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Content and metaphor : making meaning of voices

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Abstract

The purpose of this qualitative study was to explore how people who hear voices have learned to cope with their voices, and how they attribute the function or role of the voice(s) in their lives. This thesis asked whether traumatic, lived experiences are related to the content of voices. This study used a narrative-inquiry approach to speak with nine adults about their experiences hearing voices. The interview questionnaire was adapted from the Maastricht Interview and Construct (Escher & Romme, 2000). Participants were interviewed in person or over the phone.

The recovery model was the theoretical basis for this study. This model addresses the notion that people can live meaningful lives despite mental health challenges. The recovery approach to mental health treatment values peer-based methods of support, and encourages the belief that mental health diagnoses do not define personal identity, nor expect medication to be the only treatment option. This thesis used ideas of recovery based on the Hearing Voices Network, which encourages people to broaden their awareness of hearing voices, visions, or other unusual or extreme experiences.

The nine interviews demonstrated that people who hear voices are able to find value in these experiences, and lead complete and fulfilling lives. Eight of the nine interviewees identified traumatic experiences in childhood (as well as in adulthood) as contributing factors to their experience hearing voices, and additional mental and emotional distress.

CONTENT AND METAPHOR: MAKING MEANING OF VOICES

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CHAPTER I

Introduction

This thesis contends that hearing voices is not merely the symptom of a neurological, or psychological disease, but rather a coping response to adverse life events. Contemporary psychiatry focuses on the voices themselves as the problem to be addressed, rather than exploring what problems the voices might be communicating. This thesis utilizes a trauma informed framework, as well as a psychoanalytic lens in order to outline how unconscious processes including repression and sublimation may impart traumatic experiences to the phenomenon of hearing voices. In *Trauma and Recovery*, Herman (1992) defines trauma as, "…an affliction of the powerless. At the moment of trauma, the victim is rendered helpless by overwhelming force…Traumatic events overwhelm the ordinary systems of care that give people a sense of control, connection, and meaning" (p. 3). Utilizing a recovery-oriented approach to mental illness, this paper asserts that pathologizing voices creates a barrier to holistic, and psychological treatment by denying a relationship between lived experience and the content of voices.

This study uses interviews with nine voice hearers, and recent literature regarding voice hearing as a trauma response to examine how adults find meaning and cope with their voices. Though many people who hear voices find this to be intrusive and unwanted, voices are not always negative, commanding, and controlling. Some people have positive relationships with their voices, or may even find hearing voices to be a helpful or comforting experience. Yet others hear a combination of negative, positive, or neutral voices and have complicated, nuanced

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relationships with each of these voice characteristics. In all of these circumstances, hearing voices may be tolerated and understood with multiple forms of treatments, including medication, psychotherapy, and a supportive social network.

A multi-faceted approach exploring schizophrenia, psychosis, and voice hearing is implemented in order to understand the emotional and psychological experiences of people in turmoil. A variety of theories including psychoanalysis and notions from the recovery movement will provide a clearer picture into the role of trauma and power in the treatment of hearing voices. Hertz writes, "The Recovery Movement (Ahern and Fisher 2001; Anthony 1993) has challenged us to focus less on the pathology of the person with schizophrenia and more on the potential for growth, to recognize that recovery does not mean cure but the development of new purpose as one grows beyond the "catastrophe of mental illness" (2011, p. 317). This thesis suggests that people benefit when they are able to accept their voices and develop their own interpretations of voice significance.

In *Illness as Metaphor* Susan Sontag wrote, "Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick" (1978, p. 3). Though this passage refers specifically to physical ailments, the same notion can be applied to mental wellbeing. All people are capable of falling into severe depression, anxiety, or even psychosis given the correct ingredients of genetics, environmental stressors, and personal psychology. However, the medicalization of mental illness is set on differentiating between health and disease. Shaun Hunt, a current voice hearer who now provides trainings with the Hearing Voices Network, and was once diagnosed with schizophrenia has said that, "Recovery begins with hope" (Personal communication, Shaun Hunt, 2014). Without hope there can be no chance to regain a sense of control in life, as this automatically

brands voice hearing as an illness. The nine people who shared their experiences as voice hearers for this thesis confirm the core values of the recovery movement; it is important to normalize hearing voices as a coping response, to listen to the stories people tell, and to value their experiences.

CHAPTER II

Literature Review

This paper theorizes that the content of hearing voices may be understood in connection to early traumas. Though this research does not solely focus on the cause and effect relationship between life events and the onset of hearing voices, this thesis addresses the question of how people create meaning from hearing voices by establishing relationships between voice content, lived experience, and coping strategies.

This literature review presents findings that may contribute to decreasing the stigma associated with hearing voices and psychosis by drawing associations between adverse life events, traumatic experiences, and the subsequent development of hearing voices. Using first person narratives, scientific texts, and study reviews, this chapter highlights the history of the biomedical model of mental illness, and makes a case for recovery oriented care for those with mental health diagnoses. One of the main tenets of the recovery movement is awareness of how language is used when discussing mental health challenges. This involves avoiding pathologizing language referring to people as "schizophrenics" (Hornstein, 2009). Auditory hallucinations are described as "hearing voices," and psychotic experiences are considered as "extreme or altered states of consciousness."

This topic is significant for social work practice because it may positively affect the way people who hear voices are treated in the mental health system. People who hear voices are often stigmatized as "crazy," allowing doctors, psychiatrists, social workers or other mental health professionals to marginalize voice hearers as people who are unable to make decisions for

themselves; this usually means that voice hearers are stripped of any control over their treatment, and denied options for alternative forms of care. In a personal account documenting an involuntary 12-month hospitalization, Gray (2009) cautions others of his experience, and that they might not be discharged from the psychiatric unit if they question their psychiatrist, their diagnosis, or speak with staff about hearing voices. Gray (2009) writes that after interviewing hundreds of former psychiatric patients, many of them "had to suppress and hide their voices in order to be considered well, stable, and healthy." The thesis argues that being healthy and hearing voices are not mutually exclusive.

An evaluative study by Nkouth (2010) analyzed qualitative data through interview transcripts and found that among a group of 12 identified voice hearers, they benefited most from therapeutic groups that encouraged the instillation of hope, belonging, and de-stigmatization. People who hear voices are frequently medicated in hopes of removing the phenomena of voices with no exploration into whether the content of their voices has any significance. While some people may not want to derive meaning from hearing voices, and find the medication that manage their voices helpful, relating content to life experience may allow alternative forms of effective treatment to be used.

Hearing voices will be defined as Longden's definition of, "(a) a percept-like experience in the absence of appropriate stimulus, which manifests as (b) a human vocalization, which is experienced in (c) a conscious state and is (d) not induced by organic or state-dependent circumstances" (2012, p. 28).

Trauma & Dissociation

This section reviews studies that evidence causation between traumatic childhood experiences, and the onset and content of hearing voices in adulthood. Additionally this section

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explores voice hearing as dissociative symptom, rather than only a sign of psychotic thinking (Dorahay, 2009; Longden, 2012). Although auditory hallucinations are often considered to be a psychotic presentation, many people who identify as hearing voices do not have a psychiatric disorder (Longden, 2012, p. 31; Cooke et al., 2014).

There is a body of evidence that suggests connection between experiences of childhood trauma and the onset of hearing voices in adulthood (Romme, 2013). Individualized accounts of hearing voices may shed light on the reality of this phenomenon, which clearly affects each person differently. Rather than viewing voice hearing as a disease or symptom of a disease, understanding the role it plays in a person's life serves to humanize this experience, rather than reducing it to a neurological process to be resolved with the right medications. Bendall et al., (2010) note that, "People with serious mental illness, including those with schizophrenia have been found to have higher rates of PTSD from childhood and adult traumas than found in the general population (Calhoun et al., 2007; Kilcommons & Morrison, 2005; Mueser et al., 2004).

Another study, *"Voices from the Storm: A Critical Review of Quantitative Studies of Auditory Verbal Hallucinations and Childhood Sexual Abuse"* found that 36% of patients with auditory hallucinations and 22% of non-psychiatric patients reported childhood sexual abuse. The studies reviewed overwhelmingly found that people with auditory verbal hallucinations were more likely to be survivors of childhood sexual abuse than individuals who do not experience voice hearing. McCarthy-Jones (2011) found that 56% of psychiatric patients with a history of childhood sexual abuse also reported having auditory verbal hallucinations.

The authors of "Childhood Trauma and Auditory Verbal Hallucinations" (Daalman, 2012) suggest that there is an established association between hallucinations and traumatic childhood experiences. However, this study specifically explored the connection between

physical and sexual childhood abuse and auditory hallucinations. The authors note that it is unclear whether traumatic experiences in childhood contribute to the content of auditory hallucinations, or whether childhood trauma can activate susceptibility to experience hallucinations in general. In order to study any possible connection between trauma, hallucinations, and the emotional content of said hallucinations, the study used non-psychotic participants as well as people with a psychiatric disorder who hear voices.

The findings for this study showed that those people who identified as hearing voices experienced a greater frequency of childhood sexual and emotional trauma than the control subjects. However, no distinction was found between the frequency of childhood trauma and positive or negative emotional impact of the voices. The study concluded that childhood trauma puts one at risk to hear voices. Limitations of these studies discussed reliance on participants' self-reporting. The authors of several of the studies suggest that people may under-report sexual abuse due to feelings of shame or guilt.

In a review of studies, Bendall, Jackson, and Hulbert (2010) found that it was difficult to make a direct, cause and effect connection between childhood trauma and psychosis. While they did discover that between 28% and 73% of studies showed an incidence rate of childhood trauma in psychotic groups, intrinsic methodological problems such as defining childhood trauma, and the nature of retrospective reporting make a definitive conclusion unlikely. However, 6 of the studies reviewed showed strong indications of a relationship between childhood trauma and psychosis. The authors then asked, what is the relationship between trauma, delusions, and hallucinations? Through further research they provided two popular theories. The first study suggests that while many individuals experience unusual brief hallucinations or paranoid thoughts absent of trauma, childhood trauma influences the development of maladaptive

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schemas, which contribute to the establishment and preservation of such delusions and hallucinations (Fowler, Garety, & Kuipers, 1995; Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001).

A second theory explains the connection between hallucinations and childhood trauma as symptoms of Post-Traumatic Stress Disorder (PTSD), suggesting that hallucinations and delusions are deviations of intrusive thoughts, flashbacks, and nightmares (Morrison, Frame, & Larkin, 2003). Bendall et al., writes that, "both hallucinations and flashbacks are sensory experiences with no corresponding external stimulus that are subjectively experienced as real, and both are often associated with fear and threat" (2010, p. 302). These hypotheses are supported by "Dissociation, Trauma, and the Role of Lived Experience: Toward a new Conceptualization of Voice Hearing" (Longden, 2012), which considers more evidence that hallucinations (both in psychotic disorders as well as non-psychiatrically diagnosed populations) may develop as a stress response to exposure of traumatic situations.

"Trauma and Hallucinatory Experience in Psychosis" (Hardy et al., 2005) looked at related themes that explore whether the content of hallucinations in trauma survivors with psychosis was associated with the trauma experienced. The author's found that for half of those who experienced trauma and had hallucinations the content of their hallucinations was thematically related to trauma experienced, and for 13% of people, the content was directly related (Bendall, et al., 2010). This example shows the thematic relationship between the content of a hallucination and lived experienced, "…the report by a woman (who had been severely emotionally abused by her mother) of hallucinations of her neighbour criticizing her. Thus the hallucinations were schematically related to her traumatic experience of verbal abuse including harsh criticism by her mother" (ibid, p. 302).

Dorahay's (2009) study, "Auditory Hallucinations in Dissociative Identity Disorder and Schizophrenia With and Without a Childhood Trauma History: Similarities and Differences," examines the role of dissociation and voice hearing, which compared the role of voice hearing in those with a schizophrenia diagnosis and those with dissociative identity disorders (DID) amongst those who reported child abuse. This study inspected various characteristics of voice hearing along with childhood maltreatment and pathological dissociation in three samples. Overall there were 65 participants in this study, sampled as such: schizophrenia without child maltreatment (n=18), schizophrenia with childhood maltreatment (n=16), and DID (n=29). It was hypothesized that due to the shared childhood trauma history and heightened propensity for dissociation compared with the schizophrenia without maltreatment group, the dissociative identity disorder and schizophrenia with maltreatment groups would look similar on many aspects of voice hearing (Dorhay, 2009). Overall, the voice hearing experience seemed much more pervasive in DID compared with schizophrenia, with the phenomenology and prevalence of many aspects of auditory hallucinations appearing somewhat different between DID and schizophrenia, regardless of maltreatment history in the latter group.

A study backed through the International Consortium on Hallucinations Research (Thomas et al., 2014) focused on the possible psychological therapies for auditory hallucinations. The therapies described in this study are derived from models of cognitive therapies. More recent methods involve the use of mindfulness and acceptance-based techniques to help make connections between voices and views of the self, others, relationships and personal history. The therapeutic techniques discussed in this article show that psychological therapies have been widely effective for people with positive symptoms, but more research must be done to better understand hearing voices (Thomas et al., 2014).

Peter Bullimore (2010) writes about his own experiences of hearing voices, attributing them to abuse he suffered as a child,

> I would play against something I could hear but could not see. At first I felt it was an imaginary friend, but on reflection it was my first signs of starting to hear voices. At first they were reassuring, but the problem with abuse is it escalates and gets more intense, which creates more fear and the paranoia grows" (p. 173).

Bullimore is able to directly connect his negative childhood experiences of abuse to his paranoia and subsequent voice hearing. He writes about being diagnosed as schizophrenic and forcibly hospitalized many times, which only increased his paranoia. Bullimore is only able to begin managing his voices and accepting treatment when he starts psychotherapy.

If auditory verbal hallucinations are seen under the guise of meaningful experience, rather than as psychotic disorders, then could the use of psychoanalysis or psychodynamic theory be used as a tool to better understand voice hearing (Pixley, 2012)? Though Freud (1914) wrote that psychotic patients were "unanalyzable," this does not mean that they are untreatable. Abramson (2010) found that while psychoanalytic and psychodynamic work can be extremely successful in treating psychosis, most clients have limited financial resources and there are few clinicians who possess the appropriate theoretical training and supervised experience.

However, Abramson (2012) found five principles helpful in treating patients with psychotic presentations. These principles are safety within the therapeutic context, empathy, validation of client experiences which will enhance ego strength, and encouraging the clinician to be a "real person," and defying the traditional stereotype of the blank canvas, in order to help the client develop a stronger sense of self. Using treatment modalities that are more consistent with traditional forms of psychotherapy may be key to validating the client's experience of

hearing voices, and allow deeper exploration into the meaning of their voices. Hertz (2011) writes that regardless of what has "caused" schizophrenia or psychosis, both experiences can be understood using traditional forms of psychotherapy. Mental health professionals are quick to dismiss patient's drives, affects, and relational longings as delusional thoughts, without considering there may be meaningful rationale attached for the client (Hertz, 2011, p. 309).

As discussed by Pixley (2012) a sample of 103 participants with a history of auditory verbal hallucinations were evaluated using standard diagnostic evaluations and did not appear to meet DSM-IV-TR requirements for any of the psychotic or delusional disorders. "Some difficulties with psychodynamic psychotherapy attending to benign auditory and visual hallucinations," (2012) cites Lukoff (1985) asserting, while some psychotic episodes may become long-term disorders, other psychotic experiences have had positive outcomes for individuals. If psychiatric interventions considered the possibility of positive outcomes from psychosis there could be an opportunity to discuss meaning from these episodes. Pixley (2012) further suggests that hallucinations are "preconscious or unconscious material that has broken into consciousness; this material is thought to be significantly relevant to a patient's psychodynamic structure" (p. 384). This information suggests that delusions and hallucinations are analyzable through traditional means of psychodynamic psychotherapy.

The Biomedical Model of Mental Illness

A biomedical approach theorizes that the causal foundation of mental illness can be scientifically understood, drawing on theories from molecular biology, genetics, and psychopharmacology (Garnar and Hardcastle, 2004, p. 365). Biopsychiatry attributes "mental illness to a deficiency or excess of neurotransmitters, to hormonal imbalances, or to genetic predisposition…" (Thachuk, 2011, p. 146). Paul Greengard's 1972 paper, "Dopamine-Sensitive

Adenylate Cyclase in Caudate Nucleus of Rat Brain, and its Similarity to the 'Dopamine Receptor'" has been integral for the field of neuroscience and current research into brain structure (Ravindran, 2011). Further insights into the biological and neurological foundations of schizophrenia and other mental health issues are a necessary research tool for the development of psychiatric medication, and for cognitive as well as behavioral therapies. A firm knowledge of neuroscience, including an understanding about how memory and emotional regulation is affected by trauma and substance use may also strengthen clinical knowledge. However, using a purely biomedical model to explore mental health has the potential to simplify the role of lived experience in mental illness, creating a reductionist view for treatment options (Thacuk, 2011).

In a recently published article and Tedx talk given in December of 2014, Dr. Canli notes that sixty years of research into depressive disorders has produced no cure, yet researchers have documented that "depression is associated with biomarkers of inflammation." Dr. Canli has noticed what many others in the mental health field have concluded over the years; depression is not fixed simply with the use of anti-depressants. In fact, the argument that SSRI's (serotonin reuptake inhibitors) cure depression because the brain lacks serotonin has been likened to the notion that Advil cures headaches because the brain has an Advil deficiency (Hornstein, 2009). Because an organic source of clinical depression has not been discovered, nor a permanent remedy found, Dr. Canli hypothesizes that Major Depressive Disorder is the result of inflammation in the brain due to parasites, bacteria, or infection (Re-conceptualizing Major Depressive Disorder as an Infectious Disease, 2014).

Dr. Canli relinquishes the notion that depression may have a variety of causes, including genetic predisposition, environmental factors, and emotional and psychological influences. He embraces depression through a fully medical model of neurological illness. *Models of Madness*

(2013) focuses on Schizophrenia-rather than depression- as a disease that has fascinated scientists for hundreds of years, and been studied in hopes of uncovering both a cause and a solution to its existence. The authors of *Models of Madness* (2013), John Read and Jacqui Dillon, expertly research how the disease model of illness has perpetuated harmful stereotypes about extreme states of consciousness, as well as preserving denial about the real emotional, and environmental impacts of traumatic experience. Ultimately their research provides a platform to understand and treat madness using a combination of medical, social, and psychological approaches,

> The medical model facilitates distancing from people who have suffered the worst of what we humans can do to one another. Rather than draw closer to someone in emotional pain and listen to their story, the medicalization of distress encourages us to see them as having a context-less 'illness', to be frightened of them, to pull away, and to call in the doctor" (Read & Dillon, 2013 p.394).

It is important to understand that while there are genetic and biological factors to mental illnesses, environmental, social, and psychological aspects must be considered as well. The biomedical model equates mental illness to physical illness, which Thachuk (2011) writes, "…reinforces notions that persons with mental illnesses are of a fundamentally "different kind," (2) entrenches misperceptions that they are inherently more violent, and (3) promotes overreliance on diagnosis labeling and pharmaceutical treatments" (p.140).

It can be harmful to reduce the emotional, behavioral, and cognitive impairments to biological disease since this not only limits treatment options, but also challenges the nature of mental illness as psychological and physiological reactions to hostile life events. Romme notes that "in psychiatry hearing voices is the result of a disease, and not as a reaction to problems in

life that make people feel powerless. The person's problems are thus neglected and seen as irrelevant, making the solving of their life problems more problematic" (2013, p. 7-8).

In the psychiatric and medical community, hearing voices are called "auditory hallucinations," and are often perceived as a symptom of psychosis or schizophrenia. On the website of the National Institute of Mental Health the diagnosis "schizophrenia" is described as a, "…chronic, severe, and disabling brain disorder that has affected people throughout history" (2013, http://www.nimh.nih.gov/health/topics/schizophrenia/index.shtml). A long-term report compiled by the British Psychological Society found that, "Up to 10 per cent of people will at some point in their life hear a voice talking to them when there is no-one there…A number of surveys have revealed that many people hear voices regularly. Most of these people have never thought of themselves, or been thought of as mentally ill" (Cooke et al., 2014, p.15). This statistic is challenged by a description of auditory hallucinations published by the Psychiatric Times,

> In most cases, auditory hallucinations are unintentional, intrusive, and unwanted...
> A person with insight will acknowledge that the experience is abnormal and will report less interference with daily activities than a person with no insight (Waters, 2010, http://www.psychiatrictimes.com/schizophrenia/auditory-hallucinations-psychiatric-illness).

Waters acknowledges the data that 10%-40% of the population hears voices and are not considered mentally ill, however, he uses biologically based theories such as "temporal lobe epilepsy, delirium, dementia; focal brain lesions; neuroinfections such as encephalitis; and cerebral tumors," (ibid) to explain the phenomenon. In *Models of Madness* (2013) Professor Read writes about scientific contributions of Emil Kraepelin and Eugene Bleuler, considered the

two "grandfathers" of modern psychiatry. Read contests they "were jointly responsible for the invention of 'schizophrenia'" (2013, p. 20). In this chapter Read explains that the contemporary definition of schizophrenia came into existence through the result of a medical community searching for meaning through categorization. "In 1822, one physiological cause for one form of madness *was* found. Bayle's discovery of brain damage in '*dementia paralytica*' was later identified as syphilis. This fuelled hope that other mental "illnesses" with physiological causes might exist" (p. 20).

In 1893 Kraepelin declared having found a group of people whose decline began during adolescence and persisted into a permanent state of dementia, which he termed "dementia praecox" (Read, 2013). The behaviors he claimed were symptoms of dementia praecox had already been named by two other diseases: "dementia paranoids," and "catatonia." Kraepelin combined the symptoms of these illnesses and labeled them "dementia praecox," (Dillon & Read, 2013) effectively producing a disease with "36 'psychic' symptoms and 19 types of bodily symptoms" (2013, Read, p. 22). Read writes, "Kraepelin claimed he had discovered an incurable degenerative illness. When people who he says have the illness get better, he says they haven't got the illness. He is then left with a group of people who don't get better and uses them as evidence that the illness exists…" (2013, p. 22).

This logic is still used today to corroborate the notion that schizophrenia or psychotic disorders are "incurable," and those who do get better must not have been very sick in the first place. A 2014 radio interview with Dina Tyler touches on this issue when Dina is asked what obstacles she faces in her day-to-day work, challenging the traditional mental health system. When she was younger, Dina had been forcibly hospitalized and medicated, but with the right support she was able to recover control of her life. For Dina this meant finding the right therapist

and being around people who didn't feel "toxic," though she warns that to this day she is susceptible to triggers that may cause her to "disconnect," and "retreat." Now the co-director of the Bay Area Mandala Project, co-founder of the Bay Area Hearing Voices Network, and staff member at an early psychosis intervention program, Dina answers that one of her biggest challenges is working with the families, stating,

> People doubt my experience. That what I have gone through is not of the magnitude that their sons or daughters have gone through. That I'm somehow different or was never really that ill to begin with. I have to say to them; they're seeing me at the best I'm ever doing in my life…they're really seeing me "recovered" or whatever that word means. It's somewhat offensive to me to be called as part of the worried well that I was not as sick as other people were. Saying to someone that is doing better now that they were never once where these other people are, it really creates that there's no hope for recovery. That we're just somehow different. But I don't believe that (Tyler, 2014, October 9).

Receiving a diagnosis of Schizophrenia can be treated like a death sentence by the medical community because patients are told that their illness may prevent them from leading fulfilling lives, holding a job, or having stable relationships (Bullimore, 2010, p. 175). This outlook on mental illness does not provide much hope to those living with frightening internal experiences. Though the bio-medical model acknowledges that proper treatment can alleviate symptoms of Schizophrenia, this mode of thinking can also be demoralizing, and contribute to a sense of lost power and control.

The Recovery Model

While mainstream medical models teach that auditory hallucinations are symptoms of a serious disease that should be remedied, the recovery approach to treatment of hearing voices

requires hope that the voice hearer will learn to manage the negative effects of hearing voices and to find meaning in this experience. One group that works with voice hearers to understand their voices and help them live full and complete lives is the Hearing Voices Network, who explains their view of recovery, "to mean 'living the life you choose, not the life others choose for you' (whether those others are family, friends, workers or voices)" (2014, http://www.hearing-voices.org/voices-visions/). The Hearing Voices Network (HVN) was founded in 1987 in Holland (Sapey, Bullimore, 2013, p. 2) and in 1988 established in Manchester, England (Hearing Voices Network, 2014). While the Hearing Voices Network is an international organization, it is for the most part, each support group is peer run. The goals of this group are to raise awareness about voice hearing, visions, tactile sensations, and other sensory experiences (2014, Hearing Voices Network). The Hearing Voices Network provides support to people who hear voices, visions, or have unusual or extreme states by creating an opportunity to come together to speak freely with one another, learn skills, and grow from their experiences.

Hearing Voices support groups were first brought in the United States in 2010. In Western Massachusetts there are 11 active support groups, the highest concentration in the United States aside from California, according to a map listed on the website (2014, Retrieved from http://www.hearingvoicesusa.org/find-a-group). This organization provides peer-run support groups, training for facilitators, resources on hearing voices, and even has a telephone line that people can call for additional resources. The Hearing Voices Network approaches voice hearing with a vastly different system than the typical medical model of mental illness by shifting power to those who are "experts by experience."

The Hearing Voices Movement views voice hearing as a normal part of human experience, and posits that anyone can be susceptible to hearing voices. This approach to voice

hearing is less stigmatizing and more empowering to those who experience hearing voices. Corstens (2013) wrote that 89% of participants who heard voices identified at least one negative childhood experience including, neglect, psychical/sexual/emotional abuse, and bullying. In 94% of the cases it was possible to discern that these underlying psychological issues were symbolized through the voices. This article implies that accepting voice hearing as a coping mechanism rather than as a disease or symptom of a disease may greatly impact the individuals overall experience of hallucinations, and broaden their treatment options.

Professor Marius Romme and Sandra Escher are two leading psychiatrists and researchers who have been at the forefront of the hearing voices movement and who helped establish these support networks. Their research began after Marius Romme commenced work with a woman named Patsy Hage. She is a voice hearer who challenged Romme to expand his thinking and accept her voices as real (Hearing Voices Network, 2014; Dillon, 2013). Hage worked closely with Romme and Escher to develop the Maastricht Interview and Construct (Romme, Escher, & Hage, 2000), which is a tool to help clinicians, providers, and voice hearers better understand voices, the origin of voices, and how to best move forward with treatment. Through their research Romme and Escher found that about one-third of voice hearers did not find their voices to be distressing and had never been in contact with psychiatric services (Romme, Honig, Noorthoorn, & Escher, 1992). Voice hearers who were not able to cope with their voices were much more likely to have received psychiatric treatment. Romme found that by treating a patient's voices as real experiences rather than a hallucination, he was able to learn much more about the voices, their origin and meaning, and to find better ways of helping people.

The Maastricht Interview and Construct (Romme, Escher, & Hage, 2000) serves as an analytic measure to understand and incorporate the voices in a meaningful way, rather than

obliterating them with medication. While many voice hearers do find medication in small doses to be helpful in dealing with the negative impact of hearing voices, medication alone is certainly not the only method of treatment that exists (Romme, 2013).

Romme, Escher, and Hage (2000) created the "construct" as a tool to help the construction of a psychological formulation to place voice phenomenology within a historical framework for use after the Maastricht Interview was conducted.

> …The construct utilizes specific areas of enquiry (voice identity, characteristics and content, triggers, history of voice hearing, personal history of the voice-hearer) to explore two fundamental questions about representation: (1) who or what might the voices represent; and (2) what social and/or emotional problems may be embodied by the voices…The "meaning" of experience is not imposed on the voice-hearer, but co-constructed in a process of collaboration and exploration, then subsequently employed to guide an individualized intervention plan that applies information about voice manifestation and emergence to promote recovery (Corstens, Escher, & Romme, 2008; Longden, Corstens, Escher, & Romme, 2012; Romme & Escher, 2000, p. 2).

Reframing both the language, and the root cause of hearing voices can lead to a dramatic restructuring of the treatment process. Romme (2013) describes this process through the recognition of voices as metaphor. Understanding that while the voices communicate with the voice hearer, the message they mean to convey may not be immediately apparent. The stigma of hearing voices may encourage voices to take a negative foothold for the voice hearer, especially if their voices stemmed out of negative or harmful experiences. For instance, Romme (2013) writes,

When Ami looks in the mirror and sees the homeless woman she once was, her voices says: 'what a disaster', Ami first thought she was being scolded, but now she knows that the voice gives her realistic advice…So when the voice says 'what a disaster', for Ami it seems to be a metaphorical way of expressing: 'Ami looks not well cared for'…Her voices has not changed, but Ami has changed her relationship with it in that she now listens for the purpose behind what the voice is saying, in order to understand what the voice wants to say to her…. (p. 63).

However, it is important to note that not all voice hearers are just misunderstood, and many people who hear voices have very real and terrifying experiences of voice hearing or psychotic experiences. For some people hearing voices is an awful reality consisting of voices that shout terrible things at the person, or command hallucinations telling the voice hearer to harm themselves or others. These negative and destructive voices may be interpreted and understood as tortured components of the person's inner thoughts and feelings about themselves. While some voice hearers find ways to control and minimize their voices, others cannot and must live with them, even if this means that they must scream at the top of their lungs or self-injure to make the voices quiet down or stop.

Alternatively, the onset of hearing voices is not necessarily tied to negative life experiences. A study titled "Auditory Hallucinations as a Personal Experience: Analysis of Non-Psychiatric Voice Hearers' Narrations (Faccio, Romaioi, Dagani, and Cipolletta, 2012) found participants who identified as voice hearers, but had never sought psychiatric care for their voices. They cite material stating that while 2-3% of the population experiences auditory hallucinations, only 16% of this population could be diagnosed with psychosis (Young *et al.* 1986; Tien, 1991; Verdoux et al., 1998; Verdoux & Van Os, 2002). Their study concluded that a

number of self-identified voice hearers associated positive experiences with their voices and that their voices were helpful in daily life, "…voices also gave them advice, solutions or they strengthened positive emotional states that hearers were feeling. Therefore, the influence of the voices was for the most part benevolent and this benevolence increased over time" (Faccio, *et al.,* 2012, p. 764).

Hearing Voices and Spirituality

Voice hearing in the context of spirituality may be a useful framework for people who do not subscribe to a strictly psychological or medical model. For some people, situating hearing voices as a spiritual experience may help lessen distress, and increase coping mechanisms (McCarthy-Jones, Waegeli, & Watkins, 2013). Historically there are examples of religious figures who spoke with God or who heard God's voice and in many cases they were not considered to be "crazy," but were instead valued for their gifts of communication (Gale, Robson, Rapsomatioti, 2014).

In the context of religion, people who speak about communicating with God are not necessarily seen as sick. Using a range of sources, Watkins (2010) has attempted to create a set of guiding principles to distinguish between voices that are spiritual versus psychotic in origin. He notes that voices are likely to be seen as spiritual in nature if they are, benevolent and gentle, occur in longer monologues and/or "discourses providing spiritual guidance," appear as a "heavenly choir," or from celestial or supernatural origins (e.g. God, angels, spirits) (McCarthy-Jones et al., 2013, p. 253). In opposition to this people who have experienced psychotic disorders have described their voices to be, extremely negative or hostile, make running commentary on the voice hearer's actions, thoughts, or feelings, make commands, and deliver threats for non-compliance (Watkins, 2010).

Of course these are not concrete differentiations of spiritual and psychotic voice characteristics. People who identify as spiritual and see their voices as such may have negative experiences hearing demons, while those with psychotic disorders may hear voices that are benign, pleasant, or helpful (Crowley & Jenkinson, 2009; McCarthy-Jones et al., 2013). A third criteria set to incorporate a level of emotional effect of voice hearing, "with spiritual voice-hearing being that which occurs in the absence of psychological suffering and social/occupational impairment, with life becoming more meaningful and the experience making the individual concerned with helping others" (Menezes & Moreira-Almeida, 2009; McCarthy-Jones, 2013, p. 253). Understanding the spiritual or religious orientation of each voice hearer will be important for treatment, especially if clinical and psychodynamic work is involved.

The previous data suggests that there are multiple ways to conceptualize hearing voices. Some cultures and religions attribute voices to a divine nature, while others conceive of voices as hallucinations caused by a brain disorder. The biomedical model searches for an explanation using a chemical and biologic lens, whereas the psychological reasoning of voices weighs life experiences such as individual, environmental, and social factors more heavily. The recovery model posits that labeling and pathologizing voices as an illness can be unhelpful for those struggling with mental health issues.

A recovery approach also suggests that eradicating voices is not necessary for treatment. The following qualitative study hypothesizes that people are able to derive value from hearing voices, and that analyzing these experiences might provide meaningful insight into voice presentation, content, and lived experience. The guiding framework for the study uses a recovery-based approach, which empowers those who hear voices to gain control over their lives by understanding their voices, without having to medicate them away. However, it should be

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stated that this researcher supports the decisions each person makes for their treatment. Many of

the study subjects found medication helpful in dealing with the emotional fall out of hearing

voices, and this allowed them further clarity to explore voice meaning and content.

CHAPTER III

Methodology

Research Purpose and Question

The purpose of this study is to learn more about how people who hear voices have learned to cope with their voices, and how they attribute the function or role of the voice(s) in their lives. Attaching the label of a mental or medical illness to explain the phenomenon of hearing voices can erase a sense of personal meaning or identity from the voice as it becomes attributed to an element of disease (Dillon, Read, 2013). Hearing voices is commonly seen as a serious symptom of mental illness, often treated with anti-psychotic medication (McCarthy-Jones, Davidson, 2012). This thesis contends that hearing voices is linked to dissociative symptoms related to traumatic experiences (Corstens & Longden, 2013; Bentall, Wickham, Shevlin, & Varese, 2012; Longden, Madill, & Waterman, 2012a; Read, van Os, Morrrison, & Ross, 2005; Shevlin et al., 2011).

This theory concludes that there are reasons why people hear voices, that the voices appear to convey valuable information and messages, and that the voice hearer is able to decipher this information, given the tools to do so and the right support (Romme, et al, 2011). While hearing voices may disrupt daily life for some people, others find value their voices, and the ability to draw meaning from these experiences creates access to a deeper understanding of the self. The following nine interviews demonstrate that many people who hear voices are able to find value in these experiences, and lead complete and fulfilling lives. Learning to understand

their stories supports those in recovery from extreme, altered states of consciousness, while ignoring the meaning of this expression serves to further isolate and pathologize the voice hearer.

Design

This researcher selected the narrative inquiry approach as the best method to answer this research question. This method focuses specifically on peoples' stories and their experiences of hearing voices. Because the research question asks about the unique experiences and coping responses of individuals, gathering data using a qualitative, narrative approach is the most appropriate tool. Tracy (2013) writes about storytelling aspect of the narrative inquiry approach, "Even when people lie, exaggerate, and forget (Riessman, 1993), narrative provides a window for understanding how others interpret a certain situation and create a reality that they, in turn, act upon" (p. 29). Qualitative studies generally require a minimum of 12-15 participants, however only nine interviews were collected for this thesis. The interviews consisted of eight semi-structured topics, which asked a total of 11 questions adapted from the Maastricht Interview (Escher & Romme, 2000). The reason for using this particular questionnaire will be discussed later on in this chapter.

The informed consent form and questionnaire were designed using person-centered language. This means using phrases such as "do you hear voices?" rather than "do you have auditory hallucinations?" Since this thesis topic focuses on people's lived experiences of hearing voices, being diagnosed, and/or being forcibly hospitalized and medicated, it has been very important to de-emphasize purely clinical language. Developing a quantitative survey would require applying a fixed language that would not allow the participants to define their own experiences, and would therefore limit their answers.

In November this researcher attended a three-day training for clinicians and allies

working with those who hear voices, sponsored by the RLC (Recovery Learning Community) of

Western Massachusetts and the Hearing Voices Network USA. The facilitators, Shaun Hunt and

Peter Bullimore, both identify as voice hearers who have been previously diagnosed with

schizophrenia. They were told they would not be able to have relationships, families, or hold a

job. Now they both work for the Hearing Voices Network in Sheffield, England, and are

sponsored by this agency to provide trainings for mental health professionals around the world.

The purpose of this training was on how to use the interview tool, the Maastricht Interview and

Construct for Voice Hearers (Escher & Romme, 2000).

Professor Marius Romme and Sandra Escher developed the Maastricht Interview, in

conjunction with Patsy Hage, a patient of Dr. Romme's. This interview tool is used to help the

voice hearer and the clinician gain a clearer understanding of what problems the voices represent

through recognizing the context and developmental history of the voices. Ultimately, the

interview, report, and construct are meant to help the voice-hearer uncover ways of coping with

voices by developing insight into what the voices are trying to communicate, who/what they

represent, and how they function in the person's life.

Corstens and Longden (2013) note, "In order to relate these factors to voice hearing, the

construct utilizes specific areas of enquiry (voice identity characteristics and content, triggers,

history of voice hearing, personal history of the voice hearer…" (p. 2) to determine the triggers

that may immediately precipitate the onset of voice hearing, and the environmental factors that

may put the voice hearer at risk for emotional and mental vulnerabilities. The Maastricht

Interview is separated into 15 sections, each topic asks an average of five sub-questions. During

the Maastricht Interview training Peter and Shaun explained that because the questionnaire asks

many detailed questions that may bring up unpleasant experiences of trauma and abuse, the interview tool has been designed for use over the course of several sessions between the voice hearer and their counselor. A written report is summarized from the interview. The report divides the interview information into sections that ask about the nature of the experiences (do the voices occur all the time or only in times of stress, etc.), characteristics of the voices, history of the voices, triggers, voice content, impact of the voices on the voice hearer, the voice hearers relationship and coping strategies with the voices, a section on any childhood trauma, and lastly the social network of the voice hearer.

The report is designed to use short, declarative sentences based exactly on what the voice hearer has said, without adding interpretations. The report is further condensed into the construct, and formulated in conjunction with the voice hearer. The construct attempts to translate what the voices mean, rather than compile a summary of information.

The following example illustrates the usefulness of the Maastricht Interview. At the training we practiced interviewing the facilitators and wrote reports and constructs from these interviews. This researcher has changed the identifying information in this example, leaving in just pseudonym first initial of the voice hearer. This is an example of a section from the report that the researcher wrote of one of the facilitators, summarizing the four main voices he hears, the tone of these voices and examples of what they say:

What do the voices say?

"… The soft voice can be calming, "like a friend." The soft voice can help J study, and when he plays music the soft voice can give J encouraging feedback. The annoying voice can have a similar sense of humor to J and can tell him jokes and make him laugh, but sometimes at inappropriate times such as a job interview. This voice can also say negative things about J, such

as, "Why are you doing this?" "You're crap." The random voice is often neutral and a "mish mash of sounds." The grisly voice is very scary and dark, tells J he is worthless, "you're a piece of shit" (Gabriner, 2014).

The construct takes the information gathered in the report and breaks it down further trying to understand what the voices represent. The information from the report has been simplified for the construct, and has been given meaning through interpreting what the voices mean:

Construct:

Soft voice is calming, "like a friend." This voice can help him study.

Annoying voice will sometimes tell J jokes and make him laugh. This can happen at inappropriate times. The voice also says, "Why are you doing this?" "You're crap."

Random Voice is always neutral and a "mish mash of sounds."

Grisly Voice says, "You're a piece of shit."

What they represent:

Shame, lack of control, sense of safety and love, self-loathing, guilt, and lack of family support.

The construct and report are useful tools for understanding where the voices come from and the purpose that they serve. This method, "summarizes core areas of difficulty, respects and refers to client views on accuracy and expediency, integrates systemic, social and/or political factors, is amenable to constant revision and re-formulation, and uses an available evidence-base to link theory with practice (e.g., the demonstrated link between voice hearing and psychological stress)" (Corstens & Longden, 2013, p. 5). The construct is co-developed with the voice hearer so that meaning is not imposed onto their experiences.

The voice hearer takes an active role in exploring what the voices represent in order to create an individualized treatment plan that encourages recovery. The Maastricht Interview and

Construct (Escher & Romme, 2000) fosters awareness that "…constructing meaning and narrative from distressing symptoms, including those in the context of psychosis, can help elucidate unresolved emotional conflicts and, in turn, promote hope, understanding, empowerment, reflectivity, and psychological adjustment (e.g. British Psychological Society Division Clinical Psychology, 2011; Johnstone & Dallas, 2013; Stainsby, Sapochnik, Bledin, & Mason, 2010)" (Corstens & Longden, 2013).

The Maastricht Interview and Construct are the foundations on which this study was built, and guides the theory of interpreting the unique stories of each voice hearer. Due to time limitations the full Maastricht interview, report and construct were *not* employed for the purpose of this study. Instead, the questionnaire used 8 of the 15 topics from the original interview, not including an introductory series of demographic questions (age, sex, race, marital status, employment, and housing status.) The questionnaire developed for this research project refrained from asking directly about experiences of trauma or childhood (sexual) abuse, however, some of the questions elicited responses that included experiences of trauma. The eight topics asked about the nature of the experience of hearing voices, including questions which asked how many voices the participant hears, memories of when the voices started, and whether they can carry a dialogue with the voice(s). It also asked for the participant to speak about voice characteristics, triggers, coping strategies, examples of what the voice(s) say, how the participant explains the origins of the voices, treatment history, and lastly the social network.

These eight topics were chosen because they cover a wide range of information about the experience of hearing voices without asking for details about traumatic life experience. One question in the interview asks, "As a voice hearer you have probably wanted to find an explanation for why you hear voices. Here we are interested with what you might think causes

the voices and how you identify them. Some people feel that voices can be related to trauma, do you connect to this?" This question allowed participants to give a "yes" or "no" answer, but follow-up questions regarding specific details about trauma were not asked. In a few cases participants chose to speak about traumatic experiences, and this topic appeared throughout the interview. Some participants answered interview questions at earlier stages of the interview. For instance, the first two questions asks the person to speak generally about their experience hearing voices, and then to speak about the first time they heard voices. In answering these first questions, several participants volunteered information about traumatic experiences, or answered questions concerning the onset of voices, specific triggers for the voices, or the use of medication, compelling this researcher to modify the order of interview questions.

Sample

The inclusion criteria for participating in this study requires participants to be over the age of 18, and to identify as someone who hears voices, regardless of the presence of a mental health diagnosis. Two participants never received a mental health diagnosis, though eight participants stated experiencing psychosis at least once. Seven participants have been given a diagnosis of schizoaffective disorder or schizophrenia, though only two participants identify with these labels. Additionally, eight participants hold multiple diagnoses including post-traumatic stress disorder, clinical depression, or (mild-severe) anxiety. One participant has a diagnosis of dissociative identity disorder as well as post-traumatic stress disorder (PTSD), and schizophrenia.

A variety of age, gender, sexual orientation, race and ethnicity were encouraged, however, due to the population of Western Massachusetts (the geographic location of all participants) and the nature of the project, finding a wide range identifying marks among

participants was not promising. Participation in this study was voluntary; interviews lasted on average between 30-60 minutes.

The following table documents the demographic information for all nine participants including their age, number of children, race or ethnicity, gender, marital status, housing conditions, and employment status. Seventy-seven percent of participants in this study are female identified, while 22% identify as male. Sixty-six percent of participants hold full or part-time jobs or student status. Sixty-six percent of participants are in long-term relationships or married, while 33% are single. Seventy-seven percent of participants either own or rent their homes, while 22% reside in subsidized housing.

Table 1

Demographic Information

Participants	Age	Children	Race/Ethnicity	Gender Identity	Marital Status	Housing Status	Employment Status
Hannah	25	0	Caucasian	Female	Partner	Rents	Student
Jules	35	0	Caucasian	Female	Partner	Rents	Part-time
Ezra	28	0	Caucasian	Male	Single	Subsidized	Unemployed
Sandy	61	1	Caucasian	Female	Married	Owns	Part-time
Robert	54	0	Caucasian	Male	Partner	Rents	Unemployed
Stephanie	27	1	Caucasian	Female	Partner	Rents	Part-time
Danielle	29	0	Caucasian	Female	Partner	Rents	Full time
Beth	53	3	Caucasian	Female	Single	Subsidized	Retired
Mara	43	0	Caucasian	Female	Single	Rents	Part-time

All nine participants are cis-gendered and Caucasian. One participant identifies as lesbian. They range in age from 25-61. Based on employment and housing status, the six participants who work part or full time and rent or own homes may fall into a middle class socio-economic bracket, while three of the participants who are either unemployed, or use subsidized housing may have a lower socio-economic status. However, it is unknown if participants rely on further financial assistance from the government or if they have financial support from their families.

Recruitment

      After receiving approval from the Human Subjects Review Committee (Appendix A), recruitment for this study began through word of mouth, and an email advertisement (Appendix B) sent to the clinician's at this researcher's internship agency. Ultimately only nine interviews were completed. Two participants were recruited after speaking directly to this researcher about the study. One of these participants was located through the Maastricht Interview training attended in November, while another is a friend of the researcher who expressed interest after hearing about the topic. After some difficulty recruiting participants, an amendment to the original proposal was submitted and approved (Appendix B), allowing an advertisement to be posted on Craigslist (Appendix B).

      This advertisement became the most successful tool for recruitment in this study. When a potential participant responded to the ad this researcher emailed them a copy of the informed consent form to read and make an educated decision about participation. Four participants were found using Craigslist, while three others emailed stating their interest, but never responded to subsequent emails. This researcher did not push people to participate if they did not respond to the follow-up email. Two other participants were found with help from the coordinator of the peer support services at ServiceNet who connected this researcher with two peer advocates who run a Hearing Voices group in Amherst, MA.

      The approved amendment (Appendix B) to the Human Subjects Review Committee also allowed this researcher to reach out to local mental health organizations and present this thesis at the weekly meetings of two local clubhouses (The Green River Club in Greenfield and the Starlight Club in Florence) where all members of the clubhouse are peers who experience some form of mental illness. One participant was found through this method. This researcher met with

two facilitators of a Hearing Voices group in Northampton operating through Windhorse Integrative Mental Health. The director of the Greenfield Recovery Learning Community (RLC) helped distribute the informed consent form to members of the organization, though neither of these prospects garnered participants, one person expressed interest but did not respond to an email asking to set up a time to meet.

Ethics and Safeguards

To ensure participant confidentiality, all identifying information including names has been changed. Four interviews took place in public, semi-private locations and two interviews were conducted over the phone from the privacy of the researcher's home. This researcher conducted two interviews in a private study room at the Smith College Nielsen Library. One participant was interviewed in her office, located in a ServiceNet building in Northampton, while another participant came to the researcher's office in the ServiceNet Outpatient Clinic in Greenfield.

Although this researcher initially stated that she would not conduct interviews in a participant's home due to safety concerns, three of the interviews did take place in the participant's home, where the researcher used judgment to determine her own safety. Two of these interviews occurred in the participant's home due to limited access to phones and the ability to travel. In one case the PCA of an interviewee stayed as a safety measure (for a participant who had physical needs) throughout the interview. This was an event the researcher had not foreseen occurring, and therefore there was no area on the informed consent to accommodate this. Instead the researcher asked for verbal consent from the participant and proceeded from there.

Participants read and signed the informed consent form (Appendix C) to confirm they were aware of the risks and benefits of participation in this study before the interview began. Eight interviews were recorded using a portable audio recorder. The informed consent form gave participants the option to be interviewed but not audio recorded, and only one participant chose this option. The researcher wrote down the interview responses in a notebook, which was stored in a locked desk. Before audio recording began participants were told verbally and in writing that they were able to stop the interview at any point, they did not have to answer any questions they did not want to, and that they were able to pull their information from the study at any point up until the date specified in the informed consent.

The audio recordings were then transcribed, and all identifying information was removed or changed to maintain participant confidentiality. Transcriptions and audio recordings were kept on a password-protected computer. Following Federal Guidelines the information will be stored on this device for up to three years before it is destroyed. Participants were informed that there would be no monetary or gift compensation for taking part in the study. They were made aware that benefits of participation included the possibility that their stories could provide insight to the mental health profession and mental health community at large regarding treatment opportunities for those who hear voices.

The interview questions (Appendix D) ask participants to speak about various life experiences, some of which have the potential to bring up upsetting memories or feelings. Participants were encouraged to contact their support network(s) in case they left the interview wanting emotional care. This researcher offered participants a list of local resources (Appendix E) they could contact if they were feeling vulnerable after the interview. The resource list includes a peer run crisis hotline in addition to the CSO (Clinical and Support Options) crisis

phone number, as well as location and contact information for hearing voices support groups, and recovery oriented communities. If a participant was connected to the ServiceNet organization, a referral back to the participant's clinician was offered. All but two participants declined the resource list.

Data Analysis

The method used for coding and analyzing data was borrowed from "The origins of voices: links between life history and voice hearing in a survey of 100 cases" by Corstens and Longden (2013) who note, that, "no established method exists for assessing links between life events and voice phenomenology…" (p. 5). In order to understand the data collected from the constructs, Corstens and Longden (2013) used a variety of references to code the constructs, including theoretical and empirical literature, the work of Romme and Escher (2000) and clinical knowledge. Using these orientations, five topics were established and coded according to specific criteria. Because the study constructed for this thesis project was an altered version of the original Maastricht Interview and Construct (Escher & Romme, & Hage, 2000) some very specific data relating to characteristics of voices and life experience were not collected. Corstens and Longden (2013) created the categories for analysis, from which they were able to code for voice content and characteristics, triggers, history of the voices, and who or what the voices represent.

Content was coded based on, and adapted from, the work of Corstens and Longden (2013). For the purpose of this research project coding for voice content and characteristics focused on "commanding, criticizing, threatening, making premonitions, interacting with one another, making direct references to trauma, speaking in a foreign language providing advice or encouragement" (Corstens & Longden, 2013, p. 5). In creating my own codes this writer created

simplified sub-categories, coding commanding and criticizing characteristics as "negative/unfriendly," and helpful or encouraging voices were coded as "positive/friendly." A "neutral" code was established for people who didn't categorize their voices as negative or positive. This researcher did keep separate codes for voices speaking in foreign languages and voices that made premonitions.

While the researcher tried to stay true to the model of coding used by Corstens and Longden (2013) she found pieces of information that were not taken into account by their coding structure. For instance, it was important to create a code for the emotional impact voices had on the voice hearer, as many participants made it clear that hearing a particular voice, whether or not it was negative or friendly could result in more emotional stress, unrelated to the content of the voice itself.

Triggers were coded for "specific circumstances (e.g. social situations, a particular room in one's home) and/or particular emotions (e.g. guilt, shame, anger). Data were coded as "not identifiable" if there were no obvious triggers for voices" (Corstens & Longden, 2013, p. 5). The section on voice history "refers to proximal life circumstances that precipitated voice onset (i.e., events that occurred within six months prior to voices first manifesting)" (Corstens & Longden, 2013, p. 5). Coding for this section included interpersonal stressors such as, physical or mental illness, family conflict, bereavement, relationship break-ups, experiencing excessive criticism, and witnessing violence. Experiences that do not fall into these categories will be labeled "other." Lastly, the section on what the voices represent will use the following coding to understand the emotional significance of the voices: shame and guilt, self-esteem, anger, comfort and safety. Data were coded as "not identifiable" if there was no clear correspondence (Corstens & Longden, 2013).

In order to analyze this unstructured data, the researcher used a computer program called NVivo, which allowed her to upload the interview transcripts, create codes and subcategories, and sort the information accordingly. While the basic coding structure taken from Corstens and Longden (2013), the researcher discovered that categorizing elements of these interviews into one code was not as simple as it initially appeared. While the researcher wanted to code information without bias, she was in the position of having to interpret what category a specific phrase or interview section belonged in. For instance, when one participant explained that when she feels negatively about herself (a self-identified trigger for the voices) one voice in particular can be comforting and say that she is beautiful and misunderstood by others. So this example could be categorized under "triggers," as well as "voice content," and "coping." The process of coding the same phrase into multiple categories occurred multiple times throughout the data analysis process.

This researcher created two subcategories, voice frequency and voice quality under the code "voice characteristics and content," as another method to organize the data. Voice frequency refers to how often the person hears the voice, i.e. daily, in times of distress, or a singular event. A code titled "voice quality" was developed in order to separate data from individuals who gave descriptions of how the voice spoke, unrelated to the content of speech. Voice quality refers specifically to times when people described the voices having a particular identity, such as a name, or if the voice seemed familiar in some way, rather than completely random. Many people spoke about times when the voices took on a certain characteristic in tone and rate of speech. However, they did not assign these qualities to positive, negative or neutral.

CHAPTER IV

Findings

The idea that voice hearing is related to dissociation and trauma (Morrison, Frame, & Larkin, 2003; Read et al, 2005) rather than only a symptom of psychosis or schizophrenia is the theoretical foundation for the study. This framework presents the notion that hearing voices does not exist in a vacuum of psychosis, but is connected to lived experiences. Understanding these experiences can provide relief and lead to positive changes for the voice hearer. The major question asked in this thesis is: how do people who hear voices draw meaning from these experiences? What role does trauma and dissociation play in how the voices manifest? And, can voice content be metaphorical? Just as grief is known to be a natural psychological and physiological response to loss, psychosis and hearing voices may be seen as a natural response to various degrees of abuse and suffering (Cooke et al., 2014). In a 2013 TED talk, Eleanor Longden, a voice hearer, academic, and researcher on the subject of hearing voices, speaks about her experience as "a sane reaction to insane circumstances."

The findings of this study suggest that people who hear voices are fully capable of finding meaning in their voices, and that this may be a profound, and integral part of recovery. In *Living with Voices, 50 Stories of Recovery* Romme writes,

> In these stories recovery is shown to mean functioning well and being independent in the circumstances people have chosen for themselves. It means finding a purpose in life- a personal and social recovery- not a clinical recovery where eradicating the voices is the main issue in the recovery process. The stories are good examples of how getting rid of voices is neither necessary, nor that important. Many of the fifty people kept their voices

but changed the relationship in a way that the relationship became helpful ones. All got

rid of the distress from their voices because they changed their relationship with them.

(p.7)

The tables in this chapter serve as a visual summmery of the information gathered from

research participants. The six tables display the percentage of responses to each set of questions,

which are as follows: frequency of voices, the onset of voices including age and precipitating

factors, voice content and characteristics, triggers for the voices, and methods of coping. Each

table presents the data as it was coded from the interview transcripts. This table illustrates the

percentage of frequency with which participants reported hearing voices. Out of nine

participants, 63% hear voices chronically (throughout the day), while 9% hear voices

infrequently (less than once a day), and 9% heard voices during one incident.

Table 2

Frequency of Voices

Frequency of Voices	N	%
Chronic (daily or weekly)	7	77
Intermittent (isolated events)	1	11
Singular Experience (occurred once)	1	11

Hannah describes only hearing voices during brief, psychotic episodes. Robert explained

that he heard voices on two isolated incidents, and identified these moments as the beginning of

his illness; since starting treatment he has not experienced hearing voices again. While all

participants besides Danielle have experienced psychosis or been hospitalized for other mental

health issues, seven participants do not consider their experiences of hearing voices only as a

symptom of psychosis or schizophrenia. Sandy, Stephanie, Mara, Jules, Ezra, and Beth describe

hearing voices on a daily or weekly basis and note that at times of extreme mental

distress their voices are likely to become louder, more intrusive, and negative in content (2013, p. 5).

While at least Sandy, Jules, and Robert identify as Christian and Ezra identifies as Orthodox Jewish, their understanding of what it means to hear voices all fall within border of "mental illness." Each person has a different relationship with their voices, and some participants, such as Sandy and Stephanie even had close relationships with voices they found particularly helpful or comforting. However, while all nine participants have been impacted in different ways by hearing voices, some commonalities emerged through data analysis. Eight participants gave an explanation that trauma is related to why they hear voices or have experienced extreme mental distress. Participants also shared treatment models and coping techniques. For instance, seven participants found medication to be helpful in managing the negative effects of hearing voices, and all interview participants stated that supportive friends, family, and providers were essential to their treatment and recovery. While seven participants had at one point been given a diagnosis for Schizophrenia or Schizoaffective disorder, two participants, Sandy and Danielle have never received a psychiatric diagnosis related to hearing voices.

Eight participants said that at one point voices had provided a negative emotional impact, regardless of whether negative content was present. However Sandy, Stephanie, Mara, and Ezra also had positive experiences and did find some of their voices to be helpful. And while both Robert and Hannah reported that their voices were neutral, neither good, nor bad, the effect of hearing the voices was frightening.

It is important to note that eight of the nine interviewees identified traumatic experiences in childhood (as well as in adulthood) as contributing to their mental and emotional distress.

Eight participants said they felt trauma was directly related to their experiences hearing voices. Understanding and coming to terms with trauma may be vital for understanding and coping with hearing voices. This study concludes that each participant has a unique understanding of the significance of hearing voices, as well as how these experiences have shaped their identity and their relationships with others. The experience of hearing voices extends beyond the content of voices to treatment received, access to resources, and whether participants have a supportive network of treatment professionals, friends, and family.

A total of nine people were interviewed either in person, or over the phone. The shortest interview lasted 11 minutes, while the longest interview concluded just after an hour. The average length of time for interviews was 40 minutes. Demographic data of participants have been summarized in the methodology chapter. The research questions were carefully adapted from the Maastricht Interview (Escher, Hage, & Romme, 2013). The questionnaire asked participants to speak about hearing voices in a way that could provide a detailed history about their interactions, relationships, and perceptions of the voices without asking participants to speak about specific traumatic experiences. Judith Hermann (1998) writes, "The telling of the trauma story inevitably plunges the survivor into profound grief. The descent into mourning is a necessary but dreaded part of the recovery process" (p. s148). Hermann refers here to the beginning stages of recovery, however, any time trauma is recounted could result in re-traumatization for the survivor.

This researcher believes that if questions relating to significant or traumatic experiences in childhood had been raised, a much fuller picture of what it means to hear voices and how participants make meaning of those voices could be revealed. This constraint is one of the major drawbacks to this study. In order to fully "make sense" of the voices a complete history must be

present. Because of the limitations of this study only fragments of this image exist. It is not this researcher's intention to make interpretations for the voice hearer. A number of participants were interested in uncovering what their voices mean, and provided useful insight into what they believe their voices are trying to communicate. This information will be presented in the discussion chapter.

All participants currently reside in Western Massachusetts, an area of the country that has a fairly expansive recovery community including multiple groups sponsored by The Hearing Voices Network. This is a peer run support group, which operates in 4 locations throughout Hampshire, Hampden, Berkshire, and Franklin County. All participants had at one point or another been connected to peer run recovery and support services. The recovery community has provided useful resources and skills to several of the participants, including three who facilitated hearing voices support groups in separate locations around Massachusetts. Access to peer led support groups connects people who hear voices or experience extreme states of consciousness with each other and might normalize frightening and isolating experiences.

Building connections with other voice hearers offers multiple perspectives on coping and recovery strategies that would otherwise be inaccessible for those navigating traditional mental health channels. According to the official Hearing Voices Network USA website, registered support groups exist in 18 states across the country, though 12 of these states offer less than five groups. Pennsylvania hosts seven registered groups, while Massachusetts holds eleven groups across the state (2011-2015, http://www.hearingvoicesusa.org/hvn-usa-groups-list/list/1).

While eight people had at least one experience seeking professional treatment for hearing voices or other mental health challenges, Danielle was the only participant who had never sought treatment for any kind of mental health issue. Danielle was the outlier in nearly all her responses

as she identified her overall experience of hearing voices as neutral and benign. Danielle's experience was unique on multiple levels, as she did not consider childhood trauma to be a factor in hearing voices and she was also the only participant who spoke about other family members hearing voices. In this case Danielle's mother reported hearing voices herself and told Danielle that this was "normal." Though Danielle hears voices on a weekly basis, she does not feel the voices have disrupted her life, other than times when they shout her name as she falls asleep.

The British Psychological Society Division of Clinical Psychology has compiled a report titled, "Understanding Psychosis and Schizophrenia: Why people sometimes hear voices, believe things that others find strange, or appear out of touch with reality, and what can help" (2014). They write,

> A number of surveys have revealed that many people hear voices regularly. Most of these people have never thought of themselves, or been thought of as mentally ill. The main thing that appears to distinguish them from those who come into contact with mental health services is the extent to which they, or those around them, find the experience distressing or frightening (p. 15).

Danielle seems to fall into the percentage of people who hear voices and are otherwise untouched by psychological distress. Another outlier in this study was Beth, who has a diagnosis of dissociative identity disorder (among several other diagnoses). She was the only participant who asked not to be tape-recorded during the interview. Beth told this researcher that her therapist has discovered 28 "alters" who reside within Beth. Beth's responses to each question were not always clear, and it didn't become apparent until close to the end of the interview when Beth explained she hears multiple sets of voices. Beth referred to these as her "inside voices" and "outside voices." She clarified that her "inside voices" are those of her alters, who might speak to

her throughout the day. Beth said that many of her alters are protective of her, as well as comforting. However, Beth identified the "outside voices" (external voices that appear when Beth's core personality is present) as always critical. Beth is almost constantly in a highly dissociative state. This researcher asked if Beth was aware if any of her alters hear voices, but she was unable to answer this. Beth does attribute her dissociative personality and additional voices to severe childhood abuse.

Onset

These two tables document the results of what age participants first heard voices, as well as if they remember what was occurring in their life prior to the onset of hearing voices. Table 3 shows that 22% of participants started to hear voices in childhood, 33% first heard voices during adolescence, while 44% of participants began to hear voices as adults.

Table 3

Age Voices Began

Age when voice(s) began	N	%
Childhood	2	22
Adolescence	3	33
Adult	4	44

Table 4 shows that 22% of participants identified a traumatic experience occurring before the onset of their voices, while 22% attributed a significant loss such as losing a relationship as a factor to first hearing voices. Another 22% stated that they first heard voices during a psychotic break, and 33% of participants could not identify an event or feeling that precipitated hearing voices.

Table 4

Onset of Voices

Onset –Was there a precipitating event?	N	%
Traumatic experience	2	22
Significant loss	2	22
Psychotic episode	2	22
Not Identifiable	3	33

It is important to understand that hearing voices exists within a context of life history. Eight participants said that their voices had changed significantly since the onset; nine participants responded that the number of voices they heard fluctuated, while seven reported that some voices became more or less dominant and antagonistic. This question is further addressed in the section of voice content and characteristics. However, because an adaptation of the Maastricht Interview (2014) was used, questions about hearing voices focused more on the present. The full version of the interview tool would ask participants to elaborate on and explore in detail how their voices changed over time.

Of the nine people interviewed, Hannah is the only participant who only hears voices during reported "psychotic breaks." Hannah said she's had many psychotic episodes since she was 13-years old, each of these psychoses occurred in tandem with severe depression, and on more than one occasion resulted in inpatient psychiatric hospitalization. Hannah suspects she was hearing voices for a several years before she was able to identify them as voices. But she remembers the first time she was conscious of hearing voices. It was the last day of middle school:

I was extremely depressed and was living in the house with my abusive father, and um, I wanted to die. And I didn't have any sense of reality, I remember like rolling on the floor, um, and thinking that like, you know that thing that happens when someone is suicidal and there are intrusive thoughts, you can look at anything, your mind processes, 'how

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can that kill me?' You know? Anything. So while this was occurring it was just like

conversations in my ear, where there weren't any, just nothing to do with me at all, but

just, occurring (Hannah, personal correspondence, 2014).

Mara, Jules, Stephanie, Ezra, and Beth all report hearing voices chronically or on a daily

basis. However, for those participants who have multiple voices, many of them reported that

certain voices appeared with more frequency than others. Danielle and Beth said they have heard

voices since they were children, and both women described that while there had been an

evolution of voices since the initial onset, they are unable to distinguish how many voices they

used to hear and how these voices have progressed to the present day. Neither of these women

remembered exactly how or when their voices had started.

Robert was the only participant who reported two isolated, brief incidents of hearing

voices and both times he identified hearing the voice of God. Robert heard God for three nights

in a one-week period when he was eighteen, and again for a few moments when he was nineteen.

Robert said that at this time he was drinking alcohol and smoking marijuana with his friends. He

remembers trying a "funny tasting pot" the night he first heard the voice of God, though he

doesn't believe this had anything to do with beginning to hear voices. To this day Robert cannot

pinpoint whether there was a reason why he started hearing this voice. Robert was later

diagnosed with paranoid schizophrenia and spent several years in a state mental hospital. When

he speaks about his relationship to trauma, recovery, and coping, he is referring to recovery from

paranoia and delusional thinking.

Seventy-seven percent of participants stated that they were going through stressful life

changes at the onset of hearing voices and were vulnerable to depression, anxiety, and psychotic

episodes during these times. Of these participants 88% said their early voices dominated with a

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negative or aggressive tone, though most participants heard multiple voices at once, which oscillated between positive, to neutral, to negative. Ezra, Jules, Mara, and Stephanie all describe multiple weeks of paranoid or unusual thoughts that precipitated the onset of hearing voices. Jules, Sandy, and Ezra experienced significant loss and change at the onset of hearing voices.

Stephanie struggled with mental health issues since she was a teenager, and has been hospitalized multiple times for depression and mania. She remembers that when she was younger and had more energy she would hear "fun voices" during manic episodes that were similarly outspoken to her personality. Then Stephanie would be hospitalized and medicated, and the voices would retreat. About 6 or 7 years ago Stephanie started to hear voices regularly. She suspects this incident was triggered by lack of sleep, which plummeted her into a deep psychosis she had never experienced before. This was the beginning of Stephanie's battle to find meaning within psychosis and hearing voices, without pathologizing these experiences:

> I was really losing touch with reality for a while, and I ended up in my favorite spot
> in Barnes and Nobles and I was drinking coffee, I was standing by the window and I
> heard this voice start singing, 'happy birthday Mary Magdalene.' And- yeah, it was
> really dramatic for me. And then I remember going to the bathroom and all these, it
> was fast, other voices started. There was a couple and then there was a couple more.
> There were so many back then. After the Mary Magdalene thing there was all this stuff
> about the "new world order" and it was confusing. So I was getting mixed
> messages at the time whether I was Mary Magdalene, and I thought these voices were
> from Jesus. And, I believed they were married. And there was this other moment later
> that I'm thinking that the government is doing this to me (Stephanie, personal
> correspondence, 2015).

Jules had just begun college and believes that being in a new environment coupled with sudden separation from her close-knit family triggered the onset of her voices. Jules identifies the voices she hears as other people thoughts. It is impossible to say how many voices she's heard over the years and how they have changed, because her voices are so dependent on where she is physically located. Ezra's memory of the onset of hearing voices is difficult for this researcher to follow. Throughout the interview he changed his timeline, adding and shifting elements to his history. His method of telling this story seems equally chaotic and confusing to what the experience of first hearing voices may have been like. As this researcher attempted to clarify his interview responses, Ezra gave increasingly abstract descriptions. What follows is this researcher's attempt at assembling a linear timeline from a chaotic, and disjointed experience that involves two major breakdowns, each resulting in hospitalization.

Ezra first heard voices at the age of twenty-four after his fiancé ended their engagement. Ezra believes that a significant event is that he started smoking cigarettes, as this is when he first became "symptomatic." Though Ezra is not certain how smoking is related, he offered the explanation that perhaps he is allergic to tobacco. Ezra then started having bizarre thoughts, believing his TV was sending him messages. After smoking marijuana on a road trip he describes first hearing the voices. Ezra said that "something shifted," he started asking questions of a philosophical nature and receiving answers. At the time, Ezra was a doctoral graduate student but once he started hearing voices, he could no longer concentrate and dropped out of his program. Ezra became depressed, which worsened when he was unable to find work. Eventually he fell into a catatonic state that ended after an involuntary psychiatric hospitalization.

Sandy spoke about becoming aware of hearing voices when she was thirty years old, though she suspects she had been hearing voices for much longer than this without being

conscious of their presence. The first time Sandy noticed her (current) voice was after using an Ouija board to contact spirits with her first husband. Sandy remembers this as a destructive period in her life when she was "partying a lot," and her husband was emotionally abusive. Sandy's voice appeared during an incident with the Ouija board, when she began seeing letters from the board appearing in the air and hearing a voice that called himself Michael. This struck Sandy as significant because a few years prior her friend Michael had died in a sudden, and tragic accident. The voice eventually told Sandy that they didn't need to communicate through the Ouija board anymore, and that's when he "moved into" her head. Though Sandy now has a good relationship with this voice, she remembers him ordering her to do things she didn't want to do, and saying very damaging things about herself.

Mara first heard voices when she was eighteen years old, after an uncle was verbally abusive towards her. Mara recalls that due to her previous trauma history, the conversation with her relative caused her to emotionally breakdown, and she eventually lost touch with reality. She believed that World War III was going to break out in her hometown, and that she was an undercover cop. Mara started hearing multiple voices at this time, she describes that during this period of time she "stopped living," meaning that she was unable to care for herself, and she stopped sleeping, eating, and bathing. After trespassing on a neighbor's property, she was placed in a psychiatric hospital and diagnosed with schizophrenia. Currently, Mara hears at least three voices, and has a positive relationship with two of them. Mara says the voices she hears now are some of the original voices that first appeared.

Eleanor Longden (2013) empathizes that when she started treatment for hearing voices, it was the voices that were the scariest and meanest to her that needed the most compassion. She comes to this conclusion after learning to think about her voices as parts of herself that needed to

be expressed, but had been suppressed. Longden (2013) speaks to the fact that negative voices may reflect words or ideas from an abuser. They can also represent ways the voice hearer felt during the abuse, or his or her feelings as a result of the abuse. A frightening voice telling the hearer that he or she is going to die, or is in danger, may have to do with feelings of fear and safety. A voice that says the person is worthless may be a reflection of his or her feelings of self-worth. Moments of extreme psychological distress coupled with lack of emotional support, and a history of abuse, neglect, and trauma can make it very challenging for the person hearing voices to understand what is happening to them.

One ideal outcome from use of the Maastricht interview is to help people learn about who or what the voices represent in order to help change their relationships to these voices. However, this level of comprehension is only possible when a full history of life circumstances including trauma is discussed. Four of the participants, Mara, Stephanie, Hannah, and Sandy spoke freely about what they thought their voices could represent. These participants' thoughts on their voices will be presented in the discussion chapter.

Table 5 presents the outcomes for how interview participants experienced the tone and quality of their voices, as well as if they had visions or heard sounds that differed in nature form their voices. While 55% of participants reported hearing at least one positive voice since the onset, 100% of participants reported having either unfriendly voices, or negative experiences with voices. Fifty-five percent of participants stated hearing a neutral voice, and 66% of participants heard non-human sounds in addition to hearing voices. Seventy-seven percent of participants had experienced visions at one point. All participants described their voices having a negative emotional impact on their lives.

Content and Characteristics

Table 5

Voice Characteristics

Voice Characteristics	N	%
Positive/Friendly	5	55
Negative/Unfriendly	9	100
Neutral	5	55
Sounds	6	66
Visions	7	77
Negative Emotional impact of voices	9	100

This section served to understand as much information about the person's history of hearing voices by asking questions relating to how their voices currently present, and how they have changed over time. Questions were raised about how many voices participants heard, the frequency of each voice, and the tone and quality of the voices (do they shout, whisper, sound angry, etc.) Interviewees were asked to describe if their voices had names, genders, or ages, and if they felt their voices had been positive and friendly, negative and unfriendly, or neutral. Additionally, the interview addressed questions regarding the presence of other sounds (non-human noises), and whether participants ever had visions. In this section participants were also asked to speak about their relationship to their voices and whether they have been able to hold conversation or dialogue with their voices.

One hundred percent of participants stated that they're relationship with their voices and the voices themselves had changed over time. Eighty-eight percent of participants said that at one point or another they heard multiple voices. Robert was the only participant who was very clear that only one voice had ever been present, and he heard this voice only on two separate incidents when he was aged eighteen and nineteen.

Stephanie, Mara, Robert, and Ezra, 44% of participants, were able to identify names for some of the voices. In Mara's case, she has named the voices herself, while Stephanie, Robert,

and Ezra were informed of the voice's identity by the voice. Danielle's voices do not have names, and Beth was unable to answer this question. During the interview with Hannah, she answered questions about her voice's identities that she had never considered before. Most notably, Hannah recounted that she often hears a younger man and an older woman speaking to each other, though sometimes a third voice is present. Hannah described her voices as "haughty" and "high society," yet they never address her directly, and she feels that she is eavesdropping on them. Hannah is unsure if her voices have remained the same over the years, or whether each psychotic episode brings about a new set of voices.

Positive/Friendly

Seventy-seven percent of participants said that at one point they had at least one friendly voice, including Ezra, who received advice from the voice he identifies as the voice of God. Ezra could ask the voice philosophical questions and the voice helped him to get rid of excess material in his life. Ezra also spoke about early experiences with his voices, when they would remind him to take care of important tasks so he wouldn't worry about them later on. Sandy's voice helped her change her lifestyle and stop "partying" as much. Though her voice commanded her in ways she didn't like and sometimes told her to do things she didn't want to do. It also helped Sandy divorce an abusive husband and check into a hospital when she wasn't taking care of herself.

Stephanie, Mara, and Sandy found that some of their friendly or positive voices were very helpful in supporting them through difficult moments. Often these difficulties included dealing with the emotional fallout of depression, stress, or negative voices. Mara described one of her comforting voices as a middle-aged male named Van Gogh. Mara said she talks to this voice, "when I'm really upset and the voices says I'm beautiful on the inside and the world

misunderstands me" (Mara, personal communication, 2015). Stephanie describes a voice she hears called Mary Magdalene who Stephanie finds to be extremely comforting, although she believes that this voice has also changed somewhat over the years. When Stephanie was first diagnosed with schizophrenia and hospitalized as an adult she was hearing voices that told her she was Mary Magdalene. Now Stephanie says, "I usually hear her at least once a day, but I wish I heard her more, like it's a very guiding voice. She always has the wisest wisdom. She's definitely very calm, and very like, comforting, and not like mother at all, but like a spiritual figure. I can't explain it and she doesn't say religious things at all. I can't explain it (laughs)" (Stephanie, personal communication, 2015).

Neutral

Sixty-six percent of participants reported hearing at least one neutral voice. Danielle stated that her voices have always been neutral and have not changed tone. Robert also felt that the voice he heard spoke to him in a neutral tone, even though it gave him commands. Sandy and Stephanie also recall hearing neutral voices at times, though in Sandy's experience, her voice sometimes alternated between negative and neutral tone and content. Stephanie has heard many voices since the onset, many of which have disappeared, though she knows a portion of these voices have ben neutral. Hannah stated that her voices have always seemed neutral although she can't remember specific dialogue. In the past Hannah has struggled not to listen to her voices, as she finds the experience confusing and upsetting. At the end of her interview Hannah stated that if she did ever hear voices again she might try and pay more attention to what they are saying.

Negative/Unfriendly

One hundred percent of participants reported having some kind of negative experience with voices, either through content or impact. Danielle said that the only negative part of hearing

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voices for her is if they disrupt her sleep, and Hannah spoke about the very negative emotional

impact of what it meant for her to hear voices, though both women described the content as

neutral. Robert was another participant who spoke about how the content of his voice was

neutral, though the outcome of hearing voices was negative. This is because the voice Robert

heard identified itself as God, and Robert did not feel he could disobey God. Though Robert

heard this voice on two occasions, he believes it was the beginning of a much longer illness

involving delusional and paranoid beliefs. The voice gave Robert commands to take off his

clothes in public, which eventually caused him to be hospitalized for three years in a state mental

hospital.

The most common scenario occurring for 55% of participants was to hear a combination

of benign or friendly voices, interchanging with critical voices throughout the day. All

participants who spoke about voices that were negative in content said that their voices are

highly critical of them, and make mean and derogatory comments. Stephanie and Mara both said

they hear a dominant, male voice that is loud and aggressive on a daily basis. Mara reflected on a

time before she had good techniques for dealing with her critical voices, "I mean, it got to a point

where like I said, I was yelling at the top of my lungs in my kitchen, and was like throwing

punches in the air, they were attacking me, and saying, just oh my gosh, saying really bad things

about me constantly, constantly. And I um, I just got really upset and threatened them. It was just

a terrible time" (Mara, personal communication, 2015).

Sandy and Ezra spoke about voices that shifted between helpful or neutral to negative and

threatening. Sandy recalls years ago, when disobeying her most dominant and angry voice

caused her to have severe headaches that felt as if her head would explode. Jules says she always

hears voices that are critical of her. These voices take on the form of family members, friends,

and co-workers. Sometimes she will also hear the voices of strangers if she is in public, and these voices comment on Jules's actions in the third person. Beth was the only other participant who stated that her voices are always negative. This researcher did not press Beth to speak in further detail about the content of her voices as she said that the more she speaks about them, the crueler they become.

Ezra said that his voice(s) have changed significantly over the years, oscillating between helpful and negative. Although he said that right before his second major break, when he was coming off of medication his voices were "pretty friendly, But as I started getting to a rut, then they became less friendly and more antagonizing" (Ezra, personal correspondence, 2015). This might imply that for Ezra his voices are affected by what else is happening in his life. Rather than seeing voices as dictating positive or negative moods or emotional states it seems likely that life circumstance also shape the path the voices take. Sandy had a similar experience with her voice, though it sounds like Sandy's relationship to her primary voice had also evolved quite a bit over time. She told this interviewer about an incident when she became scared of her voice and sought help for this, though while she was hospitalized her voice would sometimes ask how she was feeling. Sometimes Sandy tried to talk to her voice and ask it to go away, to which it would reply, "I can't do that right now." When asked about the evolution of her relationship to her voices she said,

> …It was a long roller coaster ride of going back and forth between scary and friendly, scary and friendly. Um cause this all started at the very end of 1983, we were getting a-long pretty well through 1984, with a few times that were weird though. Like telling me to go home and go to bed when I was on my way to work. That happened towards the end

of 1984 and um, probably by 1985 everything was good (Sandy, personal

correspondence, 2015).

Sounds

Sixty-six percent of participants described hearing other sounds in addition to hearing

voices. Danielle said that she sometimes hears sounds but not often. Danielle also thinks that

sometimes her voices speak a foreign language she can't decipher. Ezra described hearing, "a

ringing in the back of my ear. It sort of goes on and off." Although, when asked for an example

of what his voice says now, Ezra said, "um it's sounds, it's not really saying things anymore, it's

more like buzzing sounds" (Ezra, personal communication, 2015). Jules said that in the past

she's heard electrical shocks and electricity. Jules also described an isolated time in her early

twenties when her voices became extremely positive and during this period she also heard "robot

voices and machine voices" (Jules, personal communication, 2015). Stephanie said that in

addition to the voices she sometimes hears the sounds of her upstairs neighbors having sex. And

Beth describes hearing "bangs and swishing sounds." She adds, "There is some hearing loss in

the right ear so the voices and sounds are louder in the left ear and then travel across my head

from right to left" (Beth, personal communication, 2015).

However these participants did not specify how long they hear these sounds for, or if they

always or sometimes occur in conjunction with other voices. Hannah had an interesting

description of hearing other sounds in addition to her voices. She described the sounds as a,

"hallucinatory unreality," elaborating on this notion that the voices are situated in a context.

"Like we're talking right now, and you just clicked your pen. That's part of the context, so, yeah.

So, with the audio hallucinations it feels so real and it seems so real that it's confusing because

there is context. Contextual noise." The researcher asked, "Would you say kind of like background noise?" "Yeah!" (Hannah, personal communication, 2015).

Visions

Of the 77% of participants who reported having visions, 33% said they have somewhat regular visions, while Robert, Ezra and Hannah spoke about infrequent visions that occurred once or twice. Sandy describes her visions as "psychic dreams." Sandy elaborated that she'd had many vivid dreams over the years where she was given a premonition that later came true. When asked about whether she has had visions Mara responded that she, "sees things other people can't see." Mara spoke about a sustained vision, which sounds like the embodiment of one of her comforting voices. The vision appears as a man who holds her on the couch when she becomes upset. Mara described this person as someone she feels close to, and who acts like a friend or a partner. Stephanie on the other hand talked about very frightening imagery, "occasionally I'll see something that's like disturbing. Like, I'll see somebody's head being cut off, like when they're standing right there and they're not having their head cut off…" (Stephanie, personal correspondence, 2015). During the brief episodes when Robert heard voices he also had visions of God, who he described as looking athletic, with long hair, dressed all in white. Ezra did not describe his visions, though he said they led him to develop an idea called "resonant theory" regarding "evolutionary physics."

Triggers

This table shows the percentages for both external and internal stimuli that triggered participants to hear particular voices. Fifty-five percent of participants were triggered by thoughts of or interacting with specific people like an ex-partner, or a by a situation such as needing to concentrate at work. Twenty-two percent of participant's voices became more

intrusive or more negative in content when they were speaking about their voices. Thirty-three

percent of participants were triggered by the time of day, 44% were deeply affected by stress,

depression, or thoughts about low self-worth. At least 22% of participants spoke about how

changing medication had impacted their voices, and 44% of participants could identify no

specific trigger for their voices.

Table 6

Triggers and Stimuli for Hearing Voices

Triggers and stimuli for hearing voices	N	%
Talking about the voices	2	22
Time of day	3	33
Specific People or Circumstances	5	55
Stressful emotions and/or thoughts of low self-esteem	4	44
Medication changes	2	22
Other	4	44

While some participants such as Stephanie, Beth, and Mara spoke about hearing voices

almost constantly, there may be specific events, people, or a time of day that lead to particular

voices coming forward. For others, such a Hannah, the presence of depression and anxiety puts

her at risk for hearing voices. The purpose of gathering this data is to know as much as possible

about what stimuli might activate hearing voices, and if there are certain events or situations

when participants hear particularly positive or negative voices. This information is valuable

because it allows the voice hearer to take preventative measures by learning coping skills and

gathering resources if they are in a triggering situation. It also is important to distinguish triggers

for current voices from the onset of first hearing voices, which was addressed earlier in this

chapter. Ezra and Stephanie have both been triggered by medication changes to hear more

dominant voices. Ezra described gaining a lot of weight after he had been put on a certain

medication so he was looking to reduce his dosage. Ezra worked with his psychiatrist to do this,

but in doing so he had another breakdown. He started hearing six or seven voices, which commented on his actions. Ezra found himself visiting a foreign country, and wound up back in the hospital.

Among the nine participants interviewed for this study, the most common trigger for hearing voices were stressful emotions such as depression or anxiety, as well as negative thoughts about self-worth. Stephanie, Jules, Mara, and Hannah all cited low self-esteem as a major trigger for hearing voices, though each woman has a very different relationship to how these feelings affected them and their voices. For instance, Jules told this researcher that her voices do not always keep a consistent identity. This is because Jules hears, "real people's loud thoughts or voices, so these are people who are sometimes in the room with me, or they're in another state…people in my family. Sometimes people at work, sometimes community members in my old community where I grew up in. Sometimes community members in this community, and I feel- and it's always kind of persecutory" (Jules, personal communication, 2015).

Jules said that a major trigger for hearing voices is stress, which is brought out by being around her family. Jules described going to a family event a few weeks before the interview took place that set up a chain reaction of overwhelming situations and uncomfortable feelings that lead to hearing her family harshly criticizing her:

> …I started to hear their thoughts in my head about what they were thinking about my life now and I couldn't stop hearing them. I told you that I went to see my mom at dinner on Saturday, and all my brothers and sisters, I've got five of them, they're all really successful and like, it's just, I've started, for months now I've been hearing criticism of me because I only work part time (Jules, personal communication, 2015).

For this reason, Jules develops intense anxiety when she has to be in situations with her family, which leaves her more vulnerable to hearing negative voices. Her fears then become a self-fulfilling prophecy. Hannah also becomes trapped in a cycle of depression and isolation until she is unable to function and crashes into psychosis. This researcher and Hannah spoke about how social situations and being around other people can trigger feelings of low self-worth:

Cause it's like a mirror... And when you have this distorted perspective in the first place, you think, you could like look at situations with people and it could communicate anything. Or just that you're a total monster, a total freak… when I was untreated, or not being properly treated for depression then that would be like so serious, and so sad, so, I hate myself so much…Cause also when you hate yourself, your self is a trigger. And that's what it is about other people, because being around other people makes you exist more…Yeah, that's the whole thing. You don't have to exist when you're not around other people, and that feels amazing when your existence is so miserable and so uncomfortable. It alleviates that a little bit. But, so that's I think why it's such a trigger, cause it really makes you exist so much and that's so uncomfortable when you're not feeling well (Hannah, personal communication, 2015).

Stephanie and Mara both spoke about how being alone during the night can be a powerful trigger for their most, aggressive and dominant voices. Stephanie described that recently at work she often ends up having to stay late to finish paperwork and ends up being the last person working on the floor. She said,

Now I have days where I'm just exhausted from them. I'm in a building for several hours by myself on campus, it's a very old campus, and uh it's spooky and like, I'm like inundated with voices, and especially one particular one, which is, like, a creepy

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sounding voice. And um actually has, part of the pitch sounds like my ex-boyfriend. Just

like, every time I hear it I think of him and I go, "ugh" but um, so on Sundays I'm usually

exhausted because if I stay in that building, it's just constant like scenarios being said

over and over in my head, that are going to happen or trying to scare me

(Stephanie, personal correspondence, 2015).

As each participant learns what triggers activate their voices, they have also developed

strategies for dealing with difficult voices and situations. All participants besides Danielle have

mental health challenges like depression and anxiety, PTSD, or struggle with altered states of

consciousness. For many interview participants, coping with their voices also addresses these

other mental health issues.

Coping

This table shows the percentage of participants who were able to cope using the stated

techniques. Fifty-five percent of participants found distracting themselves useful, 33% relied on

positive or comforting voices to soothe them, 44% of participants turned to religious or spiritual

practices or explanations as a way of coping. Seventy-seven percent of participants described the

usefulness of psychiatric medication, and 55% of participants found hospitalization helpful.

Table 7

Coping Methods

Coping Methods:	N	%
Distraction	5	55
Comforting Voices	3	33
Religion and Spirituality	4	44
Medication	7	77
Hospitalization	5	55

One hundred percent of participants stated that having a job, the ability to keep busy, and

having close relationships with others were a necessary part of coping with the distress of

hearing voices. 44% of participants explained that they would call a friend or family member and talk to them, whereas the other 66% of interviewees meant in a more general sense that having supportive friends, family, therapist, or other mental health professional was helpful for their recovery and keeping them grounded. The ability to lead a normal life that includes, meaningful work, family, and friends is essential for good mental health. Pathologizing voice hearers further isolates and stigmatizes their experiences, while ignoring the underlying cause of distress.

Distraction

Fifty-five percent of participants said distraction was a coping method they use, such as watching TV, going for walks, or listening to music. Mara and Jules both said that music and TV help by making the voices less present. Jules said she ends up watching a lot of TV because of this, and is trying more active coping techniques to take care of herself, such as taking baths, doing yoga, or calling the crisis hotline. Jules has also found that with a lot of practice and training from the Hearing Voices Network she is starting to be able to speak with her voices and carry on some conversations, which she has found to be helpful. Ezra and Robert both said that going for walks was a useful tool for distraction. Stephanie is the only participant to use visualization as a coping tool,

> I have this skill now where I put them in the back of my mind. I picture them almost being wound into the back. Like picture a typewriter, when you feed the paper in…so that's what I picture…. and that's how I put it in the back of my mind. And visions, I used to picture a guy with a black curtain, like an old fashioned curtain and I would picture him pulling it down over the vision. And I mean, it takes doing this skills thousands and thousands of times- for me it did. And even now, it takes a lot before it will work (Stephanie, personal communication, 2015).

Comforting Voices

Of participants who are able to carry conversations with their voices, 44% said that speaking with their voices was a helpful coping strategy. Stephanie had taught herself many of the techniques used by those in the hearing voices network. She learned how to talk back to some of her voices and ask them to leave her alone, or to set boundaries with them and only speak to her after a certain time of day. Stephanie says that it took many years for her to get to that point with her voices, and it is still a work in progress, but improved significantly since she became trained as a hearing voices facilitator.

Mara said that while she does have at least one voice that is very critical of her, she also hears two voices that provide company and are comforting. Mara stated, "I feel like I don't get enough human contact. Cause I really don't have a family and I don't get enough human contact, so the only human contact I get is the voices…and that's why they're so important to me because they honestly keep me stable!" (Mara, personal communication, 2015). Sometimes Mara speaks out loud to a voice named Mr. Smiles, which can cause her distress when strangers think she is speaking to them. To remedy this Mara wears a hat that covers her eyes, will find somewhere quiet to converse with the voice.

Mara also works part-time as a peer advocate through ServiceNet. She described that working and helping others who are going through the same things she has been through is very important to her. Occasionally one of Mara's voices will try to distract her while she works so she puts on big headphones and listens to music. Mara also has a voice that tells her she is sick and needs medication. Though she said this is not her most critical voice, Mara sees the voice as helpful if it reminds her to take medication. She has also learned to talk back to this voice and tells it, "If I were really sick then I wouldn't be working."

Religion and Spirituality

Sandy has also established a positive relationship with her current voice, though she says it wasn't always this way, she now thinks her voice as a "spirit guide." And while they used to have many conversations, Sandy now says she has a difficult time distinguishing what are her own thoughts, and what is the voice. Sandy and Ezra both felt religious or spiritual connections to their voices. Sandy describes herself as a spiritual person, and when she was looking for an explanation for why she hears voices, she contacted a mental health hotline and told the woman on the phone about the premonitions. The woman told Sandy she was a White Witch and directed her to a priest, as well as to a church that works with Mediums. Sandy did follow through with these places for a short time, but said that it didn't fully answer her question of why she was hearing voices so she stopped going. Sandy's voice has remained a positive force in her life.

 Since the onset of hearing voices Ezra has become an Orthodox Jew. He has found comfort and solace in prayer, "I reach a new level of awareness, I think. My awareness goes up, and as my awareness goes up, the voices are still there, but they become more controllable through my own thoughts" (Ezra, personal correspondence, 2015). Ezra explained that his logic for becoming religious involved, "asking for forgiveness from a higher power," to see what effect that might have on his illness. Ezra's voice reduced to one, which he now believes to be the voice of God.

Medication

Seventy-seven percent of participants found medication to be a helpful part of coping. Hannah relies on taking Risperdal when she starts becoming very depressed. She has learned to recognize the warning signs of her depression and knows that she can take her medication to

prevent her depression and anxiety from spinning out of control. Jules stated, "Yeah, I know that if I didn't take my anti-psychotic I really don't think that I would be alive" (Jules, personal communication, 2015). Mara and Robert were also very happy with how their medication is now, though Mara says that the medication hasn't completely removed her voices, it makes them quieter and less intrusive. This allows her to tolerate hearing voices throughout the day.

The general consensus from participants taking medication on a regular or daily basis is that it helps quell the emotional fallout of hearing voices, though the medication does not completely remove the voices. Robert noted that the early neuroleptics he was prescribed resulted in tardive dyskinesia, involuntary muscle movements, which affect his ability to play music. Ultimately, these participants appear to have benefited from having access to the right kinds of medication, though for some, there have been unwanted side-effects along the way such as weight gain, tremors, lack of sleep, and other disturbances.

Hospitalization

While 88% of participants had been hospitalized on an inpatient psychiatric unit at least once, 55% of participants said that at least one hospitalization had been useful or positive for them. Participants found hospitalization helpful at times when they were in crisis and felt out of control. For Sandy, who brought herself to a hospital once, this was a way of containing some her inner chaos, while both Ezra and Hannah received medication management during their inpatient stays. Though all eight participants who had been hospitalized described having at least one negative experience in the hospital, most reported that those experiences still provided some relief. Beth, Mara, Robert, and Stephanie had traumatic experiences on psychiatric units at times when they were restrained and forcibly medicated. Stephanie describes feeling dehumanized when the psychiatric staff spoke about her as though she wasn't in the room.

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Support System

All 100% of participants stated that having supportive friends, family, and a good work environment were integral for their recovery. Stephanie works part-time as a peer counselor in a psychiatric hospital, helping others who experience extreme, altered states. She has a long-term boyfriend and a young son. While Stephanie's boyfriend is aware that she hears voices, it is not something they talk about very often. Some members of her family are aware of this as well, including her mom who was an active part of treatment when Stephanie was a teenager. Stephanie said that since she first started experiencing symptoms, one of her sisters has become a psychiatric nurse; having a common language has drawn the two of them closer. Stephanie also has many friends in the recovery community and plenty of co-workers who she speaks to about hearing voices. Stephanie also sees a therapist, takes medication, and practices recovery aligned techniques for hearing voices including mindfulness practices. Stephanie finds all of these relationships to be important parts of her ability to function.

Sandy works part-time doing odd jobs, but stated that she doesn't want to have too much responsibility. She is married and has an adult son. While Sandy's current husband knows that she hears voices, they also don't speak about it as Sandy says her husband finds it difficult to talk about. Her adult son does not know that she hears voices, but it is the importance of these relationships that keeps her grounded.

Robert does not work but he says he keeps himself busy and is a musician. He has a long-term partner who is a part of the recovery community and goes to the Green River Clubhouse daily. While Robert also uses medication, "they help, but my partner helps even more because if I didn't have her I'd be even more delusional…She just makes me more stable, but then again I help her in the same way, so" (Robert, personal communication, 2015).

Hannah now has a team of providers including a therapist, outreach worker, and psychiatrist who help her. Hannah said that a number of her friends from high school are aware of what she has been through and sometimes she can talk to them about it, though Hannah said that she usually tries to avoid speaking about hearing voices because it is brings back scary memories. Hannah described having several boyfriends in the past few years that have seen her experiencing psychosis. While her current partner is aware that she is susceptible to this, it is not a common topic of conversation. However, he is very understanding of her mental health needs.

Beth is no longer married but she has three adult children. She said that while one of her children is aware of her dissociative identity diagnosis, they don't ever speak about it. She did say that her children are unaware that she hears voices in addition to this. For 25 years Beth worked as a legal secretary, though she said that it was her alter called "Sue" who worked this job. After Beth's children grew up and her marriage ended, Beth described a decline in her ability to emotionally function. On top of this she started experiencing multiple health problems. Beth now uses a PCA who works closely with her. Beth sees a therapist who she likes very much, as well as having a psychiatrist and multiple outreach workers.

Danielle is very open with those in her life about the fact that she hears voices. She said that her mother and brothers all know, as does her girlfriend. She works full time in the service industry, and being able to keep stable relationships is necessary for maintaining a life of normalcy. The ability to continue living and working, not to be weighed down by labels of "mental illness," allow those who hear voices to cope better with difficulties that are largely misunderstood, especially by the professionals trained to help them.

CHAPTER V

Discussion

Though hearing voices can be a symptom of psychosis, there are many people who hear voices on a regular basis who are not chronically psychotic. There are also people who hear voices that have never received treatment for mental health issues because their voices have not caused them distress (Cooke et al., 2014). The nine participants interviewed in this thesis demonstrate that there is a diverse range of experiences for people have hearing voices. While it takes practice to do so, many people who hear voices are able to think critically about their voices and develop strategies to cope with these experiences. Studying the people who are not distressed by hearing voices implies that voice hearing lies on a spectrum where voices can be intrusive, but also has the potential to be pleasant, benign, or even helpful.

This finding counters the belief that hearing voices is always a negative and debilitating experience. This result is supported by "Auditory Hallucinations as a Personal Experience: Analysis of Non-Psychiatric Voice Hearers Narrations" (Faccio et al., 2012) who concludes that voices might be positive experiences and that voice hearers need to feel that they can listen to their voices without being stigmatized for it (p. 766). By examining first person accounts of psychosis, trauma, and hearing voices, as well as relying on research conducted by Romme and Escher (2011), this thesis links together life experience with the content and manifestation of hearing voices.

A secondary goal of this thesis is to diminish the stigma associated with hearing voices by challenging the biomedical medical model of mental illness. Thachuk (2011) notes that people with mental illness are often perceived as dangerous, difficult to treat, and are sometimes

blamed for their illnesses (Hayward and Bright 1997). "Collectively, these stereotypes create a context that many of those diagnosed with mental illness describe as more painful and debilitating than the illness itself" (p.141). One conclusion to draw from this research is that it may be more harmful to disregard the experience of the voice hearer, and doing so could further exacerbate their mental distress.

Drawing connections between traumatic experiences and the content of hearing voices can create meaning for the voice hearer, rather than reducing the experience to a symptom of psychosis or schizophrenia. Effective treatments for hearing voices varies on an individual basis depending on whether the person is spiritual, wants to use medication, cognitive therapy, psychotherapy, alternative medicine, or a combination of treatments. This thesis supports the philosophy of the Hearing Voices Network, a peer based recovery movement originating in the United Kingdom and the Netherlands that helps voice hearers take control of their lives by changing the power dynamics between themselves and their voices. The recovery model of mental illness, as well as an anti-stigma approach to hearing voices falls in line with both feminist theory (Thachuck, 2011) and trauma theory (Herman, 1992). Romme writes that,

> …The anxiety, powerlessness, guilt feelings, etc., are all metaphors of the power
> relationship in the traumatic situation and emotional neglect period. In the recovery
> process, they will take back power and will express their own power in relation to their
> voices and their problems. They also create choices that make it possible to take
> responsibility for their life and emotions, and by doing so heighten their self-esteem.
> Gradually they discover that voices are expressing emotions, and these emotions are
> those the voice hearer experienced as the result of the traumatic situation. The recovery

process is one of turning points in the relationship with the voices, with the person becoming more powerful and independent (2011, p. 9).

This foundation of this thesis relies on previous research demonstrating a causal relationship between childhood abuse and trauma to the development of mental health problems such as depression, anxiety, and PTSD (Zubin & Spring, 1977; Read, Fink, Rudegair, Felitti, & Whitfield, 2008). "Child Maltreatment and Psychosis: A Return to a Genuinely Integrated Bio-Psych-Social Model" (Read et al., 2008) writes that poverty is a significant factor for adults who develop schizophrenia or psychotic disorders. As both race and socioeconomic status are extremely influential in the development of mental illness, the fact that neither of these areas was fully addressed in this thesis is one limitation to this study. Therefore, the interviews presented here must be read in the bio-psycho-social context of nine Caucasian, primarily middle class adults, raised in New England.

Further research on this subject would benefit from a larger, racially and economically diverse sample size. Participant results may also be skewed due to the fact that 77% of interviewees had accessed Hearing Voices support groups. If this study were conducted in an area of the United States without a high concentration of recovery support groups, it is possible participants would have a different set of coping tools, and attitudes towards hearing voices and mental illness. It is also possible that many of the providers in Western Massachusetts are also influenced by the multiple peer-sponsored organizations located in this region, and thus are more accepting towards using recovery-aligned approaches to treating voices hearing.

Another limitation to this study is that this researcher did not collect information regarding participant's spiritual and religious beliefs as one of the demographic questions, nor was this topic included on the questionnaire. However 66% of participants did speak about their

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connection with religion or spirituality, either in relation to life history, voice content, or coping techniques. This information implies that people who hear voices may have more positive outcomes and benefit from spiritual belief systems; and at the very least, might have different experiences or interpretations of hearing voices than those who do not identify as spiritual. In future studies on the subject of hearing voices, this researcher encourages others to ask questions relating to religious belief and practice.

Despite the study's restrictions, 88% of interview subjects associate childhood trauma with the subsequent development of depression, PTSD, dissociation, psychosis, and hearing voices. Examining voice content sheds light on what problems the voices might represent for the voice hearer, and allow them to better cope with the distress of hearing voices (Faccio et al., 2012). One approach to understanding voices is to further investigate how trauma is expressed in the individual. If "Trauma robs the victim of a sense of power and control over her own life…" (Herman, 1998, p. 145) then traumatic experiences may shatter a sense of self. Without proper care and treatment, severe trauma leaves children especially vulnerable to PTSD, dissociation, hallucinations, and delusions (Morrison, Frame, & Larkin, 2003; Bendall, Jackson, & Hulbert, 2010). Romme (2013) and Dillon (2013) both agree that voices may be manifestations of other problems the person has experienced but is unable to confront.

At least 22% of participants described childhood sexual trauma from their caregivers. These two participants later experienced severe Post-Traumatic Stress Syndrome (PTSD), as well as the development of psychosis and hearing voices. Another 33% of participants experienced verbal, emotional, and physical abuse as children, while an additional 33% did not specify their early traumas but cited these as formative experiences in the development of their mental health struggles. In order to make sense of these horrific experiences, trauma and

subsequently psychosis may manifest in the psyche with a unique logic that operates outside of language (Read et al., 2008; Abramson, 2010). The child who was violated and whose pain was never heard might grow up to hear voices that persecute and criticize. This is why recognizing voices as metaphor become an integral part of the recovery process.

At least one participant spoke about understanding her voices as metaphors. She found this practice to be a helpful way of extracting meaning from hearing voices, though she is not always sure what her voices are trying to communicate, she acknowledges that understanding the complex emotions underlying her voices will take more time and practice to perfect. Romme (2013) writes about understanding the connection between hearing voices and metaphors,

> There is nothing mystifying in what voices say, but the metaphorical meaning has to be translated in order to understand the problem. It is not so strange that voices are metaphorical, because what they say points directly to the problems that are difficult to accept for the voice hearer. In this way the metaphor protects the voice hearer from direct confrontation with their emotions (p. 64).

This reasoning posits that hearing voices is a useful defense that shields the person from confronting emotions they have not been able to face. Speaking freely and openly about experiences of hearing voices without judgment from friends, family, or mental health professionals may be one step towards healing.

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APPENDIX A

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November 25, 2014
Emma Gabriner

Dear Emma,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Seth Dunn, Research Advisor

RESEARCH PROJECT CHANGE OF PROTOCOL FORM – School for Social Work

You are presently the researcher on the following *approved* research project by the Human Subjects Committee (HSR) of Smith College School for Social Work:

«Project_Name» Content and Metaphor: Making Meaning of Voices
Emma Gabriner, MSW Candidate
Seth Dunn, LICSW

…………………………………………………………………………………….

I am requesting changes to the study protocols, as they were originally approved by the HSR Committee of Smith College School for Social Work. These changes are as follows:

1. My original proposal stated that I would only meet with participants in person to do interviews. However, I realize that it is unrealistic to speak with each participant in person due to accessible private locations, scheduling conflicts, and geographic distance. While I am limiting participants to Massachusetts, one of my confirmed participants lives 3 hours away and I cannot guarantee this participant the required privacy and confidentiality if we were to meet for an interview in a different town. While in-person interviews is my preferred interview style, I am suggesting that the phone may be used to conduct interviews in cases were it is not feasible to meet criteria for confidentiality, and where geography, traveling, and scheduling would impede either the researcher or participants ability to participate. I am not offering Skype as an option because this application does not work well on my computer and I do not want to add unnecessary complications to this process.

2. I am having trouble recruiting participants for my study, and while I am primarily using my internship agency, reaching participants through their clinicians is proving challenging. I consulted with another master's student researching the same subject at a different institution. Her primary method of recruiting participants has been through craigslist, which she found very helpful. I suggest that I may post the following advertisement to recruit participants:

   Do you identify as someone who hears voices? Have you heard voices in the past? I am reaching out to the community to find people who currently or formerly have heard voices and would like to talk about their experiences. The goals of this study is to learn how people make sense of and understand the voices they hear in an attempt to de-stigmatize these experiences. I am looking for individuals willing to be interviewed for a research study that is part of my MSW (masters of social work degree) at the Smith School of Social Work. While this is a sensitive topic, it can be liberating to speak about it in a non-judgmental environment. If you or anyone you know has these experiences and would like to participate, or if you have questions please contact Emma Gabriner. Participants must be over the age of 18. I am asking to use a local mental health resource as a tool for recruiting participants for my project. Previously I have been using craigslist and ServiceNet as a hub to find participants for my study. Lately I have been having trouble locating more participants and it was suggested that I contact the Green River Club, a local clubhouse located in Greenfield, MA. I spoke with their director who invited me to present my project to the clubhouse members during one of their weekly staff meetings to find participants. I am proposing that I be able to expand my participant recruitment methods to speaking in person, with local mental health organizations. I have also been in contact with the director of the Greenfield Recovery Learning Community (RLC) who helped me distribute information about my project to their community members. I will forward an email letter from John Semon, the director of the Green River House, as well as from Samadi Demme, the director of the RLC.

…………………………………………………………………………

__x__I understand that these proposed changes in protocol will be reviewed by the Committee.

__x__I also understand that any proposed changes in protocol being requested in this form cannot be implemented until they have been fully approved by the HSR Committee.

__x_I have discussed these changes with my Research Advisor and he/she has approved them.

Your signature below indicates that you have read and understood the information provided above.

Signature of Researcher: _____Emma Gabriner_____

Name of Researcher (PLEASE PRINT): _____Emma Gabriner_____ Date: __12/13/14__

PLEASE RETURN THIS SIGNED & COMPLETED FORM TO Laura Wyman at LWyman@smith.edu or to Lilly Hall Room 115.

***Include your Research Advisor/Doctoral Committee Chair in the 'cc'. Once the Advisor/Chair writes acknowledging and approving this change, the Committee review will be initiated.

……………………………………………………………………………….

December 16, 2014

Emma Gabriner

Dear Emma,

I have reviewed your amendments and they look fine. These amendments to your study are therefore approved. Thank you and best of luck with your project.

Sincerely,

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Seth Dunn, Research Advisor

APPENDIX C

Consent to Participate in a Research Study
Smith College School for Social Work
Northampton, MA
……………………………………………………………………………………….
Title of Study: Content and Metaphor: Making Meaning of Voices
Investigator(s): Emma Gabriner, MSW Candidate
(Seth Dunn, LICSW, Adjunct Professor, 413-695-0707)
……………………………………………………………………………………….

Introduction
- You are being asked to be in a research study about your personal experiences of hearing voices, content of the voices, and ways that you have coped with hearing voices.
- You were selected as a possible participant because you are over the age of 18 and you identified as someone who has occasional or chronic experiences of hearing voices. We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study
- The purpose of the study is to understand of how you perceive your own experiences of hearing voices, and how you have coped with hearing voices. The study seeks to explore what forms of support or treatment (if any) you found helpful, and how knowledge of hearing voices has affected any support or treatment you've received by medical or mental health professionals as well as your friends, family, and peers.
- This study is being conducted as a thesis requirement for my masters of social work (MSW) degree from the Smith College School for Social Work in Northampton, MA.
- Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures
- If you agree to be in this study, you will be asked to do the following things: Participate in a 30-60 minute long one-time interview with this researcher. This interview will be audio recorded and transcribed. This interview will ask questions about important life events including traumatic events, the first time you started hearing voices, and your personal experience of hearing voices, including the subject matter of the voices as well as your experiences seeking treatment or support.

Risks/Discomforts of Being in this Study
The study has the following risks. You will be asked questions regarding life experiences. These questions may bring up difficult memories or feelings. A list of local referrals for support and crisis resources will be provided to you. You will be asked to arrange your own support systems such as family, friends, or providers to be available to you after the interview. I will check in with you throughout the interview and afterwards, but I will not contact your personal supports for you. I will offer to work with you to refer you back to your ServiceNet clinician (if applicable) if you are feeling vulnerable.

Benefits of Being in the Study

- The benefits of participation might include gaining insight into various life experiences, and having an opportunity to talk about issues important to you.
- The benefits to social work/society are to help those in the field of mental health learn about this often misunderstood experience.

Confidentiality

- Your participation will be kept confidential. All electronically stored data will be password protected during the storage period. Paper records will be stored in a locked room. We will not include any information in any report we may publish that would make it possible to identify you. Only the researcher will have access to the audio recordings, though pieces of the interview transcriptions may be included in the final report.
- The data from this study will in no way affect the services you receive, and will not be included in your health records, nor will specific information provided be shared with your clinical staff.
- All research materials including recordings, transcriptions, analyses and consent/assent documents will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed.
- In the final report you will be given a pseudonym and any quote or piece of information that appears will be represented by this pseudonym, which has no connection to your name or identity.
- In-person interviews will be conducted in a private office.

Payment

- You will not receive any financial payment or gift compensation for your participation.

Right to Refuse or Withdraw

- The decision to participate in this study is entirely up to you. You may refuse to take part in the study at any time (up to the date noted below) without affecting your relationship with the researchers of this study or Smith College. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled.
- You have the right not to answer any single question, as well as to withdraw completely up to the date of May 31, 2015. If you choose to withdraw, I will not use any of your information collected for this study. You must notify me of your decision to withdraw by email or phone by May 31, 2015. After that date, your information will be part of the thesis, dissertation or final report.

Right to Ask Questions and Report Concerns

- You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, Emma Gabriner at egabriner@smith.edu or by phone at (914) 439-5486. If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a

research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent

- Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep. You will also be given a list of referrals and access information if you experience emotional issues related to your participation in this study.

………………………………………………………………………………….
Name of Participant (print):_____
Signature of Participant: _____   Date: _____
Signature of Researcher(s): _____   Date: _____

………………………………………………………………………………….
[if using audio or video recording, use next section for signatures:]
1. I agree to be [audio or video] taped for this interview:
Name of Participant (print):

_____
Signature of Participant: _____   Date: _____
Signature of Researcher(s): _____   Date: _____
2. I agree to be interviewed, but I do not want the interview to be taped:
Name of Participant (print):

_____
Signature of Participant: _____   Date: _____
Signature of Researcher(s): _____   Date: _____
Form updated 9/25/13

Questions are from:

INTERVIEW WITH A PERSON
WHO HEARS VOICES

Sandra Escher
Professor Marius Romme
Patsy Hage

To be used in conjunction with
Making Sense of Voices

A guide for mental health professionals working with
Voice-hearers (Mind Publications 2000)

Interview with a person who hears voices

Name of the voice hearer: ....

Background information

Date of birth/age: ....

Gender: ……………………………..

Marital status: ....

Number of children: ....

Housing condition: ....

Employment status: ....

Nationality/ethnic origin ……..

THE NATURE OF THE EXPERIENCES ITSELF

This Questionnaire has been designed for people who hear voices. It is intended to help you gain greater insight into your experience of hearing voices. It is also designed to encourage a dialogue between us about your experience and the way you cope with the voices.

1.   I would like you to tell me about your experience of hearing voices.
        How many voices do you hear? Do you hear sounds as well? Do you see visions?

2.   Are you able to carry on a dialogue with the voices or communicate in any way with them? Can you give an example?

CHARACTERISTICS OF THE VOICES

3.   If you hear more than one voice has it always been like this? Have the voices always been the same voices?

4   Are you able to indicate who the voices belong to and/or the names you have given them? In what kind of tone do they speak to you and how frequently do you hear them?

No	name	age	gender	tone	frequency
1					
2					
3					
4					
5					

WHAT TRIGGERS THE VOICES

6. Are there particular times (day, night, weekend, particular hours) when the voices are present or not present? Do you have any idea why?

COPING STRATEGIES

7. I would like to know what exactly you do, when you hear the voices. What method do you use most? How often do you use it?

WHAT DO THE VOICES SAY?

8.1 Do you hear positive (friendly) voices? What do they say? Please give an example of the exact words they use.

8.2 Do you hear negative (unfriendly) voices? What do they say? Please give an example of the exact words they use.

HOW DO YOU EXPLAIN THE ORIGIN OF THE VOICES?

9. As a voice hearer you have probably wanted to find an explanation for why you hear voices. Here we are concerned with what you might think causes the voices and how you identify them. Some people feel that voices can be related to trauma, do you connect to this?

10. TREATMENT HISTORY
Did you ever receive treatment because of the voices? Which kind of treatment?

11. SOCIAL NETWORK
Contact with others is an important part of life. First, I would like to ask you to tell me about the person with whom you have a personal relationship and other persons that are important to you. The order is not important and you are not required to give complete names. Initials or something like my son is sufficient.

RESPONSE FILE SOCIAL NETWORK

NO	NAME	knows about the voices yes/no	talks about the voices yes/no
01			
02			
03			
04			
05			
06			
07			
08			

Local Resources on Trauma and Mental Health:

http://westernmassrlc.org/
http://www.hearingvoicesusa.org/
http://www.wmassemdria.com/trauma-recovery-network/

NELCWIT (New England Learning Center for Women in Transition): 479 Main Street Greenfield, MA 01301
info@nelcwit.org 413-772-0871
Crisis Hotline: 413-772-0806 (toll free) 888-249-0806

Hearing Voices Support Groups:

RLC's Holyoke Center 187 High Street, Suite 303 Holyoke, MA Tuesdays 4:30-6:00 PM Contact: (413) 539-5941 or info@westernmassrlc.org	Behavioral Health Network 417 Liberty Street Springfield, MA Wednesdays: 2:00-3:00 PM Contact: (413) 301-9330
SerivceNet's Young Adult Drop-in Center (ages 18-30) 21 Mohawk Trail, Suite 10 Greenfield, MA 01301 1st and 3rd Fridays every month 12:30-2:00 PM Contact: Micah Matthias 413-588-1393 (call or text), or mmatthias@servicenet.org	RLC's Worcester Center 91 Stafford Street Worcester, MA Tuesdays: 11:30am-12:30 pm Contact info: info@centralmssrlc.org or (508) 751-9600 http://www.centralmassrlc.org
Windhorse Integrative Mental Health, Library 211 North Street Northampton, MA Mondays: 3:30-5:00 PM Contact: (413) 586-0207 http://www.windhorseimh.org	

Peer Crisis Services:

Western Mass Peer Support Line: Friday-Monday, 8 PM to midnight Toll Free: 888. 407. 4515

CSO Crisis Services:

Franklin County: 413.774.5411 800.562.0112 140 High Street Greenfield, MA 01301
Hampshire County: 413.586.5555 800.322.0424 29 N. Main Street Florence, MA 01062
North Quabbin: 978.249.9490 800.322.0424 491 Main Street Athol, MA 01331