graduate without any greater difficulties. As she was getting older her voices became scarier and they started to forbid her some things or commanding her what to do. As time passed by she was losing her psychological strength to confront the voices. She had never told anyone about her voices, mainly because the voices forbade her to do so. Patsy thought that the voices were somehow connected to her home so she runs away and because of that, she ended up in “juvenile section of the Department of Social Psychiatry in Maastricht” (James 2001: 32). There she met psychiatrist Marius Romme who told her that name of her illness is schizophrenia and that she has to take pills which will make the voices go away. This wasn't the case as drugs didn't help Patsy. She was curious about her experience and she started reading books about voice hearing phenomenon. A particular book caught her attention. The book was

called "*The origins of consciousness in the breakdown of the bicameral mind*" by American psychologist from Stanford University, Julian Jaynes. He wrote that before the second millennium B.C. everybody heard voices because people in that period were not conscious (Jaynes 2000). This information, as a possible alternative explanation of voices, with the fact that drugs didn't help, motivated Patsy to confront her psychiatrist. She asked him a simple question: "Do you believe in God?" When he answered affirmatively, she replied: "You believe in a God we never see or hear, so why shouldn't you believe in the voices I really do hear?" (James 2001: 31). For Patsy, voices were a real experience, which had an impact on her life, while Marius was trained to see voices as a symptom of illness. Patsy was persistent enough with her explanations that voices don't mean illness per se. Marius said "Hague played a large part in persuading me that the voices were not necessarily pathological" (James 2001: 32). This was beginning of the completely different approach to hearing voices in the context of mental health (and outside of mental health system) because it opened up different theories and explanations about an understanding of this phenomenon and brought meaning to it.

Next important step was the appearance of Patsy Hague and Marius Romme on the popular talk show in Holland "*Sonja on Monday*" where they talked about their collaboration. One of the aims of that appearance was to reach other voice hearers and to ask them how do they cope with voices (James 2001: 33). They invited people who hear voices to call and leave their contacts. The result was surprising, 450 people with the experience of hearing voices (Adams 2001: 33) called and left their contacts during the program. In 1987 in Maastricht, Patsy and Marius, with the help of local NGOs and Department of Social Psychiatry, organized the first conference for 300 people called "*People Who Hear Voices*" (James 2001: 32). The main

conclusion about this collaboration and experiences of voice hearers on the conference was to accept the subjective experience of voices in order to learn how to cope with them. This was in contrast to what psychiatrists believe - accepting and recognizing voices is dangerous because in that way people are supporting illusions of voice hearers and that approach can be “potentially dangerous” (James 2001: 33).

Marius Romme together with his wife, researcher Sandra Escher, and voices hearers began researching this experience. Marius Romme “understood voice hearing, not as a biological aberrant misfortune, but a socially meaningful and decipherable phenomenon, where the content of the individuals' voices can mirror their social world” (Adams 2001: 38). Voice hearing “onset is precipitated by individuals dissociating from emotional and experiential content, with voices emerging as (distorted) reflections of threatening, overwhelming events” (Corstens 2012: 95).

In this way, the emphasis was not on the passive position of individual who has a genetic illness but on empowering people who hear voices to found their own meaning about hearing voices experience in their life context. In other words, the approach to this phenomenon changed from “What is wrong with you” into “What happened to you?” (McCarthy-Jones 2017:314; Longen 2013). The origin story about IHVM is indicative in two mayor ways:

1. One of the values in IHVM is collaboration and equality of “expert by profession” (mental health professionals) and “expert by experience” (people with lived experience of hearing voices), (McCarthy-Jones 2017:60).
2. People who hear voices (and have other unusual experiences) are ones who define the meaning of the experience, not the mental health professional. This is extremely important if we know the history (in the first chapter) of this

phenomenon and how always someone else, who had institutional power, defined this phenomenon.

This approach quickly spread in Great Britain, thanks to the social worker Paul Baker (Baker 2015) and then to other countries all around the globe. At this moment IHVM is present in more than 30 countries, including the Czech Republic (see *Slyšení hlasu*, <http://www.slysenihlasu.cz>), and it “consists of the diverse conversations, initiatives, groups and individuals around the world that share some core values” (Intervoice 2019). This global phenomenon is supported by the International charity founded in London, named *Intervoice* “that aims to support the International Hearing Voices Movement by connecting people, sharing ideas, distributing information, highlighting innovative initiatives, encouraging high-quality respectful research and promoting its values across the world” (Intervoice 2019).

There are six basic values of IHVM that are integrated into this approach:

- (1) normalizing the experience, (2) voices are meaningful responses to the things that happened in life, (3) diverse explanations are accepted if they help, (4) take ownership to your experience and define for yourself, (5) peer support and hearing voices groups help, (6) accepting and valuing voices is helpful (voices are real), (McCarthy-Jones 2017: 61-62).

Another important aspect of IHVM is how they use the language when talking about hearing voices. They do not use medical language on purpose, because they know that language can hurt people and decontextualize the experience (*Slyšení hlasu* 2019). This is a reason why they use words like “hearing voices” and not “auditory hallucinations” or “voice hearer” for a person who hears voices and not the word “patient” or “schizophrenic”. Term “voice hearer” puts emphasis on personal

narrative and empowerment (Woods 2013). When using words “hearing voices”, IHVM doesn't consider the only experience of voice hearing. This term includes other *unusual experiences* like seeing visions (visual hallucinations), believes (delusions), (Slyšení hlasu 2019) etc.

Many psychological therapies incorporated basic values of IHVM (McCarthy-Jones, 2017: 279) or developed completely new methods influenced by IHVM like Avatar Therapy (Luhmann 2016: 218). The following three approaches in working with voices were developed originally under the umbrella of IHVM.

2.4.1. The Maastricht Approach

Dr Marius Romme and his wife Sandra Escher presented an innovative approach in working with voices in their book “*Making Sense of the Voice: A guide for mental health professionals working with the voice-hearers*”. This approach is known as *The Maastricht Approach or Maastricht Interview*, and it was developed by mental health professionals and voice hearers. Main goal is “attempt to help voice-hearers to recover by exploring the meaning of their voices” (McCarthy-Jones 2017: 279) and in order to do that “is to make explicit the relationship with the individual history and the voices” (Romme & Escher 2000: 10) and “to demystify the voices” (Romme & Escher 2000: 10). This approach (which was developed on the researches and personal stories of people hearing voices) starts with the assumption that “voice-hearing is a personal reaction to life stresses, whose meaning and purpose can be deciphered, with the voice often taking some form of a metaphor” (McCarthy-Jones 2017: 279). This approach consists of three parts.

First part is a semi-structured questioner that voice hearer explores with another person (it can be another voice hearer or mental health professional). This questioner has topics related to the personal experience of hearing a voice that needs to be explored. Topics are nature of the experience, characteristics of the voices, history of the development of the voices, what provokes the voices, the content of what voices say, how the voices are interpreted, what impact voices have on daily functioning and how the hearer copes (Romme & Escher 2000: 36). This is not meant to be questioner to fill in fast, but more like an exploration, to have "journalistic approach to asking questions" (Romme & Escher 2000: 36).

The second part is called *The report*, where you choose most important information from the answers that you have, organize them in a way "to build up as clear a picture as possible of the voices and the problems they represent" (Romme & Escher 2000: 43).

The third and final step in "analyzing the relationship between hearing voices and a person's life history" (Romme & Escher 2000: 53) is developing a Construct. The final goal of the Construct and whole Maastricht Interview is to answer the two questions:

1. *Whom the voices represent?* (e.g. abuser)
2. *What problems do the voices represent?* (e.g. unexpressed emotions).

To answer those questions voice hearer and person conducting the interview has to structure and have a clear overview of the five main areas of voice hearer's personal experience: (1) the identify of the voices, (2) characteristics of the voices, (3) the history (of voice hearing), (4) the triggers, and (5) childhood and adolescent history and development. When you finish the Construct, you need to present to the voice hearer answers for those two questions. The voice hearer is the one who chooses the

validity of your hypothesis. Voice hearer is the one to say if those answers have something to do with his life history and personal experience or not. If those answers sound truthful to voice hearer, then the Construct is the begging of treatment that has three goals: (1) to identify aspect of voices that voice hearer needs to change in order to cope better (to find out better coping skill and practice them), (2) to improve relationships with voices (usually difficult emotions of guilt, fear, anxiety or blame) and (3) to process and work with personal and social difficulties related to the original life event (like trauma), (McCarthy-Jones 2017: 280).

2.4.2. The Voice Dialogue

Another approach that came from IHVM is *The Voice Dialogue*, which is more direct approach than *Maastricht Interview*, because this approach “goes directly to the voice for information” (McCarthy-Jones 2017: 280). Dirk Corstens (former president of Intervoice) is psychiatrist from Maastricht who is well known for using this approach. The philosophical underpinning of this approach comes from the *Psychology of the Selves*, from two psychologists Sidra and Hal Stone. They assume that we have many selves and that some of them are more dominant while some of them are blocked within us (Stone & Stone 1991). They “suggest that everyone consists of numerous “selves” or “sub-personalities”, each with its own perception of the world, personal history, emotional reactions, and opinions on how we should live our lives (Corstens 2012: 96).

In IHVM the main assumption is that traumatic (or life stressing event) happened in voice hearer's life. Usually, this aspect in the context of the psychiatric system is neglected (Read, van Os, Morrison, & Ross 2005 in Corstens 2012) and

they do not engage in exploring the phenomenon because they see it as symptom of pathology and therefore it is not meaningful personal and social experience (Romme, Escher, Dillon, Corstens, & Morris 2009 in Corstens 2012). Voice Dialogue approach was “originally conceived for exploring different roles, conflicts, and tensions in social relationships, a key tenet of Voice Dialogue is that “normal” personality is essentially dissociative (i.e. we all have different personality components that exist simultaneously and of which we are not consciously aware)”, (Corstens 2012: 96).

In the context of voice hearing experience, “voices are not felt as personality parts. On the contrary, they are experienced as autonomous (possibly malicious and controlling) entities that oppress and impose upon the hearer” and “voices represent a part of the person that wants to be heard and acknowledged” (Corstens 2012: 97).

In practice, dialoguing with voices has several phases. In the first phase, the one who talks to voices (called facilitator) explains the method and philosophy behind it. The facilitator asks for the permission of the voice to talk to him directly. If permission is granted, then voice hearer concentrates on the voice and when he establishes the contact with the voice, voice hearer then physically moves and sits on another place (or chair) where he will talk as the voice. This is important because it symbolizes that different part of the person (the voice) is speaking. The voice hearer then repeats everything that voice is saying. He is in a way quoting the voice. Facilitator talks to the voice "in order to heighten awareness and understanding of voice characteristics. The method provides insight into the underlying reasons for voice emergence and origins, and can ultimately inspire a more productive relationship between hearer and voice(s)” (Corstens 2012: 95).

When voice hearer or the voice wants to end the dialogue, the talk is over. Facilitator thanks the voice, end the conversation and then voice hearer moves back to

the original chair where he was sitting at the beginning. The final phase is called “awareness phase” (Corstens 2012: 100) where, “the facilitator asks the person to stand beside him, and together they view the scene while the facilitator objectively summarizes what he saw” (Corstens 2012: 100). The voice hearer is then encouraged to talk with his voices at home, to explore the awareness about voice(s) and maybe to write a journal between the sessions.

2.4.3. Hearing Voices Groups

The third approach within IHVM is peers support groups for people hearing voices (and have other unusual experiences). Groups are very important because they are easily accessible, free and can help in recovery. Hearing Voices peers support groups are also based on researches of Marius Romme and Sandra Escher and basic philosophy that “the way to talk about hearing voices was to talk about them, to get people who heard voices to get together to talk to each other about their experiences” (Romme, Escher, Dillon, Corstens & Morris 2009: 73). The first group for voice hearers was founded in Holland, and now there are many of them around the world. As many recovery stories included participation in the Hearing Voices groups, researchers were curious about the specific effects of hearing voices groups. One research, conducted by Pennings and Romme in 1997 (Pennings & Romme 1997 in Romme, Escher, Dillon, Corstens & Morris 2009: 74), gave us clue why talking about voice hearing experience can be helpful. The participants in that research said that it was much easier for them to talk about their experiences with people who have the same (or similar) experience than with the experts. Peers accept and share the experience with others and they can find better (or change) coping strategies that can help them to have a better relationship with voices (Romme, Escher, Dillon, Corstens

& Morris 2009: 74)²⁶.

What we know from personal recovery stories of voice hearers (Romme, Escher, Dillon, Corstens & Morris 2009: 78), hearing voices groups can help to: kick start the recovery process, get help in recovery process, can help with the parts of recovery or at the end of recovery process (Romme, Escher, Dillon, Corstens & Morris 2009: 78). Hearing Voices groups are open for people with lived experience (with or without psychiatric diagnoses) and participants don't have to call up to announce that they are coming, neither they are obliged to come for some period of time - they can come as frequently as they want to.

We know that people in recovery process usually need more than only participating in Hearing Voices groups (they need individual therapy, working with trauma, emotions etc.) but this kind of setting can help to open up about personal experience or to “start overcoming shyness” (Romme, Escher, Dillon, Corstens & Morris 2009: 83). Hearing Voices groups are social (Hearing Voices Network, 2019) not psychotherapeutic groups and therefore can give “voice hearer a purpose in life again, a fulfillment of their ambition to help others; need to belong” (Romme, Escher, Dillon, Corstens & Morris 2009: 83).

Hearing Voices groups share the same values across the globe and those values²⁷ make them unique. Those shared values are: *purpose* (based on self-help, mutual respect and empathy), *respect* (different experiences and explanations are welcome), *flexibility* (themes are centered around the needs of the participants), *ownership* (they belong to the voice-hearers, not professionals), *confidentiality* (what is discussed stays in the group), (Hearing Voices Network, 2019).

²⁶ For a more detailed overview of the benefits of hearing voices groups see Romme, Escher, Dillon, Corstens & Morris 2009: 75-85.

²⁷ For a detailed assumption of the group's values and see <https://www.hearing-voices.org/hearing-voices-groups/charter/>.

All this leads to the conclusion that IHVM wants to liberate people who hear voices so that they can accept their experience as human variations (McCarthy-Jones, 2017: 278) that are “understandable in terms of individual narrative and social circumstances” (Thomas & Longden 189) and not to be ashamed to have voices.

3. Methodology and Methods

3.1. Methodology, Methods and Techniques of the Research

When using methodologies in social and cultural anthropology research, we encounter two different outlooks in this field. First one is the humanistic vision of social and cultural anthropology. The second one is more scientific (Bernard & Spencer 2002: 552).

The goal of the first one “is the understanding of people’s lives, their social life, and their culture, an understanding which requires an empathetic grasp of the point of view of the people studied” (Bernard & Spencer 2002: 552). The goal of the scientific approach is “discovery of descriptive generalizations and explanatory laws about the way society and culture work” (Bernard & Spencer 2002: 552).

There are four ways how the experience of schizophrenia and hearing voices can be understood: “ethnographic, sociolinguistic, clinical and historical” (Jenkins & Barrett, 2014: 15). In this research, I choose the ethnographic approach. Ethnography means to “write about particular culture” (SCERT 2015: 16) while emphasizing the perspective of those particular respondents (SCERT, 2015: 16). Ethnography presented here is a person-centered ethnography.

Word ethnography in social and cultural anthropology means either a *product* (Bernard & Spencer 2002: 295) or *process* (Bernard & Spencer 2002: 295). A product can be, for example, a book or article and by process fieldwork (Bernard & Spencer 2002: 295). Ethnography is also “a form of writing conditioned by the process of

knowledge construction” (Bernard & Spencer 2002: 295). The first ethnographic work is considered to be Louis Henry Morgan’s *The League of the Ho-de-no- sau-nee or Iroquois* from 1851 (Bernard & Spencer 2002: 296). The modern form of ethnographic works is highly influenced by Malinowski’s research in Trobriand Island in 1914. Malinowski defined the modern standard of ethnography as he learned the local language, made detailed notes in his diary and was a part of the local social life (Bernard & Spencer 2002: 297).

I have spent time with the respondents in different settings for almost a year (from May 2019 until May 2019). I have spent more time with some of the informers and creating a closer relationship. With the informer that I named Ondřej, I spent almost a year in close contact, making interviews and being together in different settings. Ondřej was very open and interested in my research since the day we met. With other informers, I was in contact for about 8 months with different frequency. With informers in my research, I’ve used a case study method and the narrative approach of their personal life history. My main inspiration was the book “*Our Most Troubling Madness: Case Studies in Schizophrenia Across Cultures*”. In this book, many different ethnographers from different countries used the case study method to approach their informers with lived experience of schizophrenia. A case study in this context is the “method of qualitative analysis” (SCERT 2015: 126). The goal is “obtaining a complete and detailed account of a social phenomenon or social unit, which may be a person, family, community, institution or event” (SCERT 2015: 126). In order to collect information during the fieldwork, I used different sources and techniques like life histories, interview, participant observation and field notes (diary).

In the fieldwork the notes that ethnographer records are crucial to his understanding of the phenomenon that he is researching. My field diary was a small

black notebook, where I was writing personal reflections about the contact with the respondents, feelings or emotions that came from our conversation or time we've spent together. Most of the time, but not always, I had my tape recorder with me as a witness to our conversations. Another very important, more instrumental purpose, of the tape recorder, was language. I was communicating with the respondents in the Czech language, which is not my mother tongue, but the mother tongue of my respondents. Tape recorder helped me to record some words or phrases that I didn't know or didn't understand so I could discuss them later with respondents. Not being Czech helped me to be closer with the respondents because they had more agency and importance while explaining to me some common phrases in the Czech language that I was not familiar with. Below is an example of my field notes.

From the Fieldwork diary:

November 16th. It was an unusually beautiful and warm day for November. I am meeting Ondřej in Vystaviště Holešovice. He brought with him several bags. He greets me with a smile and I've asked him what is in his bags. He answered that he brought technical equipment to help me record our interview for the video. He brought his own camera as well so that we can record with two cameras "like professionals". I had a feeling that he is trying to help me, that he is more here for me for himself. He is very cooperative and I see him as my partner, not as an informer.

He told me that we have already been in Stromovka park yesterday because he wanted to be sure that we have a good spot to record our interview. Instantly I felt gratefulness towards him.

During our interview, he said that he started to think about his experiences and voice hearing in a different way. My questions influenced him to think differently. This can be an example of our intersubjective understanding of his experiences. Also, this is an example that he is in a process of meaning making and renegotiation about his experience.

Interviews can be structured, semi-structured or highly structured, formal or informal (Bernard & Spencer 2002: 551). When the situation allowed, I have recorded our conversations on a tape recorder using a semi-structured interview. Before we would start with our interview, I would mention the main areas of the respondent's life that I am interested in and that I would like to understand better. Then I would let them talk in order to make "space for tales" (Barusch 2012: 5) without interfering. Sometimes I would let the respondent talk straight without making any additional questions, except if I had to confirm that I understood correctly what they were talking about. I did that especially because the topic that I was researching was highly personal, intimate and sensitive, therefore I did not want to interrupt the person. In other cases, it was necessary to intervene more and ask additional questions or even motivate informers to talk about some delicate part of their lives.

Life histories "provide full, first-person accounts of a wide range of experiences over time" (Bernard & Spencer 2002: 550). In my research, those are narratives and personal accounts of the lived experience of people hearing voices. In this case study of three informers, the narrative is seen as a main area of research, where few things are very important:

- The intent of the narrative;
- Context of the narrative (where the narrative is constructed, where the interviews and participant observation took place);
- Who is included in these narratives (intersubjectivity is a way that I am reading narratives presented here; part of that intersubjectivity is also a researcher, in this case, myself);

- Participant's motivation to tell their personal the narrative to me, and how did I contribute to the construction of the narrative.

Informers were most of the time very motivated to share their own stories. The main motive for them to be part of this research was because nobody talked with them in this way and because nobody was interested in them as a person. Most of our interviews happened outside, in places not in any way connected to the psychiatric or mental health system.

Part of the good ethnography is participant observation, a “long- term residence among the population being studied” (Bernard & Spencer 2002: 549). When doing fieldwork usually it is agreed that duration is a minimum one-year time in a natural social context of the studied informer, ideally in his own language (Bernard & Spencer 2002: 549). I tried to be part of the informer's life as much as the situation allowed. Also, I am learning the Czech language for a couple of years now and conversation with informers helped me to practice my Czech, as well. With another informer, I had a close relationship, especially because we recorded the film for this research. When we did interviews or met to go somewhere together we visited different places in Prague. For example, we met and talked in Vitkov, Holešovice, Stromovka, streets of Žižkov, pubs and cafes. We also met at Hearing Voices group, spent time after Hearing Voices group in local parks etc. With one informer I worked for a short period of time, so I had an opportunity to observe her in different situations. With other informers, I've gone to some lectures and public discussions about mental health and hearing voices.

Another note from the diary:

After Hearing Voices group ended, I was walking with Milena to a bus stop. We were talking about today's group and how does she feel now. She said that after a very long time she started to hear negative voices. We reflected on why does she think this was happening. She explained that story of one participant in the group reminded her about her negative life experiences. Then she stood for a while so that she can concentrate on the content of the voice. She was listening to her voice in front of me. Then I asked if she is alright, she responded to me that she hears some negative content about herself and that she needs to go home, where she feels safe so she could concentrate better.

3.1.1. Visual Ethnography

Part of my research is an ethnographic movie about one of the informers. He chose to present himself by his own name. The video was filmed for four months, we had several interviews and I also participated in the video.

In several occasions, Ondřej brought his camera (on his own initiative) to “help me” so he was recording our conversations as well.

Between our meetings, Ondřej was recording himself with his camera, in his natural environment (at home, in his neighbourhood, in his everyday walks and other activities). This video was recorded in a participatory way, where I was one of the participants of the movie and Ondřej's life. The movie is a visual representation of a person who hears voices, living with voices, constructing of his every day and meaning-making process of his voice hearing experience.

4. Listening to Those Who Hear Voices

In this part, I will present three personal narratives of my informers and their understanding of the hearing voices experience. Originally, there was another person involved in my research but she had unexpected personal and family issues and she had to move very abruptly outside of Prague, so we lost contact.

My informers are very different regarding the age, gender, professional and personal experiences, family, number of psychiatric hospitalizations etc. The main common and defining factor is that all of them are attending Hearing Voices group in Prague, they had psychotic experiences, they have a diagnosis of schizophrenia and all of them hear voices.

I have met all of my informers at the Hearing Voices group in Prague in the period from May of 2018 until May of 2019. The research, participant observation and interviews lasted about 8 months. With some of the informers, I've spent more time than with others. There were different factors that influenced this but the 2 main ones were their/mine availability and type of relationship we've built during this time (with some of them I had a closer relationship).

In each case study, I will present informer's personal narrative, their understanding and meaning-making process of the experiences related to the hearing voices and psychiatric diagnosis. Personal narratives will also help us to see intersubjective experience and social dynamics (or lack of it) for each of the informers. Each narrative has a different structure, which is influenced by informer's (inter)personal understanding of their own experience and our own intersubjective understanding of it.

I was primarily interested in these three questions:

4. How do they experience hearing voices (and psychosis)?
5. How do they construct the meaning of this experience? Has the meaning changed over time?
6. What kind of influence voice hearing experience has on their everyday life?

Each case study has different plots and themes and they are based on informer's narrative. Subchapters in the case studies are not divided according to the research questions. They are presented according to the unique themes that are visible and important in informer's life.

4.1. Case Study 1

4.1.1. Ondřej: A Background Story

I met Ondřej in May of 2018, on our first Hearing Voices group meeting in Prague. I got the impression that he is much younger than he actually is. There was some kind of spiritual aura about him, the way he talked calmly and openly about his experience.

He is bold, medium height and always has a smile on his face and a pair of big headphones around his neck. Ondřej is born and raised in Prague. He is 40, single and he has never been married. Currently, he is living with his father in a large apartment. His father had a high rank in the army before the Velvet Revolution. His father wanted to commit suicide by jumping from Nusel's bridge because he thought somebody from the army was after him. This happened just before the revolution

when there was a big tension of change. His parents were divorced after the revolution. Mother is living with her new husband, a famous Czech actor. Ondřej has an older and successful brother (from the same parents) and he is working as an anesthesiologist in one of the hospitals in Prague. His brother has a family of his own, wife and 12 years old daughter. Ondřej got a diagnosis of schizophrenia in 2005. He was hospitalized 8 times in Psychiatric hospital Bohnice, in Prague. The last hospitalization happened a year before we met and started talking about his experiences. Since 2005 he has a Disability pension of the third degree. His pension is around 4500 Kč, which for him is barely enough to cover his living costs. His father and mother are helping him financially from time to time.

Ondřej's told me that his personal narrative is fragmented in time. Sometimes it was very difficult to follow the timeline (what happened before or after some event). He explained that he has problems with short term memory "because of the psychiatric drugs and psychosis" and long term memory because he doesn't talk about his experiences so he forgets them. His time references are major life events like the flood of the Vltava river in 2002 or Hurricane Katrina in 2005. In his narrative, a few dates were mentioned. These were the years which were significant for the timeline of his narrative.

These dates are listed below in order to follow his story:

1978 - Ondřej was born

1989 - Velvet revolution; Ondřej's father went to a psychiatric hospital

1992 - divorce of Ondřej's parents

2002 - Ondřej started feeling "beings"

2005 - Ondřej started hearing voices and had his first hospitalization

2018 - Ondřej started coming to Hearing Voices group

From his first hospitalization onward, his narrative was disrupted many. Every major event in his life (e.g. hospitalization) disrupted the continuity of his personal narrative and changed his interpersonal relations with others

4.1.2. Between two Worlds: Before and After

Ondřej's life is characterized by themes of before and after. There were several important events that changed the course of his life. Ondřej was born in a family where both parents worked. His father was a high-rank army officer before the Velvet Revolution. In the period of political change, his father was afraid that someone would kill him because of the information he knew, as he worked in Intelligence. During this period, in their family home, there was a constant feeling of fear and tension, as his father's psychological state was getting worse. One day, his father went to Nusel's bridge with intent to commit suicide. He didn't do it because he saw graffiti "Jesus loves you" and someone called the police. Ondřej's father was hospitalized in Psychiatric hospital Bohnice in 1989 and got a diagnosis of paranoid schizophrenia. This incident brought another "before and after" situation as his parents divorced and his mother and he started to live with another man. At that time Ondřej was 11. Living with his stepfather was traumatic for him because he often yelled at him and treated him badly. Ondřej felt that he doesn't belong with that family.

Ondřej describes his growing up as "normal". He went to school, had friends but he "felt alone". He didn't have a "clear picture of who he wants to be in life" and he thought of himself as "introvert" and someone who is withdrawn. After finishing high school, he started studying at the University of Economics, but he was not

interested in that. He started to smoke marihuana, drink alcohol and he tried to find his place in life. His parents pressured him to find a job and earn some money. He couldn't find a meaningful job and he went on a trip to India with his friend. In India, he felt welcomed by the others and had meaningful experience because people there were not motivated by the material gain. After he came back to Prague, he was even more isolated and withdrawn. In 2002 there was a big flood by Vltava river and Ondřej felt that it was his fault. Before the flood happened, he felt guilty of not being able to fit anywhere, not being able to study or find a proper job or establish a meaningful relationship. All of his friends have moved on with his life but he was stuck. This was the beginning of his mental health issues and another “before and after” life event. This was a time that ”schiza” (Czech slang for schizophrenia) appeared:

“While walking down on Nusel's stairs back from work I felt the presence of the beings, like they were there, I started to feel their emotions”.

Before the voices appeared, he had “hallucinations of touch”, a feeling that something or someone is touching his skin. He called them “beings”. From that experience, voices developed slowly during a couple of years. The first voice appeared when he was walking on a highway near Prague. At that time, he felt depressed and lost and did not know what to do or where to go. Ondřej started to walk on a highway towards the unknown. Then, the voice of *Deire* appeared. He was 27 years. In both situations, when he experienced beings and voices, the loneliness and the lack of social interactions are seen as the main reason.

He needed understanding and support but he didn't have it. The voice of *Deire* gave him that because she is “sensitive about spiritual things, she started to feel like the centre of my being. She is my inner child, good voice, goodness in me”. She was

his “twin flame”, as he said, a part that was missing in his life. Ondřej describes her as his "soul mate" and he feels the closeness to her, even a physical one. He described that he had sexual intercourse with *Deire* as a voice and that it was fulfilling because he could feel her in his whole body. The voice of *Deire* is based on a real person that he hasn't met. Since he didn't communicate with people in his surroundings he discovered Internet community. *Deire* was a pseudonym on one of the Internet forums, a person who understood him.

Since that time he heard about a hundred voices during the last 13 years. Some voices are with him since 2005, and others changed, went away or came back later again. From time to time, new voices appear. During the period while we were meeting, he had five dominant voices, which he experienced in his head, and they were very similar to his thoughts.

For every voice that he experienced or is still experiencing he has a name and he knows who they are. All of them have their own stories:

Almighty is one of the oldest voices and he is present almost from the very beginning. This voice has both sexes, male and female, and his main function is to give him advice about almost anything. Ondřej doesn't know the age of this voice, only that the voice is old and wise. This voice is present all the time. Voice of Almighty makes other voices in symbiosis and in balance. He has a deep but yet a soft tone of voice. The Almighty has suffered a lot and is from another space and time.

Deire is a young 20-year-old woman's voice. This was the first voice that Ondřej heard. He feels an intimate connection with this voice. He considers her as "his closest person". She appears many times a day.

Mother Nature (Matka příroda) is female, without a specific age. Her function is to give advice and make predictions about something that will happen in his life. She appears many times a day.

Christian God (Bůh křesťanský) is a male, old and wise voice that gives predictions and premonitions. He is present many times during the day. He gives him pain as well so he can learn something from that experience, and not only from good experiences in life.

Jesus Christ (Ježíš) is a voice that comes in situations when Ondřej needs help or when “the bad things happen”.

Deire's voice was pleasant and supportive and Ondřej doesn't have any problems with this voice. Other voices are not that pleasant. For example, the voice of *God* told him one night to smash his head against the bathroom mirror. He did it because he felt great fear and was overwhelmed by the control of the voice. That was another “before and after” moment in his life as he got hospitalized for the first time. He describes negative experiences with voices, in situations when he feels without power over them. “Sometimes these voices are so hard on me, that I just lay on the bed and wait for voices to come”. For negative voices, he used the word “attack” (ataka). An extreme example was a situation when the voice of *God* told him that they are taking him to a “slaughterhouse (do jatky)”. Voice told him that he would be dead and that they are taking him to autopsy room (pitevna). When his parents drove him to a hospital, and when he got an injection, he experienced suffocation. At that moment, he thought that he will be dead as the voice said. He thought that the “old universe came to an end”. He woke up at the closed ward and he was courted to bed. At this point, the voice of *Almighty* came for the first time. This was a situation where he did not have any control over his life. This voice comforted him.

Ondřej is experiencing his voices in a general way as “family members”. He used this metaphor for both - positive and negative voices:

“In my case, voices are like family members. In every family, we have different periods, where positive and negative things are happening. Sometimes I am glad that I belong to that family and

sometimes not. Content of the dialogue with voices is similar like one with family members or friends”.

The function of these “family members is to raise me and teach me how to live”. When he does not understand something, he asks voices for additional explanations. Voices helped him understand the world and how to communicate with others. They thought him to communicate with them in a special way:

“They treated me like a child who does not know anything like a mother treats her child. I had other mothers, not just the biological one. These voices treated me like I was a special person”.

In an intersubjective manner, voices can be seen as something that was missing in his real life. He was growing up without parental guidance and support and his voices were, in a certain way, a surrogate family that helped him and showed him how to live.

Ondřej describes that he lives in “two worlds”. One is his intimate, inner world that he does not share with many people because they are not interested in it. The other one is an outside world that we usually call reality. His inner world he describes as “dream-like” and there he can accomplish anything. Voices belong to this world. The outside world is a material one in which he has trouble to live in and understand it. In this world, his experiences with hearing voices are not welcomed. He likes to live between these two worlds. Our relationship can be seen as a bridge between these two worlds.

4.1.3. Meaning and Function of the Diagnosis: A Legal Alien

During our first meeting, I talked with Ondřej about the concept of my research. I told him that I am interested in him and that I would like to know more about Ondřej. The counter question he asked me was “do you mean if I have childhood trauma?” This indicated that people were mostly interested in his diagnosis of schizophrenia while they were doing psychiatric anamnesis. They were not interested in him as a person. He learned to separate two aspects of himself. First one is the inner experience of voice hearing and other unusual experiences, which he keeps almost exclusively for himself. This world is closed to outside influences. The second one, the role of the psychiatric patient, is available to others.

When Ondřej got diagnosed he was initially glad that somebody knows what is happening to him. The diagnosis meant that he doesn't have to “explain anything to anybody” and that he is “more readable by the scientific society”. This second phrase means something completely different than it sounds like. It means that “scientific society” like psychiatrists and psychologists do not ask him about his personal experience as “they know his illness”. No one asks him how does he experience hearing voices. He defines his diagnosis as a “necessary evil”. It's “necessary” because sometimes he needs and wants some help from the society (pension, health insurance, medications for free etc.) and “evil” because it labels him as an outcast from that same society. The term he uses to define himself is a perfect example of his social life situation. Ondřej thinks that he is a “legal alien” in society:

O: My diagnosis means that I am “legal alien”.

A: How do you feel about your diagnosis and that you are a “legal alien”?

O: (laughter) I can think whatever I want, but I need to be careful about what I am saying.

A: What does it mean to be careful?

O: People are fragile. They do not want to know what I am experiencing. It can be hard on them.

This means that he can do or think anything he wants but what he shares with others, what comes out can be (and usually is) seen as mad. He is also thinking about others if they are too “fragile” to understand his experience. His experience is difficult and for some people hard to listen, so in order not to hurt someone who cannot bare his life story, he keeps it for himself. So he is careful when sharing about himself. In this way, the diagnosis is “self-explanatory”. He does not need to say or express anything about himself, because diagnosis “says it all”. Diagnosis doesn't allow sharing experience but gives a safe space for him to be himself but not in contact with others, only with himself and voices. This experience, not talking about a personal experience, he had in contact with his father while growing up.

The diagnosis helped him to orientate better in this “real” world but, at the same time, it prevented him to talk about his hearing voices experiences with others. In one world, when encountering people he was a “schizophrenic patient” and in the other world he created many relationships with his inner voices, and his experience had meaning. I would say that in both worlds his experience has some function and meaning. His hearing voices experiences gave him the status of a psychiatric patient but helped him as well. In his inner world voices gave him something that he was lacking in the outside world - meaningful relationships.

Diagnosis also influenced social dynamics with his family. He does not communicate with his brother and his family, because they have “their own life”. When they do see each other they don't talk much, because he is “younger ill brother”. It's a similar situation when he talks with his parents. His father, who had

similar experiences and psychiatric diagnosis, does not talk about his experience at all, nor does he ask Ondřej about his. Ondřej had intersubjective experience not talking about similar experiences within the family, with his father. For Ondřej's mother, it is sufficient to know that he has a diagnosis and that he takes psychiatric drugs. They never talked about his psychosis or hearing voices experience.

Diagnosis of paranoid schizophrenia influenced Ondřej's identity in the eyes of his family, friends and doctors. It made him alone and lonely. Since in outer world he had no relationships, he created a rich inner relationship with his voices. As we were getting to know each other better and as trusts between us grew, I felt a sort of a “third” world that we were creating, a world where he is reinterpreting his experience and his social role as a psychiatric patient. I've noticed this on several occasions. Each meeting he brought something for us to eat or drink. That was a moment where he was not a psychiatric patient nor a person who hears voices. He was just Ondřej. In this way, he could share his inner experience with me but not from the position of a patient. While he was talking about his voice hearing experiences he was renegotiating the meaning of voices and those experiences. He felt “alive” when he could talk about himself. What made him feel alive was my interest in his experiences, in him as a person and questions “that he would not ask himself”.

4.1.4. *Hearing Voices: Search for Meaning*

Ondřej's understanding of voices and other experiences supports several explanatory models at the same time. This is what Larson calls the “system of explanation” (Larson 2004). His search for the meaning of his experiences can be seen as a process where “illness experience is interpreted and negotiated as meaningful by the individual acting as a creative and meaning-generating agent constrained and empowered by the available social institutions and cultural resources” (Larsen 2004: 448). He can be seen as an active agent in “creative process of self-explanation” (Larson 2004: 462) searching for the meaning, and is trying to “connect and supplement various systems of explanation in innovative theory-building work, which I call a strategy of *bricolage*.” (Larson 2004: 462).

Ondřej has different explanations for different situations when and why he hears voices. Sometimes that can be very confusing and stressful for him - to always renegotiate the meaning of his experience. This position can be very fragile and uncertain. He takes different explanatory models to explain different parts of his experience. He explains the appearance of the voices in connection to his current life situation:

“The voices are connected with the things I was looking for. Because I was always looking for some meaning. I was alone and lonely and did not know where my life is going”.

He explains the disappearance and changing of the voices in a spiritual sense:

“Voices are changing because there are different levels of consciousness. When I climb to another level I meet different beings, different voices”.

He gives a psychological explanation for the context of his life circumstances: “It depends on my own life situation and my current mood. When I understand something, then the voices disappear”.

He separates his understanding of the schizophrenia and voices. For him “schiza” is when he doesn't feel well and is not in touch with reality. “Schiza” and voices are not the same thing. Voices have meaning and they belong to him, but schizophrenia he sees as a potential genetic thing. He welcomes the bio-medical model in explaining why he has schizophrenia because “when someone in the family has schizophrenia it is more likely that the child will have it as well”. This is very often a message that people diagnosed with schizophrenia get from the medical staff and a message that society believes in - schizophrenia is a genetic-based illness. Also, every hospitalization gave him confirmation that he is ill and that he "has" illness called schizophrenia. Ondřej also believes that “schiza” is for life, because he was reading on the Internet and was told by psychiatrists that “you can not cure it, you can only live on standby mode”.

Ondřej's voices can be separated into two groups: people-like voices and god-like voices. People-like voices "come from different people that I met in life" and “they go away when these people are no more important to me”. God-like voices are "gods, angels and entities” that are part of him and they are trying to give him some meaning. In this search for the meaning, he considers himself as a “sensitive person, that can communicate with other entities, beings and gods, where he “needs to deliver a message to this world. If I do not understand the message correctly they are mad”. Here we have a spiritual explanation of the voices, but also

an explanation about why he hears voices. He is a special, sensitive person who can communicate with other entities. He doesn't understand always what voices are saying or what do they want from him. In some situations, Ondřej is desperate to understand them and to find the meaning of his experiences. When he can't find a mode of explanation, he feels depressed and guilty because voices are mad.

This meaning-making process can be very fragile and uncertain, but in his case can be seen as a great energy investment as he is trying to create meaning of his life. Ondřej feels that it is a long process where he “needs to fight with voices for my own space”. This process is mirroring of his social dynamics within the family and wider society, where he is trying to find his own space and role. When he understands voices and his experience, it means that he feels comfortable in the life position that he is in. When he doesn't understand voices and don't have control over them, he feels “lost in a reality”.

Going to Hearing Voices group had an influence on how he understands parts of his experience:

“When I hear experiences of other people in the group, for example, that they can live with voices without using drugs [psychiatric], that they hear only positive voices and that they can control it, I have hope that I will do that as well. Some of them are reducing medications and can live without them and I am trying to do that too”.

He is still searching for his own explanation of the voices that is meaningful for him. That search for meaning is his greatest target in life:

“My greatest fear is to die without meaning. Every day I try to understand my voices. I haven't understood them fully, but it is better than before”.

His goal is to be something like a shaman in other cultures, that he understands his unusual experiences and voices in a way that he can control it so that he could have a role and position in this society. He is aware that he has changed and that he is a different person than before when he did not hear voices. He is embracing that experience in hope to find harmony with himself and his voices. Voices are part of him that he does not want to lose:

A: Would you like to get rid of the voices, if there was some magic pill for that?

O: No, no.

A: Why not?

O: Because I am a curious person and I think that voices are like a destiny. They tell something about me, I feel unique with them. I do not want to lose that uniqueness.

4.1.5. Agency in Managing Psychiatric Drugs

One of the major themes in Ondřej' life, like in the majority of people with mental health problems, are psychiatric drugs. He is taking antipsychotics for the last 13 years. These drugs have a different impact on people and sometimes they cause serious side effects and health problems. Ondřej has akathisia (inability to stay still), suicidal thoughts, feeling of numbness and emotional flatness. When he takes drugs, he cannot feel emotions and he is having trouble to hear voices clearly. He is in a dilemma, as he wants to hear voices, as they bring him meaningful messages.

Here we can also witness “before and after” theme. Ondřej hears at least five voices when using his antipsychotic medications. When he is not using them, he experiences more voices, mostly negative ones. When he is using medications he feels numb to react and talk to voices. When he stops taking the medication he feels strong

enough to control voices but that does not last long, maybe month or two. If he does not take medications for more than 2 months, he goes into a psychotic experience. If he wants to explore voices he needs to stop taking medications (or reduce them). If he wants to stay out of hospital he needs to take his medications. Here comes his agency when trying to experiment with his medications. When he feels strong and in control over voices he is reducing his medications. When he feels overwhelmed by voices, he takes a larger dose of medications. He is exploring an idea about reducing medications in Hearing Voices group and on the Internet. These are places where he can get useful information from people with similar experiences.

He wants to reduce medications because “they take humanity from me. When I take drugs, I am only a consumer, I am not creative. I want to be creative to be in harmony with myself”.

4.1.6. Hearing Voices and Everydayness

Voice hearing experience is present “from waking up until I go back to sleep”, says Ondřej. Sometimes the relationship they have is fulfilling, sometimes stressful. The fact that voices are with him all the time has a major impact on his life and his everydayness.

When he is in contact with other people, voices have different roles. If he is talking about himself, not the voices, voices are in the background and they do not interfere. But when he is talking about voices without their permission they can forbid him to talk to other people. This happened to us when we were shooting the video for my research:

A: How many voices are you listening at the moment?

O: Now I am listening 4,5,6 dominate voices.

A: Can you tell me their names?

O: (whispering to himself) I can tell him [to Adi]? OK.

...

O: They are beginning to be aggressive when I am talking about them?

A: What do you want to do, to ask their permission or?

O: They told me that we do not have their permission to continue. Maybe some other time.

A: OK, we will end.

Voices are behaving as separate and autonomous entities that he is trying to understand and establish a good relationship with them. Communication with them is a “two-way street. Sometimes I call them, sometimes they call me”. Sometimes he does what voices are saying to him, because of trust. If he trusts the voices, if they did give him good advice in the past, then he will obey them. He trusts the voices of *Almighty* and *Deire* so he does what they tell him. If he does not agree with what the voice is saying then he will do something else “if the voice tells me not to eat a sandwich and I am hungry, I will not obey him. I will eat a sandwich even if he gets aggressive”.

4.1.7. Coping Strategies

When dealing with voices, especially the negative and aggressive ones Ondřej needs to have coping strategies. Coping strategies are always individual endeavour and they represent the creative agency. Ondřej uses different strategies that can help him to cope better with his voices every day. Some of them are short term, some long term. His agency can be seen in the creativity of the coping strategies and also in being able to try different solutions. He meditates and does yoga because it helps him relax, makes thoughts go away. That also helps with the voices. Listening to music, especially music that is repetitive "underground techno that has rhythm and has a simple melody" helps him to cope with critical or more negative voices.

There are other short term strategies that he uses (alcohol, ignoring the voices or screaming to the voices to go away). In extreme situations, when he has suicidal thoughts or bad mood, he starves himself, because in this way he is "more focused on the body and sensation of hunger, then on negative thoughts". When he feels "fresh and full of energy, he listens to the voices and to what they are saying "and he tries to communicate with them. This strategy helps him to better understand his voices and his current life situation.

4.1.7. Voices as Partners

During the last 13 years, Ondřej mostly spent his time alone in his room or on the Internet. Voices helped him to "kill time, to learn something and to have fun". For example, the voice of *Almighty* is "good in telling the stories" to him when he runs,

walks or whenever he is alone. These stories are “stories of wisdom from an old man”. Ondřej sees the voice of *Almighty* as a guru because he gives him different initiations to overcome, for example, to quit smoking.

The voice of *Deire* gives him comfort and love when he needs it:

“*Deire* gives me love whenever I feel bad. She supports me. It is love in the form of one drop [of water] that falls on the rock. Drop by a drop of love makes me more open [to others]”.

Some of the voices, like the voice of *Deire*, have a profound influence on him. When the voice of *Deire* was gone for some time he was sad and cried for the first time in years. Voices can also motivate him to be more active, to get out of bed and go outside. One day before he came to Hearing Voices group he said:

“I felt terrible, I was so depressed, I didn't have energy at all. I didn't want to go to the group. At that moment, the voice of *Deire* helped me and motivated me to go. She simply said: “Go, you will feel better”. And I went”.

The voices have a great impact on his life, an impact of change. He explained that his voices changed him and his life, and he is “less egoistic and selfish... they taught me to be more open to the world”. Even when voices are more persistent or aggressive he thinks that it is because they want to change him for better “to be more independent, to suffer less and be more open”.

4.1.8. Hearing Voices Group

Ondřej was one of the first people that came to Hearing Voices group and he is coming every week for over a year now. Hearing Voices group was the first place

in years where he met other people and where he shared his experience with the voices. This group became a focal point of his life. He sees the group as:

“... free space, where I can freely talk about my own experience.

That means that nobody will analyze me or say that something is wrong or good. I am inspired by stories of others. It is a miracle for me because for years I have been listening that I need to suppress my voices. However, there in the group people are talking freely about their voices and nobody is trying to give you medications. After the group ends I feel better. Some part of my burden stays in the group and I go home lighter”.

This group is also seen as a bridge between his inner world and the reality around him. In this group he has a purpose as a voice hearer, he shares his experiences and he is supported to explore the meaning of his experiences

4.2. Case Study 2

4.2.1. Milena: A Background Story

Milena is a 58-year-old divorced woman born and raised in Prague. She has two grown-up children (a daughter and a son) who already have their own families. She mentioned that they have a “normal relationship” which she further explains. They are in contact on a weekly basis and they see each other on a monthly basis. She has a closer relationship with a daughter than with her son. Milena also has two grandchildren.

In 2003 she separated from her husband and in 2005 they divorced. They were married for 20 years. Reason for a divorce was the fact that she was unhappy with her

life. Also, her husband attempted suicide by pill overdose, which had a traumatic impact on her.

I met her in a period of her life when she “was very satisfied with life and waiting for new things to happen”. Milena and I worked together for a short period of time in the same NGO whose main focus is mental health. In the last year, she was working as a peer worker (a person with mental health issues who had recovered). She was helping other people with mental health issues on their journey to recovery. Before this job, she was working almost all of her life in different settings. Usually, she had an administrative job in construction companies in Prague. She experienced three psychotic episodes and was hospitalized each time in Psychiatric hospital Bohnice in Prague. Last time she was hospitalized in 2014. I met her in 2018.

4.2.2. Psychosis as a Transformative Experience: Lost and Found

When I met Milena for the first time I immediately felt warmth and openness from her side. There was something so authentic and magnetic about her presence and the way she was speaking. Physically, she is very noticeable. She is very tall (almost two meters), she has intense blue eyes and more than a hundred kilos. Milena seemed to be very open to talking about her different life experiences.

Her life changed when she was 42. Her husband attempted suicide. That was so traumatic for her that she couldn't live with him anymore. Before that incident, she didn't think that much about her childhood, her relationship with her parents or about herself. She thought that she had a happy and common childhood. Then she started to explore her childhood more. She started talking to her mother more intensively and

realized that she had “problematic relationship with parents”. Milena was describing a relationship with her parents, especially with her mother as "loveless" one:

“My mother was a "General" in our family. She had her way of thinking and doing things, and she did not allow me to be close to her. I did not feel closeness with my mother. This was for me kind of trauma but not the big one. In my family, there was no closeness and feelings at all. The love was missing”.

Her father was absent most of the time due to his construction job outside Prague. He died when she was 25, and she does not have a clear memory of him. Milena has an older brother, but she was not close to him during her childhood. Now they are in contact.

Her relationship with other people, especially with her family, was about “roles that they expected from me” and most of these roles she did not understand. One of these roles was the role of a wife. Milena got married when she was 27. She was not ready to get married but she "had to, because it was expected from me", she said, especially because her father died two years earlier and now she was supposed to have a responsible man in her life.

Throughout her life, when something important happened, she described it as “I felt something”. In her family, they did not talk about emotions. That was a common intersubjective experience. So, the thing that she “felt” stayed unexpressed. She remembers one of those situations:

“On my wedding day, I was sad and I cried all day. I felt something inside me was wrong. I did not want to get married but everything was prepared for the wedding already. On that day, I've sat in front of the mirror, and I was doing my hair and makeup. I heard something saying to me "don't do it". Those were my thoughts. But I did get married because it was expected from me and I did not want to disappoint anybody”.

After leaving the family home, she continued to play the role of a wife and later a mother. She was living her life “rationally”. In Milena's life, common themes are “rational” vs. “emotional”. She describes her life before the first psychotic episode as “rational” - a life that was lived according to the expectations from the society, family and her husband. After the first psychotic episode, her life became more “emotional”. After the separation from her husband and children leaving their family home, Milena was alone for the first time in her life. In that period she felt that she doesn't have any meaningful relationship, nothing in common with anyone. Milena described that period as a “great dissatisfaction in my life, I did not have energy and didn't know what I wanted from life”. In this period of her life, before her first psychotic episode, she started feeling her "emotional side of being". This is when her manic experiences arrived. Before the psychotic experience, she had manic experiences that she worked through with her psychotherapist. For Milena, the manic experience was an introduction to the emotional side of herself but also an escape from her current life situation:

“Mania is a great experience because you don't have any problems. Everything that I wanted, what I think of - I did, and I provided for myself. It was like flying. My brain worked in a different way and it was an escape from my reality”.

The manic reaction can be seen as something that was missing in her life, an excitement of the meaningful relationship. Manic experience also brings intensive emotions that she didn't have in her life with her parents and with her husband. After these manic episodes came the first psychotic episode in 2011 when she was 50 years old:

“First psychosis lasted for one week. Before I went to Bohnice, I haven't slept for three days. Then I went to Bohnice to Pavilion 27²⁸. It is called “neklid”. I was courted to the bed, restrained and I've got an injection to calm me down”.

Psychotic experience for Milena was a “battle between good and evil”, between two sides of herself -“rational” and “emotional”. Psychosis felt like “my soul wanted out but my head did not allow it”. This experience, including voice hearing, for Milena, was transformative life experience:

“Psychosis feels like you are not in your skin. You don't know or feel yourself. Thoughts and feelings were different. I lost my identity and found myself again”.

Transformative psychotic experience is not the unknown experience, when a person starts to live his own life and not the life others prescribed. Ronald David Laing, a Scottish psychiatrist, believed that psychotic episode could be a natural way to be in contact with our own being. “This voyage [psychosis] is not what we need to be cured of, but that it is itself a natural way of healing our own appalling state of alienation called normality” (Laing 1970: 136).

This psychotic experience allowed her to express herself and her emotions, even though the experience itself was hard and overwhelming:

“Now my emotions are more visible. I am more sensitive and I am now able to feel the emotions of the others I meet. The psychotic experience helped me to be more open as well”.

These experiences Milena is not defining as illness or disorder. For her, they are “altered states of consciousness which don't feel nice”. People usually don't have

²⁸ The Pavilion 27 is very infamous amongst former psychiatric patients merely because of its forced treatments and use of physical strength by the staff to calm patients down. They also use courted beds, restrains and beds with net around it for more aggressive patients. Recently, you can read personal stories of former patients on Pavilion 27 in Psychiatric hospital Bohnice on a blog (see <https://www.neklid.net>).

experience with these kinds of states of consciousness so it can be difficult to cope. Therefore it can be labelled as an illness. This altered state of mind is the transformative element that stays with a person after the psychotic experience. It “stays with you from that point on, but in a smaller, more acceptable dose”. Consequences of this experience are voices. They appeared during the first psychotic episode. Milena now hears one dominant voice every day (sometimes other appears but go very fast as well). This dominant voice she calls *The Guide* (Průvodce). He is a proof of her transformative experience because he stayed with her and reminds Milena about her transformation.

Milena had her last psychotic episode five years ago. She feels healthy, stable and happy. Milena thinks that psychotic experiences will not come back because she “is changed”. Milena thinks she had three psychotic episodes because after the first psychotic experience she didn't accept that her situation is different:

“When I was in psychosis or before that I got broken into 1000 pieces. I lost the identity of who I was, as I did not know myself. At first, after the first psychotic episode, I wanted to be like my old self. I wanted to collect all of those broken pieces and glue them back together as they were before because it was something that I had known. After the third psychotic episode, I have realized that I need to create myself again. That period was very hard - to admit to yourself that you do not know who you are or what you will be in future. So I created what my soul wants. I recreated myself according to my feelings, feelings of my soul. Psychosis was a gift for me?”.

Experiencing psychotic episodes and hearing voices as a gift, is connected to Milena's spirituality. She says that she has her own faith, which is something completely different than any other religion. She has always believed and felt that there is “something between earth and the sky”. She called it “faith” (víra):

A: Is that faith connected to a religion?

M: No, it's not. I believe in energies. I believe that we all are energy, that everything around us is energy. It is just a question if we are noticing it or not.

I feel faith as energy in my body. But it is not a religion.

Her spiritual explanatory model is a unique explanation that belongs only to her. When she uses some medical terms like hallucinations and psychosis she has her own explanations for them. This unique explanation of her own experiences comes a “believe that everything comes to a person when he is prepared for it”.

4.2.3. Meaning of the Voices: The Guide

Milena is very (self) educated person in the context of mental health literature. She was teaching young psychology students about her experiences at one University in Prague. But when it comes to her understanding of the origins of psychosis and voice hearing experience she doesn't explain it by medical terms:

“Reasons [of psychosis]...hmm...they can be many. One can be, what are doctors saying, that we have the same predisposition [genetic], but I do not believe in that. Another one goes along with what I think - I was unhappy before the first psychotic episode. I was not satisfied with my life and I did not have optimism. I didn't have a meaning of life”.

All three psychotic episodes Milena experienced in the same way, as “altered state of consciousness when the brain is working much faster and everything is unreal”. She uses words like “hallucinations” and “unreal” but not in a medical way. She has her own way of explaining these words:

“I've lived in the unreal world [during psychotic episode] where you have hallucinations. You are seeing things and you think differently. It is unreal world because others cannot see it. But for me it was real”.

Milena has negative and positive voices. She is experiencing voices from inside of her head as if they came from inside of her. First voices appeared during the first psychotic episode. They were negative and she was afraid of them. These voices talked about “bad things” - someone will take her away or she will die. These negative voices she considers to be part of the “psychosis as illness (nemoc)”. But yet again, even though she uses medical terms, she has her own explanation of these terms:

“There is a part of psychosis that was bad, overwhelming and it made me physically sick. That part I call illness. That part includes negative voices and it is a bad part of me. The other part is good and meaningful psychosis that I call a gift”.

Negative voices Milena connected with the negative emotion of fear “that someone will take her away”. These negative voices were also meaningful for Milena, not at the moment when she experienced them, but later when she was remembering her experience. Negative voices she sees as prophecy, they were trying to warn her what will happen. They were saying to her that someone would take her away:

“One day I was wondering in Prague stopping random cars in the street, thinking that people are looking for me, that they are following me. I was trying to escape because my voices were telling me that someone will take me away somewhere and I was scared. One of the cars that I stopped called the ambulance and they took me to Bohnice”.

These voices came from the negative experience of Milena's past. Milena lived unfulfilled life for a long time and voices were warning her that if she continues to live that way she would end up in a bad place.

On the other side, Milena has positive voices. Positive voices appeared both during the psychotic episodes and after. When she was hospitalized for the first time, she was taken to the Pavilion 27 and was restrained. She was more scared there, then outside. During her first night in the hospital, she started hearing a positive voice. This voice was the voice of her psychotherapist, a man that she respected and that helped her many times in the past. Milena heard the voice of her therapist calming her down and "making her company". That time she also heard voices of her brother and psychotherapist talking about her. For Milena, it was a form of "entertainment like listening to the radio to pass the time". Those voices helped her survive the traumatic experience of being restrained.

Other positive voices came after the psychotic experience. Voice of *The Guide* (which she hears now) appeared after her third psychotic episode as a "proof" that she has changed. *The Guide* appears when she needs help or advice about any life situation. Usually, she calls him when she needs something but also sometimes the voice appears on his own. This voice helps her in her new life.

Recently, the voice of *The Guide* does not appear often nor she calls him. Reason for this she finds in her current happiness in life and she does not need any advice.

Sometimes negative voices do come back but they don't last for very long. Milena understands the appearance of the negative voices as a "signal that something is not right in that moment and in her life". One day after attending hearing voices group,

we were walking together to a bus stop when Milena told me that the negative voice just appeared. I asked her does she have any idea why did it happen, because she always felt good in the Hearing Voices group. She said that the story of one person from the group reminded her about her own negative life experiences. This brought negative feelings back.

4.2.4. *Venus (Venuše)*

Milena created her own space, her own planet during the recovery process of recreating herself. She created the planet or “physical” space in her head called Venus. This inner space she created after the first psychotic episode. It was the beginning of her journey to recovery. When she needs to relax, to be alone or meditate on some important life question, she goes to that space and “there is no gravity, you can feel lightness”. In the beginning, it was a fantasy place, which became a reality and part of her. She experiences that space as physical, actual and real. The name of that place is very symbolic. She picked this name because this planet is very bright, it shines and it is visible. Milena always wanted to be visible and to shine as she does in this period of her life. Creating this space can be seen not just as a part of her recovery, but also as her agency in her recovery (or empowerment). She has found her inner strength and faith, which helped her to overcome difficult periods in her life. Her journey of understanding this experience is a lonely endeavour. Only when she had found the meaning of her experience she started to open up to others.

4.2.5. *Voices as Part of Her Life*

In the last four years, Milena hears voices almost daily. Recently, she doesn't hear voices every day, maybe a couple of times a week. Voice hearing experience to influence and shape her life as well:

“Voices changed my identity and me. Voices give me advice and they influence my daily life. Voices enriched me. Before I was common. Now I feel special”.

In the Hearing Voices Movement people who hear voices call themselves “voice hearers” (Woods 2013). This is a proud name related to their experience. The term “voice hearer” also has deeper, political connotation that involves active agency to take your own life in your own hands: “The voice-hearer' (i) asserts voice-hearing as a meaningful experience, (ii) challenges psychiatric authority, and (iii) builds identity through sharing life narrative” (Woods 2013). All of these aspects can be seen in Milena's life, even though she didn't know about The Hearing Voices Movement before she met me, nor she calls herself the voice hearer.

During the last year, Milena is working as a peer worker. Her voices help her at her job in many ways. The reason why she got this job is that she hears voices and doesn't have problems with them. She was chosen for this position to help others by her own example and personal life story of recovery. Voices, particularly the voice of *The Guide*, helped her to decide if she would take another job that she had applied for:

“I had an interview for a part-time job in one NGO - to work in some art therapy project. After I came back home I called *The Guide* and asked him what does he think about this position. He replied to me

that it would not be a good choice for me. So I declined the job offer a couple of days after. And it was a good choice because I got a peer worker job just a few months later and I enjoy it”.

On the other occasion, when she was not sure about the decision to sell the apartment where she had lived with her husband (in order to symbolically buy a new beginning, another apartment that will not remind her of her old life), “the voice said that I already know the answer”. She sold the old apartment and bought the new one. A relationship that Milena has with her voices, or more specifically with *The Guide*, is one of an equally balanced relationship. Milena still has her agency to do what she wants, because she is not overwhelmed by the voice. She enjoys his presence and advice. This voice helps her to rely on herself and trusts herself more. Milena interacts with her voices, which proved to make voices "more benign over time" (Marrow & Luhrmann 2016: 213).

She considers *The Guide* as her friend, “with the great sense of humor”, who gives her a laughs when she is sad or in a bad mood. *The Guide* is not a substitute for her friends. He is a part of her. She has a lot of friends that she is seeing on a regular basis (e.g. group of women friends she is meeting every Friday in a restaurant). They all know about her experience, mental health issues and hospitalizations, but nobody knows that she hears voices. Nobody knows simply because “they did not ask her”. This part of her experience is not important to her friends, because it does not influence their relationship. They talk about common life topics and see her as an equal and normal friend they know all of her life.

Milena is a great example that voice hearing can be a meaningful and transformative experience that is not by itself sign of an illness or problems. She

integrated all aspects of the experience in her personal narrative and all of them give her meaning. She enjoys her life at the moment partly because she likes her job. Peer worker is not just a role - personal experience is very important. This is a reason why she enjoys her job and life as well because she doesn't play a role. She is just being herself.

4.3. Case Study 3

4.3.1. Blanka: A Background Story

Blanka is a 45-year-old freelance artist originally from Brno. She graduated at the Faculty of Fine Arts in Brno. Before moving to Prague 16 years ago, she worked mainly in restoration business - restoring facades on old buildings in Brno. She lives with her boyfriend for 16 years now and together they have two under aged children. Her boyfriend is a movie director and graffiti artist.

Blanka was adopted when she was a baby. She doesn't know her biological parents. She found out about her adoption when she was 20. During the last year, both of her adoptive parents died. At the moment, she works as a peer worker in NGO in Prague. She has artistic atelier for people with mental health issues and she is teaching them to express through painting. Blanka is also a freelance artist-painter. She had several independent art shows in the Czech Republic.

4.3.2. Calling the Voices

Blanka describes herself as a very visually oriented person. She dedicated her life to visuals: pictures and paintings. She has a unique dressing style as well. She wears very distinctive and colourful clothes, for example, a dark red shirt, with dark blue pants, yellow scarf and colourful makeup. My first thought when I saw her was that she must be some kind of artist. I met Blanka on Hearing Voices group in Prague in a difficult period in her life as her father recently died.

I know Blanka for 8 months now and we were in contact during all of this time. Our communication was very interesting from the beginning. It was kind of “unstable” when we were planning to meet each other to talk. We were agreeing several times on dates and places, and she would almost regularly cancel it the day before our meeting, just to rearrange other date and time, which she often cancelled again. Finding a mutual agreement was very difficult and unpredictable. Same goes for our meetings, interviews and general interaction via email or face to face. I would rarely get a direct answer to the thing that I asked for. This had a big influence on the structure and analysis of her personal narrative presented here.

First thing Blanka told me when we met is that she always felt that she is “different”. That was the main theme that followed her all of her life. When she was a child, she felt that she is different from her parents and that she doesn't belong in that family. Her mother was a very devout Christian and she forced Blanka to go with her to church. Blanka was not interested in Christianity, and that was a major obstacle and topic of arguments with her mother.

When she was 20, she found out that she was adopted as a baby. Her world collapsed but at the same time, that gave her a confirmation that she is different and

that her feelings about that were correct. This was also a vantage point of her problems. First, she developed bulimia and started going to psychotherapy. Her psychotherapist recommended her to visit a psychiatrist who gave her a diagnosis of borderline personality disorder.

During this period of her life, she fought with her mother all the time, while father “understood and supported” her. As she was finding her way out from that family she met a man and very soon after that they got married. She was not in love but needed to live away from parents. She described their marriage as very “depressing” because they “didn't love each other”. Her husband wasn't supportive regarding her creative side (painting or writing songs). He divorced from her because she wasn't “structured and tidy person”. This was a major shock for her, even though they were not in love.

Her first psychotic experience came after the divorce:

“I remember that I've slept and then I woke up in my apartment, which was my atelier as well. I saw things moving. I saw reflections of things and people in the mirror. I was scared”.

It is quite rare that a person after this kind of experience doesn't end up in a Psychiatric hospital. But Blanka didn't. She was scared, but not overwhelmed. She knew that she “has some problems” but didn't trust psychiatry. Instead, she went to her psychotherapist and tried to deal with her divorce in this way. During this period she didn't sleep much, because she was afraid of death:

“I had a fixation on death. I see that period of my life as the start of my problems and experiences, including hearing voices. I was scared of death but at the same time, it was fascinating”.

Before she started to hear voices, Blanka was seeing things. She explained this as a part of her “artistic being” and “mystical experience” that is usual - as a painter,

she sees unusual things. She started to hear voices for the first time ten years ago, but she doesn't remember the exact circumstances that triggered it.

She is experiencing voices as coming from inside of her head, "from the brain area", and they talk to her and with her as "normal people". She hears many voices, which come and go. In her case voices does not last for a long time:

"...because they are voices of real people. I do not hear the voices of gods or angels. I hear the voices of real people. If I want to speak to someone I know I can just call him or her and his or her voice appears. It's like talking on the phone with people... literally the same".

This phone metaphor also means that she can, as with the phone, deliberately call someone and as well end the conversation when she wants. I also had experienced this kind of "clear-cut" reaction from her side, when she did not want to communicate with me. Rarely she has problems with voices. Only sometimes, when there is "some communication problem and they do not want to shut up I take Rivotril²⁹ to calm me down".

Blanka never used psychiatric drugs as a form of treatment, because she does not want to "kill creativity" but she has a "cabinet full of (psychiatric) drugs" if she needs them. Another reason why she never used psychiatric drugs as a form of treatment is because of her pregnancy. She didn't want her children to have some complications because of it.

After her father died in mid-2017, she started listening to his voice, which was pleasant for her. "It was nice to talk to my father again because I liked him". But sometimes, talking with the voices of other people can be very unpleasant for her. "Sometimes I get a feeling that I've lost myself in those voices. It's like those voices

²⁹ Usually it is used for anxiety and has a sedative effect.

are doing and telling things on my behalf as I've lost myself. That is a very unpleasant feeling.”

For her personal life and creative work, it is important to have a balance between voices. She hears voices all the time, every day. She hears many voices of different people and she needs to have them in balance. She accepted voices as a part of her being and she doesn't want to get rid of them. She experiences voices as a physical presence as well:

“Important thing is that I hear voices that are connected with my heart. Sometimes, if voices are negative, I feel physical pain in my heart. It's like somebody stabbed me with the knife. But I don't want to get rid of them, because I got used to them. They are like a part of my body. Would you like to cut a part of your body?”

4.3.3. Meaning of the Art, Death and Mysticism

The theme of death is very important to Blanka. When she got divorced, before the voices appeared, she wanted to die. But as her “will live prevailed”, she continued to research the topic of death. She has always believed in the mystical nature of the world – that there is something else beyond the visible reality. This is connected with her experience of being adopted. “I don't know why but I was always interested in Kabbalah and Judaism. My parents were Catholics and I don't know where this comes from. Maybe my real parents were Jews”.

She read a lot about death (spiritual, psychological and religious literature) and she concluded that “after death, there is something else” and “dead people can communicate with us”. Blanka was also preoccupied with this topic because she believed that she could communicate with her real parents, for whom she thinks are dead.

Blanka described that she had several close encounters with death. Some of them were accidental like a terrible car accident which she survived or when she almost suffocated from a leaking gas in her apartment. There was also one deliberate encounter with death. She was thinking and meditating on the topic of death. She wished to get closer to it. While contemplating and meditating about death, she had, what she described as a “clinical death, where I almost have died”. However, she was not ready for it yet. Reason, why she was so obsessed with death, was because she believed that in the other world, she would have a better relationship with others, than in this world.

When Blanka was obsessed with death, she had visions and was seeing “skeletons, dead people and heads”. Later, she started hearing voices. All of these unusual experiences, including hearing voices, Blanka explains as connected to her “mystical experience and ability to talk to people, dead and alive”. Her explanatory model is not at all bio-medical one. She doesn't accept the diagnosis, not she thinks she has an illness. She is trying to connect her art, psychology and Kabbalah in explaining her unusual experiences. She believes that language and numbers (like in Kabbalah) have deeper symbolic meaning. She listens very carefully what voices are saying so she can understand the deeper meaning.

This mysticism that she believes in, goes very well with the image of Blanka as an artist. She believes that, as an artist, she is different and that she has different experiences that “common man does not have”. Blanka lost her father in the autumn of 2017 and in late 2018 she lost mother as well. At that time, we were in contact via email and occasionally we would see each other on Hearing Voices group. However, she didn't want to talk about her experiences anymore. The death of her mother brought her negative voices and as soon as she would start to talk about voices, they

would become even more aggressive. So we didn't continue to see each other, but we stayed in touch.

4.3.4. Diagnosis as a Job Description

Even though Blanka had different psychological issues before she started to hear voices and have visions, she was never hospitalized. The first reason for that she presents as:

“I have an overview of my experiences. For example, I was trembling from fear once I saw something, but I've accepted it simply as a new experience. It was just an experience for me”.

The second reason why she was not hospitalized is that she has her own belief system, a mystical world that is not in agreement with psychiatry. She does not believe in psychiatry “because they label people for being different”. Third reason she finds in her family support. She has an “alternative boyfriend” who understands and supports her art and her expressive side. For him, hearing voices or seeing visions is a common thing. He doesn't see it as a problem.

In Blanka's life, voices, visions and other unusual experiences have a very important existential role. In the NGO where Blanka works for the last five years, all employees are people that have some psychiatric experience and psychiatric diagnosis. Most of them have been hospitalized before. The criterion for the job in this organization is that you have a Disability pension (for being a psychiatric patient). Blanka did not have Disability pension, because she worked mainly as an artist. Later, she decided that she would get herself one. Disability pensions are defined according to the level of impairment, psychiatric diagnosis and inability to work. If you are able to work and

function you don't get the pension. When she went to a new, young psychiatrist, she told him that she needs a pension because she hears voices. The psychiatrist wrote that she couldn't differentiate between what is real and what's not. This was sufficient for the diagnosis of paranoid schizophrenia. She got the diagnosis and Disability pension of the second degree. That was, paradoxically, her way to get the job. This situation tells us several things. First, that psychiatric diagnosis is subjective, not scientific and does not have validity. Second, that someone can still get a diagnosis of schizophrenia only because of voices. Third, in some cases, the reason for the label of mental illness is not connected to the health issues but social ones (in Blanka's case financial ones). Now, every two years when Blanka has a medical check-up, she has to lie that she is not feeling well and that she has problems differentiating reality from fiction when hearing voices. If she does not lie, she will lose the job. Blanka did this because she wanted "to provide a better life with a steady income for children and because she can be a freelance artist as well".

I have witnessed a few times that she is a very dedicated mother. Few times she cancelled our meeting because she needed to go to pick up children or she wanted to stay home with children. Her children (aged 8 and 10) know that their mother hears voices and have other unusual experiences. For them, this is common because "their mother is an artist". She also uses voices as a part of her artistic expression. Sometimes voices are telling her what to paint and sometimes she paints the voices or how she experiences them. The art helps her to be in contact with her self and to present herself to the "outside world".

5. Final Words: Discussion

5.1. Constructing the Self, Identity and Meaning with Others

In psychiatry, experiences like hearing voices were seen purely as symptoms that are “divorced from the life context” (Irrázaval & Sharim 2014). However, the intersubjective approach shows that these symptoms are meaningful and that “they are embedded in the person’s life thus their contents and meanings can only be understood within the context of that life” (Irrázaval & Sharim 2014). For hearing voices in people with the label of schizophrenia, Jenkins argues that “intentionality, agency and meaning coincide in schizophrenic process” (Jenkins 2014: 37), where voices can be understood as “intentional without being intended” (Jenkins 2014: 38) and that they belong to the self (person), therefore have meaning.

When dealing with the narrative of people with experience of psychosis, we encounter a complex picture. Questions of identity, self, recovery, personal understanding of the experience and social dynamics are equally important. All of these elements came up in conversations with informers and all of them are presented. Although identity and recovery were not the main aims of the research, they were important in my research questions.

What we know as identity or notion of self is “personal and social, or subjective and intersubjective” (Estroff 1981: 219). A person can perceive himself in a certain way but he also gets feedback from others about how they perceive him. Self and notion of identity can change in the interaction with others (Estroff 1981: 220)

and it is an ongoing process of constant “identification, interpretation, experiencing, knowing, and changing of self through interactions with others” (Estroff 1981: 220). This can be seen in all of the informer's cases. For example, Ondřej was growing up with his father who was “schizophrenic” and when he got the same diagnosis, he accepted the same identity of a psychiatric patient. As he was opening up to the outside world by going to the Hearing voices group and participating in this research, his identity was changing. He was also seen as a person whose experiences have meaning. Milena formed her identity by transforming her own being. She accepted that she was changed by the psychotic experience and she introduced the new Milena to the world. Her environment treats her as “normal” Milena, especially because they are focused on Milena's behaviour towards them, not what she experiences inside. Blanka sees herself as an artist and that identity is supported by her boyfriend. She is also perceived as an artist and “different” by her children. With the identity of an artist, an unusual experience like hearing voices goes hand in hand. Her identity of an artist is confirmed in the artistic community as well, as she has her own exhibitions and meets other artists.

When we are defining the notion of self and identity of people with lived experience it can be explained or experienced as “breaching the reality of others” (Estroff 1981: 221). When two realities cannot understand each other or be in a dialogue, then “the one who is more powerful will prevail as normal one” (Berger & Luckmann 1991: 108-109). Then the “‘crazy’ or ‘mad’ remove himself by withdrawing completely into his private reality, by killing himself, or perhaps by attempting to regain vital portions of intersubjective reality by undergoing psychiatric treatment” (Estroff 1981: 223). The important aspect of intersubjective reality with informers was the number of hospitalizations. Hospitalization means (especially the

forced one) “breach of reality with others”, when others are “more right” and have power over you. The number of hospitalization has a major impact in forming the identity of the person, recovery and intersubjective reality. Ondřej was hospitalized 8 times and every hospitalization confirmed to him that his main identity is one of the psychiatric patients. Because of this, he accepts the bio-medical model and that is why he defines himself as “schizophrenic”. Milena had three hospitalizations. Every time she was “there for few weeks”, and later she went home. Her inner faith and life experience helped her to recuperate quickly, so for her hospitalizations were a bad experience and she doesn’t identify herself as “schizophrenic nor psychiatric patient”. She is “healer” that helps others, thanks to her transformation. Blanka didn’t have experience with hospitalization. She went to private psychotherapists or psychiatrist, and recently (because of Disability pension) to the psychiatrist in Psychiatric Clinic. Her sufferings and problems are not connected with the language of psychiatry. She sees herself as an artist primarily, and then as a mother and girlfriend.

So, if a person is in intersubjective contact only with the psychiatric system, his notion of self can be easily accepted as a psychiatric patient. If a person has a chance to be in contact with people outside of mental health services, his notion of self or identity can be seen as more meaningful. If a person doesn't have contact with others, doesn't communicate or exchange opinions and experiences, that can have a negative effect on the subjective and intersubjective definition of the self. What we label as crazy “can be conceptualized as a lack of intersubjective reality” (Estroff, 1981: 223). In the context of intersubjectivity, self or identity is seen as a product of “intersubjective creation” (Jenkins 2004: 35) not as an entity.

This was also confirmed in Lindow’s study (Lindow 1986), where it was discovered that hospitalizations have a great impact on how somebody understands

his or her experiences. Someone who is hospitalized more than once, in most cases, accepts the bio-medical explanatory model of his experiences, while during the period of first hospitalization patients have different understandings of their problems (Lindow 1986:374–376 in Larson 2007: 449).

For all informers, we can say that they are using the approach in recovery known as “turning towards” (McCarthy-Jones 2017: 266) or “integration” (Larsen 2004: 458). In this approach, the person wants to explore experiences and try to find meaning. When we were talking about identity, all of the informers saw voices as a part of themselves, as something that carries meaning. They all use different explanatory models to explain that meaning. They explore this meaning in Hearing Voices group. There, they don’t feel that something is wrong with them, but that they are different than the majority of people. They are trying to integrate this difference into their life.

In this research, personal narratives of informers were presented in a spirit of existential anthropology which “directs attention to the mentally ill as individual agents and the ways in which they try to make sense of their experiences and their personal lives” (Larson 2004: 446). For informers, it is important just to talk about their experiences because “explanations provided a means of controlling their disturbing sensations and experiences by objectifying them in language” (Larson 2004: 466). Those narratives were created between informers and their social world, including me. Also, they are created between the reader and the text. Narratives are seen as a way to make experiences meaningful. When a person talks about the unusual experiences, the narrative becomes part of “non-pathologized identity” (McCarthy-Jones 2017: 267).

5.2. Post Scriptum

5.2.1. *Consequences of Ethnography*

Since I have read “*Saints, Scholars and Schizophrenics*”, I got interested in the potential consequences of ethnography. Ethnographer as a stranger who comes into the intimate space of people’s lives has to bring some change. The relationship that ethnographer has with informers can change both informer’s and ethnographer’s life. Also, when ethnographer talks about his research or when he publishes it, that can have a different kind of consequences. As people with lived experiences are often stigmatized and marginalized from the society, I did not want to hurt them by exposing their lives and “their hurt and pain” to the world (Sheper-Hughes 2001: xvii). When I talked with informers about my research, they were very happy, open and enthusiastic because finally, someone will hear them. All of them even said that I could use their real names. Because of the intimate worlds that they all shared with me, and because someone can potentially recognize informers, I have decided to keep this research away from public reach. I agreed with them that they will get my final paper, including the film, and that they can do what they want with it. I will ask the University to protect this research so that it cannot be publicly used. Only informers will have this thesis at their disposition.

I’ve experienced during the last year that dealing and talking about hearing voices can have a positive and negative impact. Positive consequences of ethnographic research were presented in Ondřej’s case. When I approached him, he was very happy that somebody is interested in him and his experiences. Our time

together helped him to find another identity besides being a psychiatric patient. This was therapeutic and he felt “alive” when I was asking him questions about himself. Being a part of this research had a therapeutic effect not just on him, but his family as well. For the first time in his life, Ondřej talked about his experiences with his family. Firstly, it was with his mother “because with her was easier to talk, she does not live with me”, said Ondřej. Later, he also spoke with his father. Ondřej said that this research and questions that I was asking helped him to organize his experiences in an understandable way so he can present his life story to family and others. Another thing that helped Ondřej to connect with his family is a film that we recorded for this research. He agreed with his family, that we will get together, watch the film and talk about it. The screening of the film will happen in summer at his mum’s house. This will be the first time that Ondřej will be in the centre of attention of his family, and that he will bring the family together so they can “start speaking about their problems” (Sheper-Hughes 2001:xx).

5.3. Ethical Questions and Other Considerations

Main ethical question is reviling intimate and delicate information about the private life of people, as I already mentioned above.

Another question is language. The research was conducted in the Czech language, which is not my mother tongue, but the mother tongue of the informers. The field data was translated into English, which is not my mother tongue as well. There is a possibility that I did not understand something that informers were saying in Czech. But the number of these situations (if happened) is minimal because everything that I didn’t understand, I double checked with the informers.

The third question is a fact that informers knew my view about hearing voices experiences, psychiatric diagnosis and psychiatric system in general. I am openly critical about how the psychiatric system works and treats people. I do not believe in psychiatric diagnosis, because they don't tell anything about persons lived experience. I believe that mental health issues are a reaction to life circumstances. Hearing voices can be seen as a meaningful reaction and in a metaphorical way, it can tell us what happened to the person. My understanding of these phenomena maybe had an influence on informers understanding. I did not share this information directly with informers, but we were together on some public debates about hearing voices, where I was lecturing.

A fourth consideration is the duration and “quality” of interpersonal relationship with informers. I've spent the most time with Ondřej. Therefore, his case study is longer, richer, with specific information. I understood him better than other informers. With Milena, I've worked, so I had a different kind of relationship. I have seen her in different life situations and we've spent more time in a professional context, then in the research context. With Blanka, I didn't spend a lot of time. The duration and quality of our time spent together reflected the structure, understanding and depth of her case study presented here.

5.4. Summary

The main goal of this thesis was answering three questions about informers:

7. How do they experience hearing voices (and psychosis)?
8. How do they construct the meaning of this experience? Has the meaning changed over time?

9. What kind of influence voice hearing experience has on their everyday life?

To do that, I've presented different perspectives and outlooks about the phenomenon of hearing voices. This thesis has five main parts. In the first part, I presented the personal motivation for writing about this topic connecting it with my life context, historical perspectives regarding hearing voices and definitions of the main terms used here. The second part is theoretical and philosophical influences from psychology and anthropology. The focus was on the meaning-making process, the importance of the narrative approach and intersubjective in people hearing voices (with the label of schizophrenia). Third part presented methodology, methods and techniques that I have used. The fourth part is case studies about informers that were part of this research. Structure of the personal narratives follows the most important themes in informer's lives connected to hearing voices experience. The fifth part is a discussion about informers and their identity. Here I also presented the consequences of ethnographic research and potential considerations when doing ethnographic work. The thesis ends with a short summary and conclusion, answering research questions.

5.5. Conclusion

We can say that hearing voices in people with experience and diagnosis of schizophrenia is a meaningful experience that is connected to their life. The way they experience hearing voices or psychotic experience is different, as well as their understanding. The meaning-making process can last for a long time and individuals are seen as active agents. Explanatory models they are using are highly influenced by intersubjective experience with others. If this intersubjective experience is present

only with the psychiatric system, there is a high probability that person will accept biomedical model and his identity as a psychiatric patient. If a person has contact with different people, institutions and groups, he has a better chance to create his own explanatory model that is not influenced by bio-medical. This also means that they have a better chance of recovery.

We can answer research questions by saying:

1. Ondřej is experiencing voices as his family and they are teaching him how to communicate with others. This experience of parental guidance, he didn't have while growing up, since his parents divorced. His explanatory model changed several times in the last few years. He uses different explanatory models. The biomedical model explains his schizophrenia as an illness, while spiritual model and model related to life circumstances explains his voices and beings. He lives with his voices every day. Sometimes he has a good relationship with them and sometimes not.
2. Milena thinks about her experiences as a gift, and psychotic experience and voices for her are transformative. She has a unique explanatory model and it is connected with her personal belief in energy and that everything is connected in the Universe. Voice of *The Guide* helps her by giving her advice.
3. Blanka is experiencing voices similar to "talking on the phone". Her explanatory model is connected with the mysticism, spiritualism, and her identity of an artist. Her voices are there when she needs to talk to somebody.

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