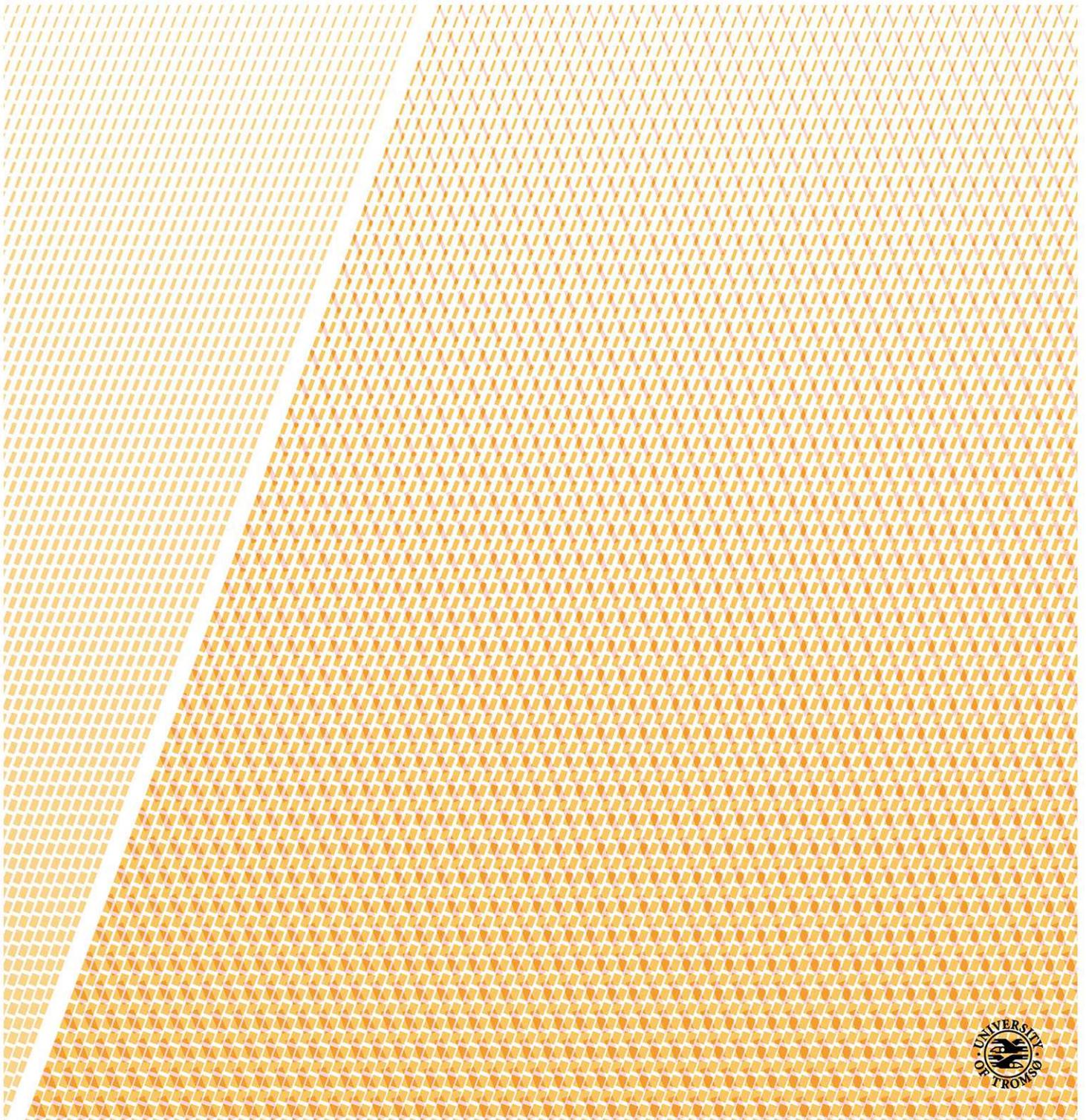


Faculty or department

# Living with voices and sounds others cannot hear

—  
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*A Dissertation for the degree of Philosophiae Doctor – Oktober 2015*





## **Kvardag**

*Dei store stormane  
har du attum deg.  
Då spurde du ikkje  
kvi du var til,  
kvar du kom frå eller kvar du gjekk,  
du berre var i stormen,  
var i elden.  
Men det gjeng an å leve  
i kvardagen òg,  
den grå stille dagen,  
setja potetor, raka lauv  
og bera ris,  
det er so mangt å tenkje på her i verdi,  
eit manneliv strekk ikkje til.  
Etter strævet kan du steikja flesk  
og lesa kinesiske vers.  
Gamle Laertes skar klunger  
og grov um fiketrei,  
og let heltane slåst ved Troja.*

Olav H. Hauge, 1966

## **Everyday**

*You've left the big storms  
behind you now.*

*You didn't ask then  
why you were born,  
where you came from, where you were going to,  
you were just there in the storm,  
in the fire.*

*But it's possible to live  
in the everyday as well,  
in the grey quiet day,  
set potatoes, rake leaves,  
carry brushwood.*

*There's so much to think about here in the world,  
one life is not enough for it all.*

*After work you can fry bacon  
and read Chinese poems.*

*Old Laertes cut briars,  
dug round his fig trees,  
and let the heroes fight on at Troy.*

Olav H. Hauge, 1966/2003

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## ***Abstract***

Hearing voices and sounds unshared by others, often termed auditory (verbal) hallucinations, is commonly known as a symptom of serious mental illness. The fact that it is not uncommon in the general population has led to research focused on hearing voices and sounds as experiences in themselves. The aim of this research project was to understand how people experience hearing and dealing with voices and sounds in everyday life and over time. One person without a psychiatric diagnosis and fourteen people with a psychotic illness participated in two to three in-depth interviews. These were mainly analyzed and interpreted with a hermeneutic phenomenological approach.

The results revealed that the woman without a psychiatric diagnosis had much in common with the participants who had a psychotic disorder; they all found living with hearing voices and sounds to be recurrently upsetting. Her daily life was, however, less frequently disrupted and she did not have to deal with other mental complaints or mental health services. The participants were recurrently struck by the experiences of hearing someone; this echoed and amplified past and present experiences with others and existential magnitudes. The participants developed ways of dealing with the opposing presences and the adversity they reflected through personal trajectories: some were linear, most were circular or spiraling. Central themes encompassed: retrieving or developing their sense of having a voice and navigating health care. Being believed by someone whom the participants trusted and could talk to about their experiences was essential to becoming more confident and developing new ways of understanding and dealing with the troublesome presences.

The results challenge nurses and other health care providers to engage in participatory dialogues and thus acknowledge voice hearer's experiences and attune their interventions and aims to the voice hearer's perspectives. Furthermore they are challenged to address past, present and future concerns or existential matters echoed by the voices (e.g. trauma, employment or meaningful activities, spiritual and religious matters).

## ***Original papers***

- I Talseth, Gilje, and Kalhovde (2012) Voice hearing over time: A qualitative study of a woman without a psychiatric diagnosis. *OJN Open Journal of Nursing*
- II Kalhovde, Elstad, and Talseth (2013) Understanding the Experiences of Hearing Voices and Sounds Others Do Not Hear. *QHR Qualitative Health Research*
- III Kalhovde, Elstad, and Talseth (2014) Sometimes I walk and walk, hoping to get some peace. Dealing with voices and sounds nobody else hears. *International Journal of Qualitative Studies on Health and Well-being*.

These papers have been printed with the permission of the respective journals.



## **1.0 Introduction**

Most of my work has been with people who have suffered from severe psychoses in mental health care settings. Relating to and supporting people who experienced hearing voices no one else could hear represented one of my greatest challenges, whether the person was in acute crisis entirely engrossed with vividly heard voice messages or in need of community mental health care to manage daily life at home. Through specialized nursing training and practice, I and other students learned to consider experiences of hearing voices as symptoms of psychoses and schizophrenia. We received training that focused on teaching people to accept that the voices were false perceptions, signs of illness and that taking adequate doses of neuroleptic medication was imperative. We were also taught to encourage and support people in diverting their attention to matters other than the voices and carefully address the feelings hearing voices evoked.

Avoiding engaging in dialogue about how people experienced hearing the voices and sounds formed a barrier between them and myself, and I eventually found these approaches to be inadequate. I was intrigued by the perspectives of Sandra Escher, PhD and Professor Marius Romme (2012) and the members of Hearing Voices Networks (HVN), who contended that hearing voices is a reaction some people have in relation to personal crises and that these people need to be emancipated and not cured. From their perspective, hearing voices is not necessarily pathological, but can result in illness if the person is unable to cope with these experiences. Consequently, nurses and other health care providers should encourage people who are troubled by hearing voices to talk about these experiences and support them in their attempts to make sense of them and otherwise cope with them (Escher & Romme, 2012).

I began to wonder whether experiences of hearing voices were merely symptoms of psychotic disorders or normal reactions some people have in relation to painful life events. How could these perspectives be integrated when attempting to understand people who have a mental illness and hear voices? What implications might this have for nursing approaches? Recent decades have seen a growing body of research in which hearing voices has been treated as a phenomenon in its own right. For example, scientists have revealed that experiences of hearing voices are not uncommon in the general population and not pathological experiences per se. However, research on nursing related to peoples' experiences of hearing voices and sounds has been limited.

In my master's thesis (Kalhovde, 2005), I aimed to understand five people's lived experiences of hearing voices and sounds through in-depth interviews. Four of the interviewees had a psychotic illness and had received mental health care. One had neither received a psychiatric diagnosis nor mental health care. The most important finding was that the participants, including those who received extensive mental health care, recounted lonesome struggles to manage everyday life with the voices and sounds. In this thesis, I aim to contribute to an understanding of how people experience hearing voices and sounds and dealing with them in daily life and over time. Consequently, I will start by taking a closer look at the predominant perspectives on hearing voices and the consequences these understandings have had for the people who have these experiences. Before I reflect on and discuss the findings presented in three articles, I will provide an overview of relevant research and illuminate my theoretical perspectives.

## **2.0 Background**

For thousands of years, perceptions of hearing voices and sounds unshared by others have been variously perceived as gifts, divine encounters, dubious or deceitful capacities, and indications of illness. Sometimes, society has acknowledged some voice hearers, but in other cases they have been ridiculed, punished and even killed because of their voice experiences (Leudar & Thomas, 2000; McCarthy-Jones, 2012). In the following I will present the most significant perspectives and practices which have formed the participants' and my own understandings. I will use the term hearing voices and sounds for the audible experiences which are not shared. When referring to those voices and sounds all can hear, I will use the term common sounds or sensations.

## **2.1 Receiving divine and spiritual messages**

We have numerous accounts of how people have experienced and dealt with hearing voices and receiving messages from a divine source. The following account from the Old Testament in the Bible is but one of many which have inspired generations of people. Samuel awoke several times because he heard someone calling his name. Each time Samuel went to Eli, his tutor, and asked if he had called. The third time this happened, Eli said to Samuel that the next time he heard the voice, he must say, "Speak, for your servant is listening" (The Holy Bible, 1. Samuel 3, 1-20). Eli taught Samuel how to understand and deal with the voice he heard; he encouraged Samuel to listen to the voice of God and share the divine messages with him. Samuel became renowned for the prophecies he received and shared. We can find similar accounts reflecting this passage in contemporary texts in predominantly Christian cultures

such as the Norwegian culture<sup>1</sup>. The following example is taken from a Norwegian publication from 1915 (Blix, 1979). The author of the text, Olea, described how she founded a charity based on what she believed to be a wake-up call from God. She was at home sewing clothes when it dawned upon her that she should visit someone in need of help. She had decided to wait a day, but “a while after the voice sounded again: ‘Go. They need you’”. When she was reminded for the third time that she should go, she stopped sewing and decided to do as she was told: “That was when she understood who the voice came from. She gathered some food and a warm skirt and went.” When she arrived at the house she had been instructed to visit, she found a woman in need of her help. Olea lighted a fire, gave her the food and clothes and the woman said, “So God does hear prayers”<sup>2</sup> (my translation). These examples illustrate how experiences of hearing voices have played an important role in voice hearers’ lives, relations to others and society.

Other common accounts involve auditory experiences of a spiritual or religious character which are confusing and troublesome and lead to withdrawal from or conflicts with others. The Norwegian poet Olav H. Hauge wrote in his diary about his lapses into what he called visionary chaos (my translation), which involved being completely overwhelmed by voices

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<sup>1</sup> Simon McCarthy-Jones (2012) gave an interesting overview of available research related to voice hearers’ experiences in other religious and cultural contexts.

<sup>2</sup>As part of their application, women hoping to be accepted for training as deaconesses in Norway at the turn of the 20th century described their experiences of hearing God’s voice calling them to do service in specific regions of the country (Elstad, 2006, pp. 210-242).

and visions (Aarnes, 2008). Hauge was unable to write or take care of himself in these periods, yet he found them necessary and important. Hauge believed that the voices (and visions) he experienced represented an important dimension in life. He therefore strove to come to terms with these experiences as part of his life and authorship, although he was forced to spend several long periods, one of which lasted four years, in a mental hospital. He wrote that he was content with the involuntary hospital admissions despite being treated with isolation and physical restraints, because the staff had not attempted to cure him with medication. He claimed that this gave him the opportunity to sort out important matters which also contributed to his writings and made him a better person (Aarnes, 2008). Eventually Hauge realized that by eating, resting and acquiring sleep regularly he could avoid becoming totally overwhelmed by the voices and visions and manage without mental health care services

The voices, visions are diverse, but it is absolutely necessary to avoid being misguided by them, but to listen to those you find worth listening to, see what you are shown, or rather allowed to see, and try to interpret it and use it. That's exactly what matters, not letting oneself be confused, and misguided. That's exactly it, not letting go of reality and everyday life and duties, else you sail of in a dream and a daze, in which day and night become one, weaving themselves together into a knot you cannot work out.... That's exactly it, not letting oneself be confused, bobbed around or wafted away like a leaf, the art of it (Hauge, 2000, pp. 377-378, my translation).

Hauge was diagnosed with schizophrenia and his experiences of hearing voices were most likely viewed as hallucinations by mental health care providers (Hauge, 2000).

## **2.2 Experiences of false perceptions and symptoms of illness**

The word 'hallucinate' comes from the Latin 'hallucinatus' or 'allucinatus' meaning "to wander (in mind)", "talk unreasonably" or "ramble in thought" (Online etymology dictionary, 09.24.2015). Etienne Esquirol, a French psychiatrist, was the first to give the generic name hallucinations to experiences of hearing or seeing something extraordinary early in the 19th century. He argued that the hallucinating person "ascribes a body and actuality to images that the memory recalls without the intervention of the senses" (Bentall, 2003, p. 350). Thus, he established the notion that there was a link between hallucinations, thoughts and memories; hallucinations took place in the heads of the hallucinating individuals. This understanding has remained fairly unchanged in medical and psychological literature for the last 175 years. For example in the Diagnostic Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM IV-TR) (American Psychiatric Association, 2000), we find the following definition: "a sensory perception that has the compelling sense of reality of a true perception but that occurs without external stimulation of the relevant sensory organ" (p. 823).

Hallucinations were categorized according to the different sensory modalities in which they appeared to be sensed, e.g. experiences of hearing something extraordinary were termed auditory hallucinations, while experiences of hearing someone talk were termed auditory vocal or verbal hallucinations. Seeing something was termed a visual hallucination, feeling something was called a tactile hallucination and smelling something an olfactory hallucination (American Psychiatric Association, 2000).

Based on studies of the patient populations of then prevailing large psychiatric institutions, European psychiatrists of the 19th century established the close connection between hearing voices, auditory (verbal) hallucinations, and serious mental illness in Western societies that we know today. Emil Kraepelin (1856-1926), German professor of psychiatry and the founder of the diagnostic system for mental disorders, described hallucinations as closely related to Dementia praecox, which he claimed was a deteriorating brain disease leading to dementia. Eugene Bleuler (1857-1939), a Swiss professor and hospital director, proposed that patients diagnosed with dementia praecox should instead be categorized in different groups of schizophrenias. He suggested that the fundamental symptoms of the schizophrenias were disordered affects and associations, autism and ambivalence. He termed hallucinations, along with other symptoms such as paranoid ideas and catatonia, as accessory symptoms (Bleuler, 1950). He nevertheless noted that “hallucinations stand in the forefront of the picture” (p. 95) and that hearing voices was common among these patients:

“The most common auditory hallucination is that of speech.... Threats and curses form the main and most common content of these “voices.” Day and night they come from everywhere - from the walls, from above and below, from the cellar and the roof, from heaven and from hell, from near and from far.” (Bleuler, 1950, p. 97).

Although Bleuler also saw schizophrenia as a chronic and deteriorating brain disease, he noted that dementia was not a main outcome and that some patients managed quite well despite having this disease. He also argued that the experiences of hearing voices were not entirely incomprehensible (Bleuler, 1950).

Kurt Schneider, also a German psychiatrist (1967-1987), established that certain forms of auditory hallucinations were more closely linked to schizophrenia. He claimed that hearing voices which referred to the voice hearer in the third person, voices which commented on the voice hearer's actions or which echoed the voice hearer's thoughts and voice experiences that were unaffected by mood, were closely linked to schizophrenia and termed them first-rank symptoms (FRS) of schizophrenia (Leudar & Thomas, 2000). The authors of the fourth revised edition of the diagnostic manual for mental disorders (DSM IV) (American Psychiatric Association, 2000), have continued to list experiences of hearing voices with these characteristics as first rank symptoms of schizophrenia, i.e. an A-criterion, along with the following additional criteria: (1) having heard voices over a certain length of time (3 months) and (2) being occupationally or socially impaired (DSM IV, B-criterion).

### **2.3 Empirical research on hearing voices**

Searches in the electronic data bases CINAHL, Pubmed, Psycinfo, Ovid, Ovid Nursing and SveMed revealed a substantial amount of research related to psychoses and schizophrenia in which experiences of hearing voices are mentioned<sup>3</sup>. Researchers have also shown that although a majority of people with diagnoses of schizophrenia hear voices (about 75%), a substantial number of people with other diagnoses also hear voices (20% to 50% with bipolar

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<sup>3</sup> I used the search terms voice hearing, hearing voices, non-clinical, auditory hallucinations, verbal hallucinations, nursing research, and epidemiological research 1990-2014.

disorder, 40% with posttraumatic stress disorder and 10% of those with major depression hear voices and up to 50% of substance abusers) (Choong, Hunter, & Woodruff, 2007; de Leede-Smith & Barkus, 2013). Additionally we find research on experiences of hearing voices related to physical illness (e.g. hearing loss, Parkinson's disease, dementia, brain lesions). There is also a growing amount of research in which researchers have focused on hearing voices and sounds as experiences in themselves, irrespective of mental or physical illness. Nonetheless, how people experience hearing voices and sounds in everyday life and nursing related to people with these experiences continue to be an understudied area.

In the study of experiences of hearing voices, there has arisen a need to define them more precisely and discern between illusions and auditory verbal hallucinations. Some researchers have attempted to distinguish between real hallucinations and pseudo-hallucinations by defining the latter as deriving from within the body of the person hearing voices or occurring when the voice hearer realizes that the voices derive from her- or himself. Several scholars have however argued that this has had no clinical significance (Baethge, 2002; Copolov, Trauer, & Mackinnon, 2004). Other researchers have argued that there is no clear division between illusions and hallucinations. Bentall (1990) suggested that auditory hallucinations were illusions of reality and proposed a new definition that underscored this aspect. He suggested the following definition: "any percept-like experience which (a) occurs in the absence of an appropriate stimulus, (b) has the full force or impact of the corresponding actual (real) perception, and (c) is not amenable to the direct or voluntary control of the experiencer" (p. 83). He has, however, later commented that even this definition is inadequate, because it does not encompass the fact that some people can experience hallucinations voluntarily (Bentall, 2006). Aleman and Larøi (2008) emphasized that hearing voices involves a range

from hearing a clear voice deriving from an external source with no counterpart, to an internal voice which is obviously not heard by others and to thought-like voice experiences. Cultural factors might also influence how the voices are experienced. For example, al-Issa (1995) noted that people in developing nations reported having seen visions more often than hearing voices, compared to people in Western societies. This author suggested that this tendency could be related to people having more distinct divisions between “real” and “imaginary” in Western societies. Johns, Nazroo, Bebbington, and Kuipers (2002) also found significant differences among ethnic groups in London related to experiences of hearing voices.

### ***Experiences of hearing voices in the general population***

We will now consider important epidemiological studies which reveal that the majority of those who hear voices cannot be diagnosed with mental disorders and do not seek or need mental health care. These studies of the prevalence of hearing voices in the general population have shown that it is quite common to briefly hear someone calling one’s name, or stating things that may or may not be relevant and comprehensible when waking up and falling asleep. These experiences are commonly termed hypnogogic and hypnopompic hallucinations in psychological and medical research and have not been found to be related to mental illness. In a study of the general populations of the UK, Germany and Italy, Ohayon (2000) found that 2.4 per cent of 13 057 participants reported having heard voices when awakening or falling asleep.

Scholars have shown that a significant minority (between 0.6% (Ohayon, 2000) and 2-3% (Tien, 1991)<sup>4</sup> heard voices and sounds when they were awake<sup>5</sup>. In a recent study of the prevalence of hearing voices in the Norwegian population, Krakvik et al.(2015) found that 7.3% had experienced hearing voices. Methodical differences involving for example the use of questionnaires or telephone interviews might account for some of the differences in the findings above. The definitions of the voice experiences and the concepts the researchers used (verbal hallucinations or hearing voices) may also have contributed to different findings. Yet another factor could be variations in the study population. If we look at studies of student populations, we find that a large number of students and young people have brief but recurring voice experiences. Posey and Losch (1983) found that the majority of 375 college students in the USA (around 70%) had more or less brief experiences of voices and sounds. Barrett and Etheridge (1992) found that around 40% of students heard voices and sounds regularly. Rossler et al. (2007) confirmed these findings in a 20 year longitudinal study of about 500 people from the age of 20 to 40. These researchers found that over 3% of interviewees were troubled by hearing voices when they were young (ages 20-23), while very few (0.1%) were troubled during middle age (ages 40-41).

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<sup>4</sup> These results also refer to the study conducted by Sidgewick et al. (1884), which Tien replicated with some adjustments.

<sup>5</sup> Tien (1991) excluded those who might have heard voices because they used drugs or alcohol or had a medical condition.

People who have survived trauma comprise another group of the population reporting high occurrences of hearing voices and sounds. Several researchers have found that it is not uncommon for widows and widowers in their 60s and 70s to hear the voices of their late spouses (13%, Rees, 1971, 30% a month after bereavement and 6% a year after bereavement, Grimby, 1993) (Olson, Suddeth, Peterson, & Egelhoff, 1985; Rees, 1971). Interestingly, most of the participants found these experiences positive, but few spoke about them to others. Other researchers have established that having survived abuse as a child, such as parental neglect, sexual abuse, physical abuse and emotional abuse heightens the likelihood of psychoses and thus hearing voices. Having survived several types of trauma and a higher degree of violence increased the odds (Shevlin, Houston, Dorahy, & Adamson, 2008). In a review of the association between experiences of childhood sexual abuse and hearing voices, McCarthy-Jones (2011) concluded that there was a clear link between these two experiences. The close association to trauma has led some scholars to argue that voice hearing is a dissociative reaction and not a symptom of psychosis (Moskowitz & Corstens, 2008).

### ***Hearing voices and sounds on a continuum from normality to illness?***

Based on the epidemiological findings above, some researchers have hypothesized that experiences of hearing voices lay on a continuum from normality to illness (cf. Van Os, Linscott, Myin-Germeys, Delespaul, & Krabbendam, 2009). In recent studies, scholars found no significant differences between the experiences of people with and without mental illness in terms of whom the voices were perceived to be, how many, where and how loud the voices were (Sommer et al., 2010). The differences that Daalman et al. (2011) found in these two groups' experiences were that the majority of those without mental illness mainly had brief

and positive voice experiences, whereas those with mental illnesses perceived the voices as more distressing and difficult to control. In a comprehensive review of existing empirical research of voice hearers without a psychiatric diagnosis and voice hearers with a psychiatric diagnosis, de Leede-Smith and Barkus (2013) suggested that hearing voices becomes pathological when the experiences persist, lead to other symptoms and cause distress and functional impairment. Consequently, there has been a growing awareness of the fact that when people hear voices, this does not in itself mean they have or will develop a mental illness. Some researchers have even suggested that it should play a less significant role in diagnostics (Waters et al., 2012). Peoples' ways of dealing with these experiences could instead be the key to distinguishing between those who will develop mental illness and those who will not (Romme, Escher, Dillon, Corstens, & Morris, 2009).

## **2.4 Nurses and health care providers' approaches to people who hear voices**

Textbooks on nursing have been heavily influenced by biomedical perspectives and nurses have been trained to view experiences of hearing voices and sounds as symptoms of mental illness completely unworthy of further discussion. In 1877, the deaconess Rikke Nissen authored the first textbook in nursing<sup>6</sup> in Norway. In the chapter concerning care of the mentally ill, she wrote that it was “utterly despicable to engage in the ill person's false convictions and sensations and thus reinforce his convictions to satisfy him and calm him temporarily” (my translation). The nurse should on the other hand avoid contradicting the

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<sup>6</sup> “Lærebok i sygepleie” (Textbook in Nursing, my translation)

patient in discussion because this could provoke “aggressive outbursts”. Instead the nurse “must patiently and calmly tell the ill person that he is wrong, and that matters are not as he imagines them to be, or she should attempt to bring his attention to something else” (Nissen, 2000, p.79) (my translation). Reinforcing reality and avoiding engaging in dialogue or having limited dialogues about peoples’ experiences of voices and sounds have continued to dominate nursing for more than 100 years (Hummelvoll, 2003; Peplau, 1990). Authors of contemporary psychiatric and mental health nursing literature have increasingly emphasized that nurses should collaborate with people in need of mental health care on an equal standing, and attempt to understand their suffering in the context of their lives and present situation (Jan Kåre Hummelvoll & Granerud, 2010)<sup>7</sup>.

A growing number of voice hearers have also called for greater engagement and support from health care providers in their process of making sense of their voice experiences (Gray, 2008; Romme et al., 2009; InterVoices, 2015). According to the view of Romme (2015), hearing voices should be seen as a sign of human variation and not mental illness. He argued that this shift of perspective should be compared with the shift that has taken place in relation to being left handed or homosexual. Furthermore, Romme and colleagues (2009) argued that the minority of voice hearers who need mental health services do so because they are afraid,

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<sup>7</sup> Hummelvoll and Granerud (2010) reviewed articles on theoretical and ideological impacts on the development of psychiatric nursing in the period from 1960 to 2008. These authors found that a prominent theoretical perspective in this period involved anti-psychiatry, psychosocial impacts, holism and pluralism, and user perspectives.

overwhelmed and feel powerless in relation to the voices. These researchers furthermore argued that voice hearing is intrinsically meaningful and related to the voice hearers' personal history. Those who hear voices do not need help to eliminate the voices, but to change their relationships with the voices and thus reduce the distress related to hearing voices, according to them (Romme et al, 2009). Romme and Escher have co-founded several national networks, e.g. in the Netherlands and the UK, and an international network (InterVoice, 2015) of voice hearers, researchers and health care providers to promote empowerment and emancipation of people who hear voices. Romme and Escher argued that mental health care providers should not automatically attempt to eliminate the voices. Instead, people should accept the reality the voices have for voice hearers and support them in making sense of the voice experiences if and when they need it. Their work has been aimed at empowering people who hear voices by validating their experiences and reducing stigma in health services and the public in general and by advocating change in available treatment through establishing networks. These networks advocate normalization of experiences of hearing voices and sounds and a restrictive drug treatment policy (Escher & Romme, 2012).

An increasing number of researchers have argued that care providers should see experiences of hearing voices as multifaceted and meaningful experiences in themselves and view them as significant to understanding and reducing the distress experienced by voice hearers. Care providers should explore the function of hearing voices (Fenekou & Georgaca, 2010), the contents of the voice messages and peoples' relationships to the voices (Beavan, 2010; Chadwick & Birchwood, 1994, 1995; England, 2007a, 2007b, 2008; Fenekou & Georgaca, 2010; Lakeman, 2001; Waters et al., 2012). With increasing immigration, nurses and other health care providers are also challenged to gain knowledge about and consider people's

cultural backgrounds. al-Issa (1995) suggested that therapists should consider the functional importance and meanings of hallucinations as well as the social settings. In the latest edition of a central textbook used in the education of nurses and other health care students in Scandinavia, the author Hummelvoll (2012) included HVN perspectives and elaborated on and specified ways nurses and other health care providers can understand and support people who struggle with experiences of hearing voices.

From the empirical studies of how nurses and people who hear voices interact, I have found that health care providers have been reluctant to engage in dialogue about the contents and meanings of peoples' experiences of hearing voices and sounds. Nurses and other health care providers' conversations with voice hearers about their experiences of hearing voices and sounds have mainly had the objective of evaluating treatment and medication. Harrison, Newell, and Small (2008) revealed that people who heard voices and had a schizophrenia diagnosis found it unhelpful and distressing when nurses dismissed their reality and avoided engaging in their understandings of the voices. Coffey, Hewitt, Higgon and Kinnear (Coffey & Hewitt, 2008; Coffey, Higgon, & Kinnear, 2004) interviewed both community mental health care nurses and voice hearers who were in contact with these nurses. These authors found that the nurses' reported approaches did not correspond with the needs reported by the service users. The nurses' approaches were mainly limited to reviewing medications, providing access to psychiatrists and "non-directive counselling", such as reassuring the voice hearer or making additional home calls when he or she reported being excessively troubled by the voices. The voice hearers appreciated the nurses' help in contacting a doctor about adjusting their medication and in distinguishing between what was mutually experienced and what they alone experienced. However the voice hearers expressed a need for nurses to

address more specifically their experiences of hearing voices and ways of coping. England (2007a) also found important discrepancies between nurses and the voice hearers' perceptions of voice hearing experiences.

Understanding people's experiences of repeatedly hearing voices and sounds in everyday life is central to promoting health and providing health care. We have seen that different ways of understanding people's experiences of hearing voices and sounds have led to different attitudes and ways of relating to those who have these experiences, both among nurses and other health care providers and in the general population. However, we know less about how people who hear voices and sounds perceive these experiences. Do they see them as symptoms of psychotic disorders, normal reactions or spiritual events, or have they integrated these perspectives? How do they deal with the voices and sounds in everyday life? Few researchers have explored people's everyday experiences of hearing voices and sounds. For this reason, I found it important to gain an understanding of people's first-hand experiences of living with hearing voices and sounds in everyday life.

### **3.0 Aims**

The overall aim of this thesis is to contribute to an understanding of people's experiences of hearing voices and sounds in daily life and over time. This thesis is based on two studies. In Study I the aim was to understand how people without a psychiatric diagnosis experienced hearing voices over time. The aim of Study II was to understand how people with a psychotic illness experienced living with hearing voices and sounds in daily life. The three articles below form the basis for this thesis and address three research questions.

Article I: How might people without a mental disorder describe living with voice hearing over time?

Article II: How might people with mental illness experience hearing voices and sounds in everyday life?

Article III: How might people with mental illness experience dealing with hearing voices and sounds in everyday life?

Article I was based on Study I and Articles II and III were based on Study II. I chose to use the phrase "dealing with" rather than "coping with" to avoid evaluating the participants' ways of relating to the voices and sounds. Coping is often defined as dealing "effectively with something difficult", whereas 'to deal with' can be defined as "doing things to fix a problem" (*Oxford American desk dictionary and thesaurus*, 2002).

## ***4.0 Theoretical perspectives***

Understanding perception is fundamental to how we understand experiences of hearing voices and sounds others cannot hear, even though these are not common sensations. The French philosopher Maurice Merleau-Ponty's (1908-1961) perspectives on perception form one of the important theoretical frameworks for this thesis. He argued that we do not constitute the world or meaning through sensation, because the world is always already meaningful to us. Sensation and understanding are enmeshed in one another; our immediate involvement with the world is irreducible, according to Merleau-Ponty (2003). He claimed that perception

“is not a science of the world, it is not even an act, a deliberate taking up of a position; it is the background from which all acts stand out, and is presupposed by them. ... man is in the world, and only in the world does he know himself.” (Merleau-Ponty, 2003, xi)

Perception evolves from a pre-reflexive level where there is no definite division between the physical and mental, subjective and objective. We do not sense the world through different modes of sensation that are miraculously translated and organized into meaning. Our sensations of hearing, seeing, touching etc. coalesce with each other and the world and form sensory fields: background and foreground (Merleau-Ponty, 2003).

Consequently, and in contrast to prevailing biomedical and psychological perspectives, Merleau-Ponty maintained that perception and sense are not merely products of the perceiver

but are operations beyond the perceiver. Perception is dialectically formed through activity and passivity. Active and passive moments intertwine and form a gestalt, a whole, although they are counterparts and incongruent. Passivity is not merely the absence of activity and vice versa. Merleau-Ponty maintained that activity is equally passivity and exemplified this by referring to the process of transitioning from wakefulness to sleep. To fall asleep one must allow oneself to be embraced by sleep, or give in to sleepiness when too exhausted to avoid falling asleep (Merleau-Ponty, 2003; Merleau-Ponty, Darmaillacq, Lefort, & Stephanie, 2010; Morris, 2010). Hearing and listening also involve being inherently passive and active; we do not listen to all we hear. If, for instance, a radio is turned on, we can hear it in the background without being aware of it until we suddenly realize that the radio is on because a song or statement has captured our attention and we begin to listen. If we have entirely forgotten that the radio was turned on, we immediately envision the events that led to the sounds and we may turn to look for the people talking or look for a radio, and perhaps we remember that there is one on a shelf in the next room. These visions also both present themselves to us and are conjured forth by us. Seeing and hearing something is also inherently being someone other people can see and hear. We hear and are heard, see and are seen. Thus, Merleau-Ponty's perspectives underscore the complexity of perception and our bodily being in the world as we live it. "The living who who perceives does not operate at a distance from the world, and is not merely bodily, but is a who who perceives *with* its world, *avec son monde*." (Morris, 2010, p.13).

Merleau-Ponty stated that a person who for example hears voices others do not hear, does not,

“hear in the normal sense, but makes use of his sensory fields and his natural insertion into a world in order to build up, out of the fragments of this world, an artificial world answering to the total intention of his being.” (Merleau-Ponty, 2003, p. 398)

Based on this statement, we can see that Merleau-Ponty (2003) also argued that these experiences involve active and passive moments. These perceptions of voices and sounds are furthermore formed in a dialectic process enmeshed in their historical, social and cultural environment in a similar way to common perceptions. Within this theoretical framework, people’s experiences of hearing voices unheard by others are not faulty judgments or beliefs; people cannot be convinced of hearing something they merely think they hear. These experiences lack the fullness of things commonly sensed, yet they have the value of reality (Merleau-Ponty, 2003)<sup>8</sup>. Merleau-Ponty signified, however, that although hearing voices unshared by others has certain attributes that separate it from other similar experiences, it is not entirely unlike them;

“Mythical or dream-like consciousness, insanity and perception are not in so far as they are different, hermetically sealed within themselves; they are not small islands of experience cut off from each other, and from which there is no escape.” (ibid., p. 340).

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<sup>8</sup> The examples Merleau-Ponty referred to and explored were those of people diagnosed with schizophrenia and his own experiences of being under the influence of drugs (mescaline).

People hear the voices and sounds in a constant flow of inherently meaningful perceptions; they emerge in daily life and are not isolated from other experiences. These theoretical perspectives highlight the importance of exploring people's experiences of hearing voices and sounds in daily life and over time.

Everyday life experiences are often termed lived experiences in hermeneutic phenomenological research. Max van Manen (2007), also a philosopher, has been engaged in research on lived experiences in the research tradition he termed hermeneutic phenomenology. Van Manen's main interest has been the process of questioning, reflecting and writing within this field of research. He argued that lived space (spatiality), lived body (corporeality), lived time (temporality), and lived relations (relationality) are fundamental aspects of lived experiences and useful categories which can guide inquiry. It is worth noting that these themes are not isolated from each other, but interconnected and do not exclude other aspects of lived experience. From my perspective, these themes have pedagogic value by underscoring that we are situated in time and with others as embodied beings, and that we as health care providers or researchers must not overlook these themes when attempting to understand peoples' experiences of hearing voices and sounds. These experiences are often termed inner, subjective or unreal (see also Section 2.2 above). Van Manen (2007) did however suggest that the themes he proposed, or existentials as he calls them, transcend all human experiences regardless of people's historical, cultural or social situatedness. This is a departure from Merleau-Ponty's perspectives, because Merleau-Ponty focused on our directedness toward and situatedness in the world.

## **5.0 Methodology and methods**

Researchers commonly emphasize the importance of method, even within hermeneutic phenomenological research (Fleming, Giadys, & Robb, 2003). The German philosopher Hans-Georg Gadamer maintained, however, that understanding has been “far too dominated by the idea of a procedure, a method” (Gadamer, 2004, p. 291). He argued that our only opportunity to acquire new understanding or reach beyond the confines of our own suppositions arises when we expose ourselves to opposing views (Gonzales, 2006). Understanding evolves only when our pre-understandings, prejudices or pre-judgments are put into play. The process of understanding is thus a negative experience since it involves refuting former understanding as fresh understanding emerges.

Dialogue, with its pattern or rhythm of questions and answers, is fundamental and guides all understanding, according to Gadamer. He emphasized that in true dialogues the questions one poses are open or critical; one does not seek to confirm what one already knows, but attempts to be open to the possibilities which lie in the answers. This also applies to the process of understanding texts (Gadamer, 2004). Gadamer stated that it is a

“hermeneutical necessity to always go beyond mere reconstruction. We cannot avoid thinking about what the author accepted unquestioningly and hence did not consider, and bringing it into the openness of the question.” (Gonzales, 2006, p.367)

It is worth noting that understanding is not so much a subjective act as it is “participating in an event of tradition, a process of transmission in which past and present are constantly mediated” (Gadamer, 2004, p. 291). Understanding is in itself a historical event; it takes place at a specific moment in time and place and is always situated (p. 312). Fleming et al. (2003) proposed five steps that should guide nursing researchers conducting Gadamerian-based research. These are: (a) deciding upon a research question, (b) identifying pre-understandings, (c) gaining understanding through dialogue with the participants, (d) gaining understanding through dialogue with texts and (e) establishing trustworthiness. These steps have guided the present studies.

## **5.1 The research project**

We conducted two studies in which the experiences of hearing voices and sounds in daily life were explored: the first study involved the experiences of people without a psychiatric diagnosis (Study I) and the second study involved the experiences of people with a psychotic illness (Study II). Both studies were conducted in Northern Norway and the participants were mainly from that part of the country.

## **5.2 Recruitment of participants**

We recruited the participants to both studies through an article in a local newspaper and a periodical on mental health. We also posted advertisements in several newspapers and flyers at a university campus and a hospital (see appendix II). Health care providers assisted us in recruiting the majority of the participants with a psychotic illness (Study II) by giving oral

and written information and consent forms to those who met the criteria (see appendix II). Common criteria for participants in both studies were that they were adults and had repeatedly heard voices and/or sounds no one else had heard for at least a year. An additional criterion in Study I was that the participants did not have a psychiatric diagnosis, whereas in Study II we required that the participants had a psychotic illness. To ensure that the participants in Study II were capable of giving informed consent, qualified health care providers were specifically instructed to consider this aspect when informing and handing out written information about the study to those meeting the criteria for participation. They also distributed addressed and prepaid envelopes along with the consent forms.

Several people (6) contacted us about participating in the study after having read the articles in the local newspaper or in the periodical on mental health. We gave the respondents oral information about the respective studies and sent written information to the only person who met the criteria for participation in Study I. One of the respondents who had a psychotic illness asked me to send the written information about Study II to his therapist, after I had explained the procedures for recruitment. Another respondent who was no longer receiving treatment for her psychotic illness received the written information and consent form for Study II directly, after I had conferred with the ethics committee.

We recruited the majority of the participants in Study II from outpatient units (seven (eight)), and community based mental health services (five). Those interested in participating in the study contacted me directly. I was acquainted with three of the participants prior to participation. Their participation in the study had not been discussed before they volunteered.

Most participants were recruited during the years 2008 and 2009. One participant was recruited in 2010. There are several reasons for the long period of recruitment. Many health care providers reported that they had limited capacity to be of assistance in recruiting participants with a psychotic illness. Some found it difficult to introduce the theme of participation, because it might jeopardize a delicate alliance or tight time schedules. Health care providers reported that many respondents meeting the criteria of hearing voices and sounds were unable to give informed consent during hospital stays and some had additional complaints, e.g. cognitive disabilities. Some of those whom received information about the study were unwilling to take part. One participant withdrew her consent before the interview commenced without giving a reason. Health issues also restricted me during several periods of the study.

### **5.3 The participants**

#### *Study I*

A 75 year old woman was included in this study. She had heard voices for nine years (first time at the age of 66). She had resided alone in an apartment in the same building as her daughter and her daughter's family for many years after getting divorced. She had close and trusting relationships with her family, friends and neighbors. She had been employed until she retired and was engaged in charity work and a number of hobbies at the time of the interviews. She was physically fit except for hypertension and knee and hip pain causing her to use a cane.

## *Study II*

Fourteen people, eight women and six men, with ages ranging from 19 to 57 (median age: 39) were included in this study. They had been hearing voices and sounds for two to 39 years and their ages when they first experienced these voices and sounds ranged from 8 to 32 (median age 16). All of the participants had previous experiences of hearing voices daily. At the time of the study, seven participants heard voices daily, six participants occasionally heard voices, and one started hearing them daily during the study. Nine participants reported having diagnoses in the schizophrenia spectrum. Three reported having combinations of other diagnoses, such as personality disorder, posttraumatic stress disorder (PTSD), and depressive psychosis. One participant had received a schizophrenia diagnosis, but was also being reassessed for PTSD at the time of the study. One participant was unable to disclose a diagnosis. Instead she showed me the medication she was taking, which included both anti-depressant and neuroleptic medication.

All of the participants had used neuroleptic medication; 13 of them had extensive experience. At the time of the interviews, nine participants were taking neuroleptics. Eleven of the participants had been subjected to involuntary hospital admissions. Seven resided alone, while four lived in supported accommodation and three with their families. One participant was married. One of them was a widow and five had once lived with a partner. None of the six participants who had children resided with their children, who were mostly adults living on their own. Most of the participants were unemployed and received disability pensions (11); three of them worked part-time and three attended school full- or part-time.

## 5.4 The interviews

I asked the participants in Study II to relate what it was like for them to live with hearing voices or sounds. Furthermore I posed follow-up questions to clarify details and encourage the participants to elaborate on matters that seemed relevant. Additionally, I presented reflective statements to ensure mutual understanding and used questions from the interview guide (see Appendix III) as prompts when required. I conducted the interviews in the anticipation that each interview would contribute to a hermeneutic learning process and did not seek to confirm presuppositions or emerging theories (see Section 4.0, Binding & Tapp, 2008 on genuine dialogue and openness of the question). Talseth conducted the interviews in Study I similarly. The interviews were digitally recorded and transcribed verbatim, with the exception of one interview, where I took notes throughout and immediately after this interview, because the participant objected to having it recorded.

I established the location, number and timing of the interviews according to the participants' preferences, within a limit of three interviews per participant. Most participants (nine) took part in two interviews, three participated in one and two participated in three. The total interview time for each participant was approximately 1.5 to 2.5 hours. Most follow-ups took place within a month (11), while three took place within six months. Most participants preferred to carry out the interviews at home (12), but two preferred to meet me at my workplace. One follow-up was conducted by telephone as requested by the participant. Talseth interviewed the participant in study I at home in January and November 2009. These interviews totalled about five hours. The total number of interviews was 29.

## 5.5 Ethical considerations

The studies were approved by the Regional Committee for Medical and Health Research Ethics in Northern Norway (P REK NORD 48/2008 and 118/2006) and the Norwegian Social Science Data Services (NSD Nos. 18783 and 15313) (see Appendix II). Nonetheless ethical reflections were also made throughout the research process (cf. Estroff, 1995; Fog, 1999; Kvale, 1996). The health care providers were specifically instructed to consider participants' potential ability to give informed consent when they informed them about the study and handed out the written information and consent form about the study. Additionally, when I met the participants, I established that they understood that they were free to withdraw from the study at any given moment and that whether they participated or withdrew, it would have no consequences for their treatment. I took special care to ensure that the participants I knew were aware of this.

I informed the participants orally and in the written information about emotional reactions that might be triggered by the interview and that, if requested, I would assist them in contacting the recruiting clinician (Study II). Before the interview commenced and when speaking of emotionally charged matters, I assured the participants that they were free to set limits for the length and depth of the interview or take a break if needed. At the closing of each interview, I encouraged the participants to convey their experiences of the interview and whether they wished to do anything differently in the follow-up. None of the participants withdrew from the project or requested assistance. Several of the participants had made arrangements to ensure that they also had someone to talk to after the interview. I carefully

modified identifying characteristics to avoid identification of the participants while preserving the meaning I understood to be conveyed in Study II, and Talseth did the same in Study I.

## **5.6 Text analysis**

We used the models outlined below as practical guides for the analysis of the transcribed interviews and notes.

### *The analysis in Study I*

In Study I, the co-authors and I followed the suggestions of Graneheim and Lundman (2004) for qualitative content analysis, with a focus on the latent contents of the texts. This model involved gaining an overall understanding of the content of the interviews by reading through the texts several times, before attending to detailed written analysis of the content. The initial step in the written analysis involved dividing the texts into meaning units (i.e. words, sentences and phrases) that were related to the aim. The next step included sorting the meaning units that shared commonalities into categories. The categories referred to the descriptive level of the texts. The meaning units were then condensed and subthemes and themes were formulated based on these condensations. The subthemes and themes denoted the interpretive level of the texts. The co-authors of this article carried out the analysis together before I read through and commented on the themes and subthemes. Finally we reflected together on the results in light of relevant literature (cf. Article I).

### *The analysis in Study II*

In the second study (Articles II and III), the analysis was inspired by the approach outlined by Fleming et al. (2003) based on Gadamer's hermeneutic philosophy. This approach involved the following four cyclical phases. The first step included writing down an overall understanding of the texts after having read them several times. Instead of reading through all the texts as one, as described by Fleming et al (2003), I chose to focus on each text unit separately in the first stages of the analyses. A text unit comprised transcripts of the interviews and follow-ups, along with notes taken after each interview regarding each participant. The next steps included exploring the meanings of sentences and sections, i.e. meaning units, in detail. I formed written interpretations based on these investigations and the co-authors and I reflected on them together. I also formed themes based on these interpretations and challenged the overall understanding of each text unit. Then the co-authors challenged these and I revised them. After this, I put into writing a comprehensive summary of the commonalities, nuances and differences encompassing all the text units and reread the themes and subthemes before revising them. When we had reached a shared understanding, that is when our understanding and those of the participants corresponded and our understanding of the entire text corresponded with its parts, we concluded the analysis. Finally, I included phrases that enlightened our understanding of the themes and subthemes in question and reflected on the results in light of relevant literature. I used the computer software NVivo 8 (QSR International, 2008) in the initial phases of the analysis and to organize the analyzed transcripts and vast amount of notes made throughout the study.

## 5.7 Methodological considerations

Researchers have not been able to reach a consensus on what constitutes the quality of qualitative research, the means by which the quality can be determined or improved, let alone the terminology that should be used (Fleming et al., 2003; Graneheim & Lundman, 2004; Guba, 1981; Reynolds et al., 2011; Sandelowski, 1993; Whittemore, Chase, & Mandle, 2001). Guba (1981) outlined the following four criteria for evaluating trustworthiness: credibility, dependability, conformability and transferability. Qualitative researchers have most commonly used the concept of trustworthiness. Whittemore et al. (2001) argued nevertheless that the concept of validity should be used, because it is well known in the whole research community and because validity is defined as “the quality or state of being sound, just or well-founded” which is highly relevant in all research. According to these authors, primary criteria of validity consist of credibility, authenticity, criticality, and integrity. Secondary criteria consist of explicitness, vividness, creativity, thoroughness, congruence and sensitivity (Whittemore et al., 2001).

Nevertheless, there are some generally accepted scientific principles which I have chosen to assure the quality of the present project. Based on a review and synthesis of 37 articles on quality assurance of qualitative research, Reynolds et al. (2011) found two main narratives reflecting contrasting approaches. The first narrative focused on quality assertion centered on the results, whereas the second narrative emphasized the scholars’ practices throughout the research process. Reynolds et al. (2011) suggested that these two narratives should be brought together to provide a flexible framework in which researchers can demonstrate principles of quality in their work. Inspired by Reynolds and colleagues’ suggestion, I will illuminate how

we might have reduced or enhanced the quality of the research throughout the research process and the results.

The overall aim of the research project was to contribute to an understanding of peoples' everyday experiences of hearing voices and sounds. Recruitment of the participants proved to be challenging and time consuming. To enhance recruitment and a collaborative explorative atmosphere in the interviews, we used phrases and concepts that were neutral, such as 'hearing voices and sounds others do not hear' instead of common medical and psychological terms, e.g. 'auditory hallucinations'. Certain concepts and phrases can be stigmatizing for the participants, hinder participation and impede openness (Enosh & Ben-Ari, 2010). One person who had read the newspaper article about the studies telephoned to convey his dismay with the perspectives he believed we had, namely that all people who hear voices are ill. He was probably not the only person to have misinterpreted the article despite the care we took to be clear about this point. Andrew, Gray, and Snowden (2008) revealed that recruiting voice hearers without a diagnosis can be difficult because voice hearers from certain milieus are sensitive to suggestions that associate hearing voices with severe illness. Enosh and Ben-Ari (2010) stated that there should be a dialectic interaction between the researchers and participants regarding e.g. negotiating concepts and the focus of the research project.

There are several possible reasons for the low response from participants in Study I. Firstly, epidemiological studies show that there are fewer people without psychiatric diagnoses who hear voices frequently over time (see Section 1.3). Restrictions concerning time, funding and my health were prominent factors which contributed to shifting the study design from several

participants to the one in Study I and the prolonged recruitment period in the second study. Having a limited number of participants enabled us to focus thoroughly on the narratives of each participant and gave us the opportunity to report on findings that may otherwise have been overlooked. Participation by both men and women in Study II enriched the data. Although the number of participants in Study II provided abundant data, it should be noted that there were no participants over the age of 60. Experiences from older people might have increased the richness of the data and results in Study II.

In the interviews I also avoided using medical expressions unless the participants used them first. Several interviewees spoke with certainty of the identity of the voices they heard. When referring to this in further questioning, I spoke of the voice as “the voice you believed to be...”, or “the voice that sounded like...”. Several researchers have argued that the quality of interviews depends on whether the interviewers promote a tolerant and non-judgmental atmosphere to enable the interviewees to convey their experiences and perspectives (Binding & Tapp, 2008; Lindseth & Norberg, 2004). By conducting open interviews and follow-ups, we also ensured that the participants had the opportunity to add to or adjust their narratives and we could explore questions that arose in afterthought and uncover misunderstandings. Several participants emphasized that being able to meet the researcher several times allowed them the opportunity to establish trust. Many participants disclosed or elaborated on important aspects of their experiences in the second interview which they had only subtly indicated in the first. Having several dialogues also enhanced the learning processes of both researchers and participants. Several participants pointed out during the interviews that they had not previously reflected on the matter in question (Article II). For example, in the first

interviews it did not occur to me that not all participants would share information about their habits regarding alcohol or drugs without being asked. When I discovered this, I began to pose questions about these matters if the participants did not volunteer such information in the remaining interviews. The quality of the interviews was good. The participants had relevant and varied experiences, they were eager to narrate and contribute to our understandings. To make sure that the 75 year old participant in Study I did not have cognitive impairments such as found in dementia, she was asked to take part in a Mini Mental State Exam (MMSE), Part I. This interview was chosen because she reported that her physician had dismissed a psychiatric diagnosis and her daughter, who was present when Talseth arrived, confirmed this information.

In the analysis of the interviews, we were attentive to the benefits and limitations of the practical guidelines outlined by Graneheim and Lundman (2004) and Fleming et al. (2003). Practical guidelines for the analysis of interviews are useful for novice researchers and can facilitate collaboration among researchers taking part in the same analysis. These authors emphasized that clarifying the meanings and uses of central concepts, procedures and interpretations may ensure that researchers have the same understanding of concepts that might have been adopted from different research traditions and different philosophical frameworks. Normative guidelines and criteria for interpretive approaches can on the other hand “overlook and flatten the features of philosophical thought that have the most potential to inspire such work productively” (Binding & Tapp, 2008, p. 123; Fleming et al., 2003). Whittemore et al. (2001) noted that creativity should be a part of the process and rigor should not hinder creativity. Qualitative researchers should “incorporate rigor and subjectivity as well as creativity into the scientific process” (p. 522). The guidelines of Graneheim and

Lundman (2004) did not explicitly address essential hermeneutical processes and concepts such as challenging pre-understandings, hermeneutic circling and the dialectics between questions and answers, as did Fleming et al., (2003; see Section 4.0). Nonetheless these essential hermeneutical processes were addressed in all of the articles (Articles I, II and III).

Instead of treating the interviews as one text, as suggested by Fleming and colleagues (2003), I analyzed the text units regarding each participant separately before compiling and comparing them. Thus I sought to ensure that we understood each participant's perspectives thoroughly. I also kept the themes as close to the participants' own words as possible while making sure that they also were unifying and abstract entities (cf. DeSantis & Ugarriza, 2000) in Study II. This ensured the authenticity of our results (Whittemore et al., 2001). When we had reached a shared understanding, namely when our own perspectives were integrated and our understanding of the whole corresponded with our understanding of its parts, I ended the analyses. We have had a substantial period of time to reflect on the interviews. According to Gonzales (2006), Gadamer maintained that time can help create the distance needed when trying to achieve a rigorous and valid understanding.

Fellow researchers, along with a number of voice hearers and people who were close to someone who was troubled by hearing voices also confronted my understandings and preconceived notions throughout the process. Comments from the journals' referees also led to new reflections and improvements of the articles. Challenging presuppositions is, as we have seen, an essential aspect of achieving valid understandings, according to Gadamer. The other authors and I challenged each other's preunderstandings and interpretations throughout

the analysis in Study II. Nonetheless I believe, in hindsight, that it would have been even better to have formed a reference group of voice hearers that could have provided their perspectives and challenged my perspectives and those of the other researchers throughout the research project. To evaluate and assure the quality of this research, we have focused on the quality of both the research process and of the results in light of the chosen philosophy. In Sections 3.0 and 4.0 I established the philosophical underpinnings of the thesis and the methods. In the first article we referred to Guba's (1981) criteria and in the last two articles we referred to Whittemore's perspectives on assuring the quality of the research.

## **6.0 Main findings in Papers I-III**

Article I: In this article we illuminated how a woman without a mental illness experienced hearing voices over a period of several years after being bereaved. We found eight themes to be central in the participant's accounts of hearing voices at two different points in time, initially and at present. These were synthesized into the following four main themes. (a) *Transitioning from being upset to being at ease, when home alone and hearing voices and sounds.* The participant heard voices from outside her home and from different rooms in her apartment when she was alone at home. At first this upset her. It was difficult for her to sleep or be alone and she often ended up wandering around her apartment or escaping to her daughter's place to relax and sleep. Ultimately it no longer mattered if she was alone at home or not when she heard the voices.

(b) *Changing from being fearful and uncertain to angry and confident when dealing with the voices and sounds.* At first the participant was afraid of the voices, angry, unhappy and terrified that she was losing her mind and developing a mental illness. She contacted her doctor about the voice hearing, but he did not think the experiences were symptoms of mental illness. Eventually she convinced her family that she was sane in spite of hearing voices. She was relieved when they believed her. She became more confident, less fearful of the voices and sounds and became angry with them. She set her mind on being able to be home alone, especially at night, despite hearing the voices and found a number of ways of dealing with the voices, such as singing songs, reading the Bible, doing household chores, and firmly dismissing the voices. Eventually she could relax at home despite hearing the voices. c) *Shifting from hearing voices and sounds frequently and repetitively to infrequent intermittent*

*voice hearing*. Initially she recurrently heard voices all through the day and during the night when she was home alone. Eventually she heard the voices and sounds intermittently, mainly at night when she was alone and attempting to sleep and during spring and summertime.

(d) *Developing from perceiving the presence of others who were absent to sensing closeness to significant others*. The participant was mourning a relative when she began to hear his and other relatives' voices. She was convinced at first that she actually heard these voices and her family disbelieved her. Eventually her close family believed her and she was able to confide with them. This relieved her of her sense of loss, reduced her fear and provided a sense of being close to her immediate family.

Article II: In this article we found that the participants' experiences varied greatly both among those who reported having schizophrenia diagnoses and among those with other diagnoses. The following themes and subthemes encompass central aspects of their experiences of hearing voices and sounds. *The participants were varyingly convinced that they (a) heard someone else or themselves*. Many participants were repeatedly "almost completely convinced" that someone else was speaking when the voices were active and intense and the participants felt bad (i.e. were anxious, exhausted, depressed or in psychosis). In less intense or quiet periods, all but one participant perceived the voices "as if" they came from someone else and deduced that the voices stemmed from themselves (Article II, p.1473). Their experiences varied between (i) hearing the voices of someone in particular (e.g. family members, friends, women or men that resembled someone they knew), (ii) hearing sounds made by people (e.g. the buzz of a crowd, church bells chiming, telephone ringing), and (iii)

experiencing the voices as something originating in themselves (e.g. echoes of their emotions, thoughts and recollections or traces of others in them).

*The participants were (b) terrified of losing their minds.* When they discovered that others could not hear the voices and sounds and when these voices intensified, the participants dreaded that they were losing their minds. Those who had been unable to take care of themselves in periods while they were depressed or in psychosis realized that their minds were not completely and indeterminately lost. *The participants experienced (c) daily life as recurrently dominated by opposing voices:* (i) hearing voices in the background made daily life harder, whereas (ii) hearing convincing voices disrupted daily life. Most participants were attentive to the voices even when they were faint and they lived in apprehension even when they were absent, because they were uncertain of when or if the voices would reappear or intensify.

Article III: We understood the participants to be in different phases of personal trajectories with initial, intermediate and final phases following a linear pattern for some and a cyclic pattern for other participants. The following themes and subthemes illuminate important aspects of how the participants experienced dealing with the voices and sounds they heard.

*(a) In the beginning and in intense phases, the participants tried to block out the voices and sounds* by: (i) keeping busy and trying to carry on as usual (e.g. attending school, work or other activities) (ii) avoiding talking about the voices and sounds they heard and (iii) resorting to desperate measures to achieve relief (e.g. attempting self-harm or suicide). *(b)The participants navigated the health care services* by (i) talking about hearing voices in due time,

that is, they waited until they were ready or desperate to talk to someone and had found someone they trusted. They also (ii) negotiated the wanted and unwanted effects of medication.

*In final and less intense phases, the participants (c) struggled to come to terms with limitations related to hearing voices and sounds through (i) learning to live with hearing voices and sounds by recognizing patterns, (ii) approaching acceptance and identifying possibilities and (iii) making sense of hearing voices and sounds. The participants distinguished between the voices they could easily ignore and those they were forced to deal with immediately. Many had accepted that they could not be rid of the voices and decided that they would make the most of their lives, despite these experiences. Many participants pondered over the voice messages and tried to resolve the issues they addressed.*

## ***7.0 Overall understanding and reflections***

The aim of this thesis was to contribute to the understanding of how people experience living with hearing voices and sounds in everyday life and over time. We have examined how a woman without a psychiatric diagnosis experienced hearing and dealing with voices and sounds over time. We have also attempted to understand how 14 people with psychotic illnesses experienced hearing and dealing with voices and sounds in daily life. The participant without a psychiatric diagnosis had much in common with most of the participants who had a psychotic illness; they all found living with hearing voices and sounds to be recurrently upsetting. However, the participant in Study I did not need to deal with other mental burdens in the same way as those with a psychotic disorder, since her daily life was less frequently disrupted and she did not have to navigate mental health services (Articles I, II and III).

In my overall understanding, the participants' experiences of hearing voices and sounds came forth as other people's intentions resounding in them; they mostly repeatedly disrupted their lives and sometimes comforted or supported them. The participants experienced the troublesome voices and sounds as the intrusive presences of people and/or divine or otherworldly presences and something deriving from themselves. Mostly, these presences echoed and amplified past and present adversity and future concerns and disrupted the participants' lives. Most participants lived in a continuous state of apprehension because these presences repeatedly and forcefully occupied their attention and evoked or amplified an array of unpleasant emotions. Some participants also experienced the reassuring presences of someone and/or divine or celestial presences which echoed and amplified past and present experiences of happiness, comfort and hope (Article II).

The participants attempted to become or remain independent and lead ordinary lives despite the periods of daily discouraging and exhausting struggles with the disrupting audible presences or the prospects of such periods (Articles I, II and III). They experienced dealing with the voices and sounds differently in the initial, intermediate and final phases according to how intense and troublesome the voices were. Most participants were distressed by the opposing presences in the initial and intense stages and tried to block them out, hoping they would vanish or fail to return. Eventually the participants with a mental illness, some sooner than others, became exhausted and their sense of being overwhelmed and powerless increased. Then most turned to desperate measures for relief, such as self-harm or suicide, which led to contact with mental health care services (Articles II and III). Eventually in the final or less intense phases, the participants engaged in struggles to come to terms with the limitations related to recurrently hearing the presences (Articles I and III). I will now reflect on the following themes: (a) perceiving presences and being perceived by them and (b) dealing with the presences and the challenges they posed.

## **7.1 Perceiving presences and being perceived by them**

In the present studies the participants experienced hearing someone who was absent. They were unable to substantiate the sources of and locations of the voices and sounds through other senses (e.g. the participants entered the room from which they perceived the sounds were coming or turned to see if the voices they heard from behind were there (Articles I and II)). When or if the participants asked other people about these experiences, they could only confirm this inconsistency. Some heard voices from within their bodies and therefore found it unlikely that others could hear these presences, although they were not always entirely

certain. Over time they recognized distinctive patterns in the voices, and thus realized that these were individual sensations not shared by others. They did not experience these presences as being mere figments of their imagination, memories, thoughts and emotions. Yet most participants also mainly acknowledged that the voices resembled them and derived from themselves (cf. Article II). We found that the participants were aware of the fact that these were unusual and unshared sensations most of the time, because they lacked the fullness of ordinary perceptions (cf. Merleau-Ponty, 2003). Our results underscore that the aspects of lived experience which Van Manen (2007) found essential (spatiality, relationality, temporality, and corporeality, cf. Section 3.0) were significant aspects of the participants' experiences of the presences. The participants established for example where the voices did and did not derive from (spatiality and corporeality), whether others heard or did not hear the voices (relationality) and they recognized distinctive features over time (temporality). Our results concur with those of Hoffman, Varanko, Gilmore, and Mishara (2008) which showed that people with schizophrenia mostly discriminate between their verbal thoughts and hearing voices.

The participants essentially perceived the presences as being directed toward them. The remarks or sounds implied that someone saw the participants, knew them intimately and could address their thoughts, emotions or actions without being present. The tones and contents of these puzzling perceptions echoed and amplified past, present and future experiences and concerns, and resounded with varying intensity in the participants (Articles I and II).

Although the participants established that these voices and sounds were perceptions of another kind, they came forth as having the value of reality. When emotionally distressed, the participants reported that they were almost completely convinced that these presences were

mutually shared perceptions. This could be related to the fact that the experiences of the presences were packed with affectivity striking them in their being (Merleau-Ponty, 2003). Many of the participants related that they had been or were depressed in addition to struggling with anxiety and that they associated this with hearing the voices. Researchers have found that there often is a close relation between the emotional state of people who hear voices and their experiences of hearing voices, regardless of the diagnostic divide between affective and psychotic disorders and having a mental disorder or not. Several researchers have for instance found that people who hear voices are more often depressed and anxious (Beavan, 2010; M. Birchwood & Chadwick, 1997; de Leede-Smith & Barkus, 2013; Krakvik et al., 2015). Max Birchwood, Iqbal, and Upthegrove (2005) also suggested that people with psychotic illnesses who hear voices can be moderately to seriously depressed as a reaction to being troubled by hearing voices.

The tone of voice was essential to how the voices resounded in the participants; most of the participants heard voices with negative tones (Articles I and II). Tone of voice is mainly understood as the way one conveys verbal messages and reveals the intent of the person speaking. The tone of voice adds emotional significance to a verbal message and increases its power (Schirmer, 2010). Researchers have shown that critical comments from significant others and their tone of voice, termed as expressed emotion (Butzlaff & Hooley, 1998) and perceived criticism (Keith, 2008) can lead to increased distress and relapse among people with psychotic disorders. Connor and Birchwood (2013) suggested that the expressed emotions of voices can also be related to increased distress and suicidal thinking. The voices the participants heard could be understood to have several layers of meanings and in the following I will reflect on some of the most significant layers.

### ***Presences amplifying experiences with other people***

Many of the participants had had painful experiences with people who had violated their limits of intimacy and who had disregarded their feelings, thoughts and needs. These participants had experienced e.g. bullying, parental neglect, physical and/or sexual abuse and a few had been raped under violent circumstances. A number of participants also mourned the loss of significant persons (e.g. a grandparent, cousin, spouse, or long-term separation from a parent due to divorce (Articles I and II)). These findings corroborate the results from a study of the prevalence of hearing voices in the Norwegian population (Krakvik et al., 2015) and a number of other studies (see Section 2.3). These studies showed that voice hearers had more often experienced trauma than people who do not hear voices, and that people who hear voices and have received mental health services more often have experienced multiple traumas.

Most participants associated the voices and sounds with traumatic encounters with others, because the voices commenced after these events. Many participants also immediately identified the voices by their tone of voice, the phrases or the themes the voices addressed (Articles I and II). Others suddenly realized who the voices resembled after years of hearing them and tied them to abuse they been subjected to (Article II). Most of those who had survived abuse heard voices telling them they should hurt or kill themselves (Article II). These findings support other research showing that people who had prior experience of being abused were more likely to hear voices commanding them to harm or kill themselves (Read, 2005). Several participants described perceiving the presence of late relatives dear to them;

some found this comforting, while others experienced it as frightening. The woman in the first study became fearful when hearing the voices of her deceased cousin and other relatives. A woman in Study II was, however, comforted by hearing the voice of a deceased relative (Article II). Experiences of abuse or the death of someone close can resound differently in us according to the relationship we had with the person, the type of trauma or how they died and whether we are young or old. It is nonetheless noteworthy that not all participants associated the themes or contents of the voices and sounds with trauma.

Our results corroborate the findings of other researchers who have found that the onset of hearing voices was often reported to be related to traumatic experiences (Romme & Escher, 1989). Although researchers have established a clear link between trauma and experiences of hearing voices (see Section 2.3), not all experiences of hearing voices are related to trauma. Hardy et al. (2005) found for instance that 40 of 75 people with schizophrenia spectrum disorder had encountered trauma. These researchers found thematic links between the voice experiences and the trauma these participants had encountered in more than half (23) of the participants, in addition to links between the voice content and trauma in five of them. They did not examine how the participants themselves associated trauma and hearing voices and sounds. Some researchers have attended to this question (Beavan, 2010; Corstens & Longden, 2013; Ensink, 1992; Romme et al., 2009). Voice hearers in Romme et al. (2009) revealed that associating the experiences of hearing voices with trauma was a process that was highly individual and took time for many. These aspects could also be understood in light of Morris when he referred to the weight of the past in perception in Merleau-Ponty's philosophy and wrote, "Present perceptual activity only operates by being incongruently lined with a weight

of the past to which we are passive, yet which is transformed in learning and habit acquisition” (Morris, 2010, p. 11).

The time and place the participants experienced hearing the voices and sounds also influenced how they experienced the presences and how the voices and sounds reverberated in them. It is for instance worth noting that most of the participants found it especially distressing to sense the presences when trying to fall asleep or rest. These experiences made it difficult for them to acquire enough rest and sleep (Articles I and II). Most participants in Study II also related diminished quality of rest and sleep to increased risk of psychoses. Hearing intrusive voices while lying in bed and trying to fall asleep appeared to increase the participants’ sense of vulnerability and being at the mercy of others. Most of the participants’ experiences of hearing someone involved a sense of being observed or under surveillance whether they were at home in privacy, at work or in hospital. It was as if they immediately and continually received evaluations from others. While some heard voice messages that addressed their current situation and came forth as dynamic, others heard repetitive and more static messages. Yet many of the participants perceived the voice comments as reflecting the attitudes they anticipated others had toward them. The participants who were receiving mental health care were in fact under surveillance and constantly evaluated by others. A health care provider whom Lorem (2014) cited, used the analogy of “fish in an aquarium” to describe how health care providers actually monitored and evaluated people’s every move in a rehabilitation unit (p.135).

The participants' experiences of sensing the audible presences also led to new hurtful and demanding experiences with other people. Many had experienced that others had not believed them, had not understood and/or had dismissed their experiences. Thus these experiences created or maintained a void between many of the participants and others. The woman without a mental illness was significantly more distressed by the voices when her family worried that she was ill and disbelieved her claims of being well despite hearing the voices (Article I). The difficulties the participants had acquiring rest, because of the disrupting presences, could be related to how they anticipated that others saw them, such as just being lazy and not ill or troubled with fatigue. Hearing the voices and sounds recurrently diverted the participants' attention to themselves and their limitations even when they were at home.

### ***Presences of existential magnitude***

I suggest that the presences represented an existential threat to the participants. All the participants feared that these experiences meant they were seriously ill and were losing their minds, when they realized that they alone heard the voices and sounds. They feared that, instead of being healthy and becoming or remaining independent, they would be permanently insane, disabled and dependent on others. They were terrified of losing control over themselves, being controlled by the voices, being alienated by others or seen as unaccountable (Articles I and II). The demeaning messages the participants in Study II heard telling them for example to hurt or kill themselves could also be understood in this light. The presences the woman in the first study experienced could be understood to amplify her vulnerability in relation to others and mortality (Articles I and II).

Additionally, the participants' fear of losing their minds could be understood as expressing that they were experiencing the unbearable. Benjamin (1989) revealed that some people with schizophrenia reported that the voices appeared at moments of extreme pain and in situations they perceived as insufferable (e.g. incestuous abuse). Kilcommons, Morrison, Knight, and Lobban (2008) suggested that the sexual assaults people with psychosis had endured shattered their basic assumptions of themselves (e.g. self-worth and vulnerability), of others and of the world (e.g. trust, justice, equality and danger) and that this was reflected in their experiences of the voices. Furthermore, many of the participants with a psychotic illness (Study II), not only experienced the voices as hindering them in managing daily life, but as jeopardizing their future. Most were unable to lead a normal life, to work, finish school or fulfill their dreams of e.g. holding down a job, or living in a house of their choosing and having a family of their own. Initially they feared losing these significant opportunities in their lives and eventually many mourned these losses (Article II).

The functional impairments the participants suffered added new layers of meaning to their experiences of hearing voices and sounds. These findings coincide with those of Jones and Coffey (2015), who found that voice hearers with a mental illness were increasingly restricted by losses of e.g. valued social roles and acceptable identities and that their identity was “transformed in the eyes of others and internally within the person.” (p. 57). Bleuler (1950) observed that his patients' experiences of voices embodied “all their strivings and fears, and their entire transformed relationship to the external world” (p. 95). Our findings are similar to those related by people who experience other chronic illnesses, in which the symptoms (e.g. pain, diffuse or specific bodily changes) take on new meanings associated with the

implications the illness has in peoples' lives (Benner & Wrubel, 1989; Ervik, Nordoy, & Asplund, 2010; Kitzmuller, Haggstrom, & Asplund, 2013).

### *Hope, purpose and belonging*

It is worth noting that although hearing voices amplified existential anguish for most participants, some also experienced audible presences which conveyed a sense of hope, purpose and belonging with others or something greater than them. Some also experienced them as sources of company, insight or correctives (Article II). These participants' voice experiences could be understood to reflect benevolent and life-affirming experiences, in addition to self-compassion, as suggested by Davies, Thomas, and Leudar (1999). Our findings showed that the content of the voice messages could not only be categorized as positive, negative or neutral. These results coincide with those of Fenekou & Georgaca (2010) and of Beavan (2010) revealing that voices could provide "advice, guidance, encouragement, criticism and comments" (p. 203). Harrison et al. 2008, found that half of the participants they interviewed who had a schizophrenia diagnosis heard voices they termed as "psychic, spiritual or religious" and found them to be guiding and helpful (p. 18). It is worth noting that the board of DSM-IV acknowledged that psychotic-like experiences with positive outcomes are not necessarily pathological and categorized them as "religious or spiritual problems" under "other conditions that may be the focus of clinical attention". The experiences of the woman in Study I and some of those in study II could additionally be understood in light of this perspective.

Several of the participants initially heard comforting voices which diminished and gave way to troubling voices, whereas one participant began to hear an encouraging voice when she was in the process of recovering. These results could be understood to reflect a diminishing or emerging sense of hope; such findings coincide with those of Connor and Birchwood (2013), who found that people with the lowest levels of depression and suicidal thoughts heard emotionally supportive voices. Our results showed that the participants perceived the presences against a background of a multitude of significant and mainly pre-reflective layers comprising previous experiences, their current situation and future concerns, in accordance with Merleau-Ponty (2003) (see Section 4.0). The next section will be devoted to reflections on how the participants experienced dealing with the presences.

## **7.2 Dealing with the presences and the challenges they posed**

The results of this study revealed that the participants' ways of dealing with the voices and sounds could be understood as not only formed by the presences and the challenges they posed, but also as forming their perceptions. The participants' ways of dealing with hearing voices and sounds were closely related to whether they perceived the presences as deriving from someone else or themselves and why they heard them. Other important factors were how intensely they perceived the voices and the control they felt they had over them. Most participants experienced the voices as overpowering when they were intense and the participants were feeling bad, e.g. depressed or in psychosis, or vulnerable, e.g. lying in bed or being home alone (Articles I and III). These findings concur with those of other studies (Chadwick & Birchwood, 1994, 1995; Paul Chadwick, Susan Lees, & Max Birchwood, 2000;

Sayer, Ritter, & Gournay, 2000)<sup>9</sup> Harkavy-Friedman et al., 2003 showed that voice hearers' ways of dealing with voices are not merely related to their contents. These and other researchers have shown that when voice hearers resist, comply or engage with the voices this is based on whether they perceive the voices as malevolent, benevolent or omnipotent (Beck-Sander, Birchwood, & Chadwick, 1997; Chadwick & Birchwood, 1994, 1995; P. Chadwick, S. Lees, & M. Birchwood, 2000), as actually being someone else, and whom they perceive it to be (Erkwoh, Kunert, Willmes, & Eming-Erdmann, 2002; Harkavy-Friedman et al., 2003).

In the initial and intense phases, most participants attempted to block out the voices, whereas some continued to attempt this. I suggest we understand the participants' attempts to block out and resist the voices as not only acquiring relief from the presences, but also as attempts to avoid acknowledging the magnitude these experiences represented. This implies efforts to avoid acknowledging previous adversity and a sense of never-ending agony or mortality, the devastating prospects of being diagnosed with a serious mental illness, or that they might be on the verge of a new period of depression or psychosis (see Section 7.1). Some participants also struggled on a more fundamental level, which involved maintaining that they actually existed or had the right to exist as individuals (Article III). These participants were more or

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<sup>9</sup> These researchers examined voice hearers' experiences within the theoretical framework of cognitive theory and used the terms "beliefs" about the participants' perspectives on the voices they heard. I have refrained from using this term, because of the fundamental differences between cognitive theory and Merleau-Ponty's philosophy of perception (Merleau-Ponty, 2003).

less permanently convinced that the troubling voices were vicious and almighty and therefore they continually resisted them (Article II). The participants' attempts to block out and resist the voices could thus be understood as a way of survival while at the same time also being a hindrance to resolving or coming to terms with the issues the voices echoed or amplified.

The findings in our study revealed that many participants' uncertainty was related to when or if the voices would return. How strong and how long they would be troubled by them was a major challenge, even when the presences were faint or absent (Article II). Recognizing patterns such as when and how the troubling presences reoccurred and what they could do to find relief under shifting circumstances reduced this uncertainty. The fact that the intensity of hearing voices subsided and intense periods did not last forever also gave room for hope (Articles I and II). Some eventually became less uncertain in relation to the audible presences and more confident after having managed to prevent new rounds of upsetting voice hearing from developing before they became too troublesome (Article III).

### ***Retrieving or developing one's sense of having a voice***

Based on our findings, I suggest that we could understand the participants' experiences of dealing with the voices in light of the relationships they developed with the presences. Over time most participants' perspectives on the voices and their ways of dealing with them developed and became more multifaceted. Some participants began to engage with the voices they previously had seen as malevolent and therefore resisted (Article III). These results correspond with those of Sayer et al. (2000). Several participants discovered that their ways of relating to the voices were similar to how they related to the persons the voices resembled.

Upon discovering this, these participants explored and found new ways of relating to the voices (Article III). For one participant, this for example meant that when she managed to set limits for the expectations of other people, she also managed to set limits for the voices (Article III). These results are supported by Vaughan and Fowler (2004) who suggested that exploring and attempting to understand the relationships between voice hearers and their voices can provide important perspectives for understanding their coping strategies. These authors found that those who reacted with suspicion and avoided dialogue with dominating and insulting voices were more distressed. Nayani and David (1996) found that people who engaged in dialogues and intimate relationships with the voices were less distressed and better at coping with them. We should however note that there are important differences between relating to these presences and relating to other people (cf. Leudar & Thomas, 2000) and that voice hearers experience the voices as deriving from other people to a varying degree (Article II). It is also worth noting that religiousness or spirituality influenced several participants in relation to how they dealt with the voices; some were empowered and some were burdened by these perspectives. These findings are similar to those of Danbolt, Møller, Lien and Hestad, (2011) and Hustoft, Hestad, Lien, Møller and Danbolt (2012).

Romme and Escher (1989) suggested that voice hearers' coping strategies evolved through three different phases. The first of these was a startling phase, which largely involved escaping from fear and anxiety. The individual then advanced to the organizational phase, which involved seeking meaning and understanding in the voices. This then culminated in a final phase in which the voice hearers found more stable ways of coping with the voices. These authors' results concur with some of the findings in the present thesis (cf. Articles I and

III). Not all of the participants in Study II had sought meaning in the voices or found stable ways of dealing with the troubling presences, as we have seen. Several participants' relations to the voices could be understood to shift in a circular way from being startled and desperately seeking relief to using more stable or sophisticated ways of dealing with the voices, according to how intense the voices and sounds were and how the voice hearers felt. Other participants maintained that these experiences were merely symptoms of illness and dealt with them accordingly (Article III). Our results could also be understood to coincide with those of de Jager et al. (2015). These researchers revealed that some voice hearers' narratives of recovery involved turning toward the voices and making sense of them, while other voice hearers' narratives of recovery involved turning away from the voices. Those who turned away managed well by relating to the voices as mere symptoms they needed to manage and avoided attempts at making sense of them (ibid).

I also note that the participants were less troubled by the audible presences when they no longer took for granted that their messages were accurate and began to value their own perspectives and preferences. For example, several participants decided to quit harming themselves despite hearing voices that commanded them to do so. Others assessed and reformulated the voice messages (Article II). Several participants could not bring themselves to talk back to vicious voices although they strongly disagreed with them. Instead they found other ways of opposing them such as answering them back in writing, by keeping a diary or making imaginary writing with a finger on the bedcovers or by faking self-harm (Article III). The woman in the first study became more confident in relation to dealing with the voices and expressed anger instead of fear. She also involved her family members. These findings could be understood to coincide with the narratives of voice hearers who have managed well, such

as Debra Lampshire and Ron Coleman (Romme et al., 2009). Lampshire recounted that she began to recover and function in daily life when she started to evaluate the voice messages she heard and to believe that she was entitled to have her own opinions of the matters the voices addressed. Ron Coleman emphasized that finding and developing a sense of self-awareness and confidence represented a turning point and was essential to his process of recovery (Romme et al., 2009). Lampshire and Coleman both emphasized that receiving support from others was essential.

Several of the participants remained bitter and angry at the turn their lives had taken, the limitations and losses of opportunities. These participants perceived themselves as victims of the malicious presences with little hope of being freed from their tyranny and could be understood to lack belief in or seriously doubt their capacity to endure the troublesome voices and sounds, come to terms with them and recover (Articles II and III). Researchers have shown that depressive symptoms such as persistent and deep hopelessness and existential distress in people not in a psychotic phase can be related to chronic demoralization. This condition is especially linked to people who feel they are disabled and devastated by long-term illness and at a loss of controlling the illness (Hausmann & Fleischhacker, 2002). Many participants developed new perspectives on their experiences in the less intense periods of hearing voices. Several participants in Study II addressed the issues the voices echoed or amplified (e.g. mourning the loss of someone significant or being in contact with emotions difficult to express and dealing with trauma) (Articles II and III) and yielded to accepting that they had long-lasting limitations because of prior adversity and the repeated presence of opposing voices. Our results suggest that for some this acceptance made it possible for them to explore new ways of understanding and dealing with the voices they heard and facilitated

their recovery process. These participants' perspectives are corroborated by other voice hearers claiming that understanding and linking their experiences of hearing voices to their personal histories were important steps toward their recovery (Romme et al., 2009).

Researchers have shown increasing interest in the process of acceptance as an essential aspect of promoting well-being and recovery among those who live with chronic or recurring conditions, including psychoses (Abba, Chadwick, & Stevenson, 2008; Khoury, Lecomte, Gaudiano, & Paquin, 2013; Shawyer, 2007). An interesting aspect of acceptance is that it involves resisting any suggestion that the complaint is a sign of personal weakness (Sayer et al., 2000; Viane et al., 2003). It is not uncommon for people with long-term illnesses to avoid accepting the limitations of the illness or the fact that one has an illness at all. This avoidance could be understood as a "quest to be ordinary" (Benner & Wrubel, 1989). Many voice hearers have understood mental health care providers' general promotion of the view that hearing voices was merely a symptom of illness as underscoring that they were weak and eternally dependent on others e.g. health professionals and on medication (Romme et al., 2009). Based on the results of the present studies, I would also suggest it was essential for the participants to have something meaningful and purposeful to engage in and that this facilitated their processes of acceptance.

At the time of the interviews, several participants seldom found themselves hindered by hearing voices in daily life. They had maintained (Article I) or had acquired part time jobs and/or social activities they enjoyed (Article III). It is also worth noting that although many of the participants had been unable to work for years, they still had hopes and plans for future employment and they were involved in activities that might lead to employment (Article III).

Being employed or engaging in voluntary work can be a potent strategy to reduce the intensity of hearing troublesome voices (Delespaul, deVries, & van Os, 2002) and other burdens (Benner et al., 1994). Having hope for the future and a sense of belonging has also been documented to be of fundamental importance to the process of acceptance and to recovery (J.K. Hummelvoll, 2012). Deegan (2003) described her own recovery process from having long-term serious mental illness and troublesome voices. She wrote that her recovery was marked by an ever-deepening acceptance of her limitations; “in accepting what we cannot do or be, we begin to discover who we can be and what we can do” (2003, p. 15). The results of this thesis suggest that many of the participants were in the process of personal recovery. Personal recovery involves being in a personal and unique process of learning to live with continuous challenges and often involves having a sense of connectedness, hope and optimism about the future, identity, meaning in life and being empowered (Leamy, Bird, Le Boutillier, Williams & Slade, 2011). People can thus be in recovery despite persistent and troubling voice hearing.

### ***Navigating health care***

All participants with a psychotic illness had received mental health care, yet all but one had initially been reluctant to seek help for the troubling voices they heard. Several of the participants had contacted health care services for matters other than the troubling voices and sounds (e.g. eating disorders, addiction to alcohol or drugs or disturbing memories of abuse). Most of the participants ended up being involuntarily admitted to mental health care, although they desperately sought relief. One way of understanding their reluctance was that most had limited trust in mental health services and doubted that mental health care providers would be

able to help, understand and believe them or take them seriously. The participants feared being labeled as mentally ill and especially being diagnosed with schizophrenia (Article III). It is against this background that I suggest we understand the relief that the woman in the first study felt when she was assured by her doctor that she did not have a mental illness. Her increased confidence in dealing with the voices might also be understood similarly.

Mental health services of today provide dignified treatment with good hope of recovery, yet being a psychiatric patient is still heavily burdened with stigma which often hinders people in seeking help (Rusch, Angermeyer, & Corrigan, 2005). Many participants also regarded hearing voices as more stigmatizing than having a mental illness such as depression and even being dependent on alcohol or narcotics (Article III). The messages several participants heard (e.g. conveying that they need not eat, wash their hair before going out, or avoid eye contact with customers), could be understood to echo or amplify the notion that others and society disapproved of them or even despised them for having mental complaints (Article II). People are generally broadly aware of the close relationship between hearing voices and serious mental illness. The media often link hearing voices to schizophrenia and dangerous behavior such as violence and murder. Information about how common hearing voices is in the general population without it leading to mental illness has received considerably less public attention (cf. Leudar & Thomas, 2000; Simon McCarthy-Jones, 2012). The attitudes among politicians and government officials conveyed in public discourse regarding the burdening expenses of people in need of disability pensions can also fuel stigma in the general population and internalized stigma in these people.

Another aspect of the participants' reluctance to seek help could also be related to their unawareness of being in need of help or that they could be helped. The participants could be understood to be not only avoiding mental health services for lack of trust, but also for lack of words and awareness of what was troubling them. Initially it was difficult for the participants to explain how they heard the voices and sounds and how others could help them, thus creating a barrier to seeking health care (Article II). Sebergesen, Norberg, and Talseth (2014) found that, while some recognized changes such as more aggressive voices as sign of psychosis, others perceived these changes as signs of an unspecific illness. Those who were able to articulate their experiences and relate them to psychosis, and had close others who understood, were less likely to experience coercive treatment.

A central part of navigating health care for most of the participants involved a journey in search of medication that provided some measure of relief from the voices (Article II and III). Many participants acknowledged that the medication was helpful in hindering or reducing acute psychoses and depressions, but were less content with their effects on a daily basis. The medication generally gave relief from other complaints such as anxiety and depression and acute psychosis. Thus using the medication had an indirect effect on the participants' voice experiences and helped to make it easier for most to deal with them. Nonetheless it is worth noting that some participants reported that, even though some types of neuroleptic medication actually silenced the troubling voices, they found the side effects more troublesome than hearing the voices (Article III). Several participants also believed that the high doses of neuroleptics they were prescribed initially hindered them in addressing the emotional issues they needed to resolve. Our results show that the participants used, reduced or discontinued medication, especially neuroleptics, for different reasons. When discharged from hospital

several discontinued their neuroleptic medication, while others adjusted the doses according to how they felt or the circumstances they were in and managed fairly well (Article III).

These results coincide with the findings of researchers showing that the effects of neuroleptics are highly personal (Tandon et al., 2008). Our results moreover concur with those of scholars who have found that choosing to take or quit taking medication is not a one-time event, and related to one specific reason, but an ongoing process (P. E. Deegan, 2007; Roe, Goldblatt, Baloush-Klienman, Swarbrick, & Davidson, 2009). By adjusting or discontinuing their medication, the participants in our study could moreover be understood to be attempting to regain control over themselves and their lives. According to Benner et al. (1994) people with chronic illness found it difficult to accept that long-term medication was necessary. She pointed out that when people with a long-term illness did not have any prospect of being cured, they were placed in an ambiguous position, where they perceived themselves as having the option of being controlled by the illness or being controlled by or dependent on medication. Additionally, most participants were aware of the fact that the effects of neuroleptics are not only debated among people who hear voices and are in need of health care, but also among researchers and health care providers. Researchers and consumer movements such as Hearing Voices Network have argued that we lack substantial enough evidence to recommend the long-term use of neuroleptics (cf. Simon McCarthy-Jones, 2012, pp. 376-380). Based on the narratives of 50 voice hearers, Romme (2009) argued that physicians should not automatically prescribe medication to patients merely because they hear voices. It is nonetheless worth noting that many participants related that mental health services and pharmaceutical treatment contributed to improving their lives and promoted their recovery, in accordance with the findings reported by de Jager et al. (2015).

### ***Trusting, talking to others and being believed***

The results of this research project suggest that trusting and talking to others who believed them represented a turning point for the participants and could be understood as facilitating the process of acceptance and retrieving their sense of having a voice. The participants were not only attentive to the voices, but they were also attentive to how others perceived them. This formed a significant layer of their understanding of the voices and how they dealt with them. Upon realizing that others could not hear the voices they heard, most participants avoided engaging others in these experiences or withheld important information about the presences until they found someone they could trust (Article III). Most participants in Study II had lacked someone they could confide in regarding previous adversity and expected this to be equally difficult when it came to their experiences of voices. Many had long been, and some still were, generally distrustful and perceived themselves as powerless in relation to other people and in relation to the voices, as in the findings of Andrew et al. (2008). It is therefore worth noting that our results suggest that being believed by others provided the participants with confidence and helped to reduce their fear of the voices. At the time of the interview, most of the participants had at least one health care provider whom they could speak with openly about their voice experiences. Many participants described that they developed and adjusted their understandings of and ways of dealing with hearing voices and sounds through speaking about them with someone whom they trusted and who attempted to understand what they were experiencing (Articles I and III). These results are similar to those of Escher and Romme (2012;1998) who found that voice hearers wanted others to accept that they actually perceived voices that seemed to derive from someone else. Shattell, McAllister, Hogan, and Thomas (2006) suggested that it was easier for people with mental illnesses to understand themselves when others attempted to understand them. On the other hand, Hem

and Heggen (2004) illuminated how a patient experienced a psychiatric nurse's withdrawal from her diverging perception of reality as rejection.

Several participants in the present study conveyed that participating in a peer group for voice hearers was empowering, because they alternated between receiving support and giving support to others and received acceptance for their understandings of their experiences of voices and sounds (Article III). Their experiences coincide with those reported by other voice hearers (de Jager et al., 2015; Escher & Romme, 2012; Thomas, Bracken, & Leudar, 2004).

Most participants however, did not confide in other people such as relatives and friends.

These results coincide with those of Olson et al. (1985) and Rees (1971) who found that a substantial number of the widowers avoided talking about their experiences of hearing voices for fear of being laughed at. The participants in the present study emphasized that, in order to trust others, it was essential that others met them with a sense of believing them (Articles I and III). To my understanding, being believed involved having other people engage in what they were actually saying and attempting to understand. The Norwegian philosopher Hans Skjervheim (2001) claimed that if we engage in dialogue with someone who states something unlikely such as hearing voices others do not hear, we might take his or her statement as a fact and try to find out why he or she is saying this. Thus we become a spectator of the other person. Alternatively and preferably, we can engage in a dialogue about what he or she is saying. In this dialogue both parties are equal and engaged in the issues in the dialogue. I believe this participatory dialogue is akin to the genuine dialogue described by Gadamer (2004) and the kind of dialogue that promotes a sense of being understood and of mutuality. It

is worth noting that people can be forced into loneliness and isolation when nobody actually listens to what they have to say (cf. Lorem, 2005).

Furthermore, I agree with Binding and Tapp (2008), who argued that genuine conversation is fundamental to providing support and care in nursing practice, and argue that this should also include those who are troubled by voices and sounds. They highlighted that important elements of a genuine dialogue, according to Gadamer's perspectives, are openness, the essence of questions<sup>10</sup> and the concept of possibilities: "This position of awareness orients us to the potential differences and similarities between ourselves and the other" (Binding & Tapp, 2008, p. 125). In a conversation an understanding that extends beyond that of either party can become a common understanding between them. This is the opening of possibilities termed by Gadamer (2004) as "the fusion of horizons" (p. 378). Although understanding can collapse in relation to people's complex experiences of hearing voices and sounds, one should always anticipate that there is something one can understand and continue to be in dialogue, (cf. Lorem & Hem, 2012).

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<sup>10</sup> This refers to truly inquiring questions instead of questions to confirm what one already knows or assumes.

## ***8.0 Concluding reflections and possible implications***

The main purpose of this dissertation was to contribute to an understanding of how people with and without a psychotic disorder experience hearing voices and sounds and dealing with them in everyday life and over time. The results revealed that the woman without a psychiatric diagnosis had much in common with the participants who had a psychotic disorder, although her daily life was less frequently disrupted and she did not have to deal with other mental complaints or navigate mental health care. The participants were recurrently struck by the experiences of hearing someone; this echoed and amplified past and present experiences with others and existential magnitudes. The participants developed relations to and ways of dealing with the opposing presences and the adversity they reflected through personal trajectories. Some participants had linear trajectories. These participants developed from being fearful and attempting to block out the presences and their existential magnitude to being more confident in limiting the impact of the troubling presences on their lives and accepting limitations (Articles I and III). Most participants' trajectories in Study II were circular or spiraling and involved recurrently being fearful and uncertain in relation to the voices and sounds. In conclusion, I suggest that the participants' ways of dealing with the voices and sounds may be understood against the background of their habits or previous ways of understanding and dealing with adversities, their perspectives on the voice experiences and themselves, the situations they were in and their relations to others (cf. Benner et al., 1994; Merleau-Ponty, 2003). Our results also suggest that being believed by someone whom the participants trusted and could talk to about their experiences of hearing voices and sounds was empowering. They became more confident in relation to the voices and developed new ways of understanding and relating to them.

## **8.1 Implications for nursing and health care practice**

Based on the results of this dissertation, I suggest that nurses and other health care providers should engage in participatory dialogues and thus acknowledge people's experiences of living with voices and sounds (cf. Skjervheim, 2001). They should be attentive to how people perceive and deal with their experiences of hearing voices and sounds under shifting circumstances and in different phases of their trajectories and lives (cf. England, 2007a; Jones & Coffey, 2012, Lakeman, 2001; Place, Foxcroft, & Shaw, 2011). The results from the present research project coincide with the findings of other researchers who claim that nurses and other health care providers should attune their interventions and aims to the voice hearer's understandings, goals and preferences in dealing with voices (England, 2007a; Escher & Romme, 2012; Fenekou & Georgaca, 2010; Lakeman, 2001) This may then facilitate them in their process of reclaiming or developing their sense of having a voice. It is noteworthy that national guidelines and political incentives in a growing number of countries accentuate the need for increased user involvement and focus on personal recovery, both in mental health care practice and in research related to people with long-term complaints.

The present findings emphasized the importance of addressing present and future concerns or existential matters (e.g. assisting people in finding or keeping a job or engaging in meaningful activities such as e.g. voluntary work or sorting out spiritual and religious matters).

Understanding the voices and sounds in light of previous experiences and linking the voices and sounds to their personal history also proved to be important for many of the participants, albeit not for all of them. Health care providers should note that not all experiences of hearing

voices derive from trauma and that the pathway to recovery for some people involves avoiding dwelling on the past and understanding the voices and sounds (de Jager et al., 2015).

The results of this study suggest that nurses and other health care providers should have a broad theoretical approach in relation to people who hear voices. Limiting the theoretical perspectives of hearing voices might constrain our understanding of voice hearers and their experiences and of relevant nursing and health care approaches (Jones & Coffey, 2012; Ritsher et al., 2004). We should instead apply a wide variety of theories to ensure that people experience being understood, and that voice hearers who need support receive individualized health care (al-Issa, 1977, 1978, 1995). Furthermore, based on the results of this dissertation, I suggest that nurses and health care providers should address stigma and self-stigma among people who hear voices and their close relatives and acquaintances. Informing people who hear voices and their family members of the multitude of perspectives on hearing voices can prove important in facilitating an open explorative dialogue and contribute to an environment that affords support and integration, i.e. an environment that hears the voices of those who hear voices.

## **8.2 Implications for research**

The present research project provided in-depth descriptions of how one person without a psychiatric diagnosis experienced hearing voices over time. Few studies have explored the daily life experiences of healthy voice hearers who are troubled by voices and sounds. Based on the findings in this research project, I suggest that studies focusing on the daily life experiences of people in different phases of their lives and trajectories could provide

important understandings. Furthermore, I suggest that researchers should explore how nurses and other health care providers relate to people who hear voices and sounds in different health care settings (e.g. specialized mental health care, general health care settings, and community health care services) and in different phases of their trajectories. Research on voice hearers' relations to close others could also provide important perspectives. Our results underline the need for researchers, nurses and health care providers to address the dilemmas people struggle with concerning the wanted and unwanted effects of medication related to hearing voices and sounds and how these are resolved. It appears fruitful to follow the research initiatives of (InterVoice, 2015) in which voice hearers are encouraged to volunteer themes they believe researchers should explore, not to mention participatory research involving voice hearers or their family members.

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## **Appendix I**

### **Documentation of Approval**

Talseth, Anne G  
Videreutdanninga i psykisk helsearbeid  
Høgskolen i Tromsø  
9293 Tromsø

Deres ref.:

Vår ref.: 200801419-5/MGA006/400

Dato: 20.05.2008

## **P REK NORD 48/2008 Å LEVE MED STEMNER OG LYDER, UTEN Å MOTTA PSYKISK HELSEHJELP - PROSJEKTET GODKJENNES**

Vi viser til prosjektleders e-post av 02.05.2008 vedlagt revidert forespørsel -samtykke. Prosjektleders tilbakemelding på komiteens merknader tas til etterretning.

Etter fullmakt har komiteens leder fattet slikt  
**vedtak:** *prosjektet godkjennes.*

I forbindelse med at forskningsetikkloven trådte i kraft 01.07.2007 ble komiteens navn endret til "Regional komité for medisinsk og helsefaglig forskningsetikk Nord-Norge (REK Nord)". Henvisningen i forespørselen må rettes opp i tråd med dette.

Det forutsettes at prosjektet er godkjent av aktuelle formelle instanser før det settes i gang. Det forutsettes at prosjektet forelegges komiteen på nytt, dersom det under gjennomføringen skjer komplikasjoner eller endringer i de forutsetninger som komiteen har basert sin avgjørelse på.

Vedtaket kan påklages av en part eller annen med rettslig klageinteresse i saken jf. fvl. §28. Klagefristen er tre uker fra det tidspunkt underretning om vedtaket er kommet fram til vedkommende part, jf. fvl. § 29. Klageinstans er Den nasjonale forskningsetiske komité for medisin og helsefag, men en eventuell klage skal rettes til Regional komité for medisinsk og helsefaglig forskningsetikk, Nord Norge. Det følger av fvl. § 18 at en part har rett til å gjøre seg kjent med sakens dokumenter, med mindre annet følger av de unntak loven oppstiller i §§ 18 og 19. Se også <http://www.etikkom.no/REK/klage>

Vennlig hilsen

Monika Rydland Gaare  
førstekonsulent

**REGIONAL KOMITÉ FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK, NORD-NORGE**  
**REK NORD**

Postadresse: Det medisinske fakultet, Universitetet i Tromsø, N-9037 Tromsø  
telefon sentralbord 77 64 40 00 telefon ekspedisjon 77649180 e-post rek-nord@fagmed.uit.no  
[www.etikkom.no](http://www.etikkom.no)

Anne Martha Kalhovde  
UNN, PSTK  
Postboks 100  
9038 TROMSØ

Deres ref.:

Vår ref.: 200605159-3/MRO/400

Dato: 30.10.2006

**P REK NORD 118/2006 Å LEVA MED STEMME OG LYDAR - TILBAKEMELDING  
FRA FORSKNINGSETISK KOMITÉ**

Prosjektet vart handsama i møte i Regional komité for medisinsk forskningsetikk, Nord-Norge (REK NORD) 2.3.2006. I referatet står det:

Dette er eit kvalitativt studie av korleis personar som har ein psykoselatert diagnose erfarar stemmar og lydar (SOL) som dei er åleine om å høyre over tid og korleis deira næraste forstår og forhold seg til dei. Forskar vil gå inn på forhold i livet som den einskilde personen sett i samanheng med det viset hørselphenomena kjem til utrykk på, og måtar den einskilde opplevar, forstår og foreholder seg til dei på. Forskar ynskjer å intervjua 10 personar som har erfart SOL i minst 1 år og vil intervjua dei frå 1 til 3 gongar ( gruppe A). Personen skal ha ein psykoselatert diagnose og bu heime. Forskar vil også intervjue 10 pårørande ein gong (gruppe B). Pårørande rekrutteras frå dei 10 personane som blir intervjua i gruppe A.

*Komiteen klassifiserar prosjektet som klinisk anvend, psykologisk og samfunnsvitenskapeleg grunnforskning*

**Komiteen har fylgjande merknadar til prosjektet:**

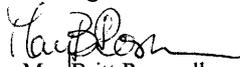
*Forespørsel/informasjonskriv/samtykkeerklæring*

Prosjektlear bør presisere nærare kva det inneber at dataene skal oppbevaras på eit sikkert sted. Prosjektlear sitt telefonnummer må framkomme.

**Vedtak:**

*Regional komité for medisinsk forskningsetikk, Nord-Norge (REK Nord) har ingen innvendinger mot at prosjektet gjennomførast.*

Vennlig hilsen

  
May Britt Rossvoll  
førstekonsulent

**REGIONAL KOMITÉ FOR MEDISINSK FORSKNINGSETIKK, NORD-NORGE**

Regional komité for medisinsk forskningsetikk, Nord

Universitetet i Tromsø, No-9037 Tromsø, tlf 77 64 40 00, e-post postmottak@uit.no, http://uit.no  
førstekonsulent May Britt Rossvoll, tlf 77 64 48 76, faks , e-post May.Rossvoll@fagmed.uit.no



Anne-Grethe Talseth  
Avdeling for helsefag  
Høgskolen i Tromsø  
Mellomveien 110  
9293 TROMSØ

Vår dato: 08.05.2008

Vår ref: 18783 / 2 / KS

Deres dato:

Deres ref:

## TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 04.03.2008. Meldingen gjelder prosjektet:

18783

Behandlingsansvarlig  
Daglig ansvarlig

*Å leve med stemmer og lyder, uten å motta psykisk helsehjelp  
Høgskolen i Tromsø, ved institusjonens overste leder  
Anne-Grethe Talseth*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, [http://www.nsd.uib.no/personvern/forsk\\_stud/skjema.html](http://www.nsd.uib.no/personvern/forsk_stud/skjema.html). Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://www.nsd.uib.no/personvern/prosjektoversikt.jsp>.

Personvernombudet vil ved prosjektets avslutning, 01.10.2012, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

  
Bjørn Henrichsen

  
Katrine Utaaker Segadal

Kontaktperson: Katrine Utaaker Segadal tlf: 55 58 35 42  
Vedlegg: Prosjektvurdering



Anne Martha Kalhovde  
Psykiatrisk senter for Tromsø og Karlsøy  
Universitetssykehuset Nord-Norge  
Postboks 6124  
9291 TROMSØ

Vår dato: 19.06.2007

Vår ref: 15313/E

Deres dato:

Deres ref:

### TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 01.09.2006. Meldingen gjelder prosjektet:

15313

Behandlingsansvarlig  
Daglig ansvarlig

*Å leve med stemmer og bydar*

Universitetssykehuset Nord-Norge HF, ved institusjonens øverste leder  
Anne Martha Kalhovde

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

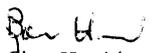
Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/endringskjema>. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://www.nsd.uib.no/personvern/register/>

Personvernombudet vil ved prosjektets avslutning, 31.12.2010, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

  
Bjørn Henrichsen

  
Janne Sigbjørnsen Eie

Kontaktperson: Janne Sigbjørnsen Eie tlf: 55 58 31 52

Vedlegg: Prosjektvurdering

Avdelingskontorer / District Offices:

OSLO: NSD, Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47-22 85 52 11. [nsd@uio.no](mailto:nsd@uio.no)

TRONDHEIM: NSD, Norges teknisk-naturvitenskapelige universitet, 7491 Trondheim. Tel: +47-73 59 19 07. [kyrre.svarva@svt.ntnu.no](mailto:kyrre.svarva@svt.ntnu.no)

TROMSØ: NSD, SVF, Universitetet i Tromsø, 9037 Tromsø. Tel: +47-77 64 43 36. [nsdmaa@svt.uib.no](mailto:nsdmaa@svt.uib.no)

## **Appendix II**

### **Information about the research project**



## En forespørsel om å delta i et forskningsprosjekt

### *”Å leve med stemmer og lyder, uten å motta psykisk helsehjelp”*

#### En intervjustudie

Det å høre stemmer og lyder er vanlig i befolkningen, uten å ha tegn til psykisk sykdom. En vet lite om hvordan de som hører stemmer og lyder selv erfarer og lever med disse erfaringene over tid, uten å motta psykisk helsehjelp. Stemmer og lyder det siktes til er slike som andre personer ikke kan høre. Stemmene blir likevel opplevd av den enkelte som tale eller lyd fra noen andre eller noe annet.

#### Vil du delta?

Ved å delta i studien er du med på å bidra til forskning som vil gi økt forståelse og kunnskap for hvordan det kan være å leve med stemmer og lyder over tid, uten å motta psykisk helsehjelp. Det vil være et viktig bidrag til eksisterende forskning i et nytt og viktig forskningsfelt. Studien er et samarbeid mellom Høgskolen i Tromsø, Universitetssykehuset i Nord-Norge og Universitetet i Tromsø.

#### Hvem kan delta?

Voksne personer som har hørt stemmer eller lyder som de er alene om å erfare gjentatte ganger i minst 1 år, har ingen psykiatrisk diagnose, mottar ikke psykisk helsehjelp og er hjemmeboende. Inntil 15 personer vil bli intervjuet.

#### Frivillig

Det er frivillig å delta. Du kan trekke deg når som helst i løpet av undersøkelsen, uten at du må gi noen begrunnelse eller det vil få noen konsekvenser for deg.

#### Fortrolig

Alle opplysninger som samles inn blir behandlet strengt fortrolig.

#### Mer informasjon

Informasjonsskriv med forespørsel om deltagelse i studien vil bli tilsendt de personer som er interessert i å vite mer om undersøkelsen og/eller ønsker å delta i studien. Ta kontakt med **prosjektleder Anne-Grethe Talseth**, telfnr. 77660656 eller 91307522.

*Anne-Grethe Talseth*  
Prosjektleder

*Astrid Norberg*  
Professor

*Anne Martha Kalbovde*  
Dr. grads student



En forespørsel om å delta i forskningsprosjektet:

## Å Leva med stemmer og lydar

En intervjustudie om å høre stemmer og lyder som noen er alene om å høre.

En vet lite om hvordan de som hører stemmer og lyder selv erfarer og lever med disse erfaringene over tid, og hvordan deres nærmeste erfarer det. Stemmene og lydene det siktes til er slike som andre ikke kan høre. De blir likevel opplevd av den enkelte som tale eller lyd fra noen andre eller noe annet.

### HENSIKTEN MED UNDERSØKELSEN

Hensikten med forskningsprosjektet er økt forståelse for hvordan det kan være å leve med slike stemmer og lyder. Studien gjennomføres som et doktorgradsprosjekt i samarbeid mellom Universitetssykehuset i Nord-Norge, universitetet og høgskolen i Tromsø.

### HVEM KAN DELTA

Personer som har en psykoselidelse og som har hørt stemmer eller lyder gjentatte ganger i et år eller mer. Inntil 15 personer vil bli intervjuet.

Personer som er interessert i prosjektet kan få utdelt et informasjonsskriv med forespørsel om deltakelse i studien av sin behandlingskontakt.

### FRIVILLIG OG FORTROLIG

Deltakelse i undersøkelsen er frivillig. Du kan også trekke deg når som helst i løpet av undersøkelsen. Alle opplysninger som samles inn blir behandlet strengt fortrolig.

### MER INFORMASJON

Ta kontakt med din behandlingskontakt hvis du vil vite mer om undersøkelsen.

Anne Martha Kalhovde  
Dr. grads kandidat

Astrid Norberg  
Professor

Anne-Grethe Talseth  
Førsteanamuensis

Til aktuell intervjupersonar:

## ***Førespurnad om deltaking i forskingsprosjektet:***

### ***”Å leva med stemmer og lydar”***

#### ***Siktemålet med undersøkinga***

Me veit lite om korleis den einskilde sjølv erfarer og lever med stemmer og lydar over tid, og korleis deira næraste erfarer det. Stemmene og lydane me siktar til er slike som andre ikkje kan høyre. Dei vert likevel opplevd som tale eller lyd frå nokon andre eller noko anna. Siktemålet med dette forskingsprosjektet vert difor auka forståing for korleis det kan vera å leva med stemmer og lydar.

#### ***1) Intervju med deg***

Om du vel å delta i forskingsprosjektet, vil Anne Martha Kalhovde ha 1 - 3 intervjusamtalar med deg om kva plass erfaringane med stemmer/lydar har hatt og har i livet ditt.

Ho er utdanna psykiatrisk sjukepleiar, har fleire års erfaring frå arbeid innan psykisk helsevern, og skal gjennomføre denne studien som eit doktorgradsprosjekt ved universitetet i Tromsø. Ho vil vere interessert i å høyre korleis desse erfaringane påverkar kvardagen din, korleis det byrja, erfaringar du har hatt i møte med familie, venner og helsepersonell og kva tankar du har om kva stemmene/lydane er og kvifor du høyrer dei. Samtale om korleis det kan vera å leva med stemmer/lydar kan vere ei god erfaring, men kan òg føre til at dei blir sterkare i ein periode. Om deltaking i undersøkinga gjer at du får vanskar kan ho formidla kontakt med dine kontaktpersonar i helsevesenet, men berre dersom du ber henne om hjelp til det.

Om du samtykkjer i å delta i undersøkinga, vil du kunne bestemme kor lenge intervjuet skal vare, kor me skal møtast, kor mykje du vil seie og kva du vil svare på.. Du vil kunne avgjere frå gong til gong om du vil at me skal møtast igjen. Samtalen vil bli tatt opp på lydband om du tillet det og det som blir sagt vil seinare bli skriven ut på papir av ein som har erfaring med dette. Utskriftene vil bli nummerert, namn og andre kjenneteikn vil bli fjerna. Koplinga mellom nummer og namn vil berre vere tilgjengeleg for Anne Martha Kalhovde.

#### ***2) Intervju med din pårørande***

Viss de møtast til intervju, vil du få eit nytt informasjonsskriv med spørsmål om du tillet at ein til to av dine pårørande kan bli spurt om å delta i forskingsprosjektet og kven det i så fall skal vera. Anne Martha Kalhovde vil vere interessert i å høyre kva tankar dine pårørande har om dine erfaringar med stemmer/lydar og korleis dei forhold seg til deg. Du kan delta i studien, sjølv om du ikkje vil at nokon av dine næraste skal delta. Dersom du samtykkjer til at dei kan spørjast og dei vel å delta, vil verken dine pårørande eller du få greie på kven som deltek i studien.

Det vil vera omlag 10 intervjupersonar i kvar gruppe.

---

**Postadresse:**

UNN, Psykiatrisk senter for Tromsø og omegn  
Postboks 6124, 9291 Tromsø  
e-post:anne.m.kalhovde@unn.no

**Prosjektet er finansiert av:**

UNN, Psykiatrisk senter for Tromsø og omegn  
Det er også søkt om midler frå Helse og rehabilitering og Helse nord

### **3) Førespurnad om deltaking i ”Stemmer og hjernen, delstudie II”**

”Stemmer og hjernen, delstudie II ” er eit samarbeidsprosjekt med professor Kenneth Hugdahl ved Universitetet i Bergen. Det er eit av fleire delstudiar i ”Stemmer og hjernen” undersøkinga som er planlagt gjennomført i Bergen, Tromsø, Stavanger, og Oslo. 10-15 personar som høyrer stemmer/lydar vil få spørsmål om å reise til Haukeland Universitetssjukehus for å gjere ei magnetresonans undersøking (MRI) av hjernen og eit intervju om symptom og stemmer ved hjelp av intervjueskjemaet PANSS. Siktemålet med denne undersøkinga er å vise at det er ulik hjerneaktivitet hjå dei som har ulike erfaringar med stemmer/lydar.

Me vil kome med meir informasjon om denne studien og ein førespurnad om deltaking på eit seinare tidspunkt, om du kryssar av for det på samtykkeskjema.

#### ***Det er frivillig å delta og opplysningane om deg vil bli behandla fortruleg***

Me vil ikkje få kjennskap til kven denne førespurnaden blir delt ut til. Du får dette skrivet frå din behandlingssjef, men du avgjer sjølv om han/ho skal få vite om du deltek i undersøkinga eller ei. Du kan vera viss på at det ikkje får følgjer for ditt behandlingstilbod, om du let vere å sende inn samtykkeerklæringa eller om du vel å delta.

Det er frivillig om du vil delta i heile undersøkinga eller berre intervjudelen. Du kan også trekkje deg når som helst, utan at du treng å gi oss ein grunn for det. Alt materiale som kan identifisere deg vil då bli sletta. Me har teieplikt i høve til opplysningane me får frå dei som deltek i studien og vil behandle opplysningane fortruleg, dette gjeld òg den som skriv ut intervjuet. Opptaka og utskriftene vil bli oppbevart nedlåst på ein sikker stad, og vil bli sletta når studiet er avslutta ved utgangen av 2010.

Anne Martha Kalhovde får veiledning ved Universitetet og Høgskulen i Tromsø, av professor Astrid Norberg og førsteamanuensis Anne Grethe Talseth. Dei vil ha tilgang til utskriftene av intervjuet. Sitat frå samtalan vil kunne brukast i føredrag og artiklar, men på ein slik måte at dei ikkje kan sporast direkte tilbake til deg eller den du er pårørande til.

Resultata av undersøkingane vil koma på trykk i artiklar i internasjonale tidsskrift, norsk faglitteratur og presentasjonar på konferansar. Som deltakar får du informasjon om resultata frå undersøkingane om du skulle ynskje det.

Prosjektet er tilrådd av Personvernombudet for forskning ved Norsk samfunnsvitenskapelig datateneste AS og Regional komité for medisinsk forskningsetikk.

#### ***Samtykke***

Du må gjerne tenkje deg om nokre dagar før du bestemmer deg om du vil delta eller ikkje. Om du vel å delta, må du fylle ut samtykkeerklæringa som ligg i konvolutt og sende den til Anne Martha Kalhovde. Ho vil så ta kontakt med deg og gjere avtale om tid og plass for samtalan. Har du spørsmål, kan de ta dei på telefonen før de treffest eller når de treffest.

Beste helsing

Anne Martha Kalhovde  
Prosjektleder  
Tlf. 77627885

Astrid Norberg  
Professor

Anne-Grethe Talseth  
Førsteamanuensis

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#### **Postadresse:**

UNN, Psykiatrisk senter for Tromsø og omegn  
Postboks 6124, 9291 Tromsø  
e-post:anne.m.kalhovde@unn.no

#### **Prosjektet er finansiert av:**

UNN, Psykiatrisk senter for Tromsø og omegn  
Det er også søkt om midler frå Helse og rehabilitering og Helse nord

## Samtykkeerklæring

(kopi)

Eg har motteke skriftleg og munnleg informasjon om forskingsprosjektet "Å leva med stemmer og lydar" og samtykker i å delta i studien.

Namn: \_\_\_\_\_

Adresse: \_\_\_\_\_

Telefon: \_\_\_\_\_

Eg godtar at Anne Martha Kalhovde tar kontakt på eit seinare tidspunkt med meir skriftleg informasjon om "Stemmer og hjernen, delstudie II" i Bergen og førespurnad om deltaking i denne studien.

Sett kryss:    Ja    Nei

Stad: \_\_\_\_\_

Dato: \_\_\_\_\_

Underskrift: \_\_\_\_\_

## Samtykkeerklæring

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Sett kryss:    Ja    Nei

Stad: \_\_\_\_\_

Dato: \_\_\_\_\_

Underskrift: \_\_\_\_\_

## **Appendix III**

### **Interview guide**

## INTERVJUGUIDE MED DEI SOM HØYRER STEMME OG ELLER LYDAR

<p><b>Åpningsspørsmål:</b> Korleis er det å leva med stemmer og lydar? Er det noko ved dine erfaringar med å høyra stemmer eller lydar som opptar deg og som du vil byrja med å fortelje om?</p>	
<b>Tema</b>	<b>Mulege Spørsmål</b>
<p><b>Livssituasjonen i dag:</b> Korleis pregar erfaringane med stemmene og lydane dagleglivet og livssituasjonen?</p> <p>Kva tankar og kjensler har den einskilde i høve til høyrsefenomena og korleis forhold dei seg til stemmene/lydane? Korleis forhold den einskilde seg til andre og korleis forhold andre seg til han/ho når det gjeld erfaringane med stemmer/lydar?</p>	<p>Kan du beskriva stemmene/lydane du høyrer?</p> <p>Korleis opplever du stemmene/lydane?</p> <p>Kva inneber erfaringane med stemmene/lydane til dagleg?</p> <p>Korleis er livssituasjonen din i dag?</p> <p>Kan du fortelje litt om korleis kvardagen din er?</p> <p>Har du andre helseplager som du ser i samband med erfaringane med stemmene/lydane? Kan du beskriva helseplagene og sambandet du meiner dei har til stemmene/lydane du erfarer?</p> <p>Kva gjer du når du høyrer stemmene/lydane?</p> <p>Korleis forhold du deg til andre når det gjeld erfaringane med stemmene/lydane? Korleis opplever du dei ulike måtane som andre møter deg på (negative og positive)?</p> <p>Korleis forhold andre seg til deg når det gjeld erfaringane dine med stemmene/lydane?</p> <p>Har erfaringane med stemmene/lydane forandra måten du forhold deg til deg sjølv og andre? Kan du fortelja litt om kva som har forandra seg?</p>
<p><b>Tilbakeblikk:</b> Få fram nokre erfaringar på godt og vondt som verkar vere viktige i høve til korleis den einskilde forstår seg sjølv, forhold seg til nye eller utfordrande situasjonar, helseplager og i forhold til andre.</p>	<p>Kan du fortelja noko om hendingar på godt og vondt som har satt spor i livet ditt?</p> <p>Kan du beskriva korleis du har forhalde deg i desse situasjonane?</p> <p>Kan du fortelja noko om det som skjedde då</p>

<p>Er det hendingar eller situasjonar som har spelt ei viktig rolle når det gjeld tidspunktet som høyrsefenomena dukkar opp, måten dei kjem til uttrykk på eller innhaldet i budskapet deira? Eller som verkar inn på den einskilde sin måte å forhalde seg til høyrsefenomena på?</p>	<p>du byrja høyra stemmer/lydar?</p> <p>Minnar erfaringane med stemmene/lydane om andre erfaringar du har hatt? I så fall på kva måte minnar dei om tidlegare erfaringar?</p> <p>Vekkjer stemmene/lydane i seg sjølv minner om personar eller hendingar som du vil fortelje om?</p> <p>Minnar reaksjonsmåtene du har i forhold til stemmene/lydane om måtar du har reagert i forhold til bestemte personar eller hendingar som du vil fortelje om?</p> <p>Kan du fortelje noko om møter med andre når det gjeld samtale om dine tankar, kjensler eller erfaringar på godt og vondt.</p>
<p><b><u>Framtidsperspektiv:</u></b> Få fram nokre tankar og kjensler knytt til framtida.</p> <p>Kva forventningar har den einskilde til framtida, - optimisme, uvisse?</p> <p>Har forventningane til framtida forandra seg gjennom erfaringane med stemmene og lydane?</p> <p>Kva forventningar har den einskilde til familie, venner, fagpersonell?</p>	<p>Kva har erfaringane med stemmene/lydane betydd i forhold til dine planar, ynskje eller håp for framtida?</p> <p>Kan du beskriva korleis det har medverka desse forandringane?</p> <p>Kan du fortelje noko om forventningar du tidlegare har hatt til framtida og forventningar du har no?</p> <p>Kva forventningar har du til andre?</p> <p>Har du tankar om korleis livet ditt vil sjå ut om 10 år som du vil dele?</p>
<p><b><u>Konkrete forhold:</u></b></p> <p>Kjønn:</p> <p>Alder:</p> <p>Oppvekst by/land:</p> <p>Diagnose(r):</p> <p>Tidspunkt for første erfaring med høyrsefenomena:</p> <p>Kontakt med helsevesenet:  tidspunkt for første kontakt  hjelpetilbodet no</p> <p>Familieforhold:</p>	

foreldre,  
sysken, - kor mange, plass i rekkja  
gift/sambuar, - når og kor lenge  
barn, - alder og kven har omsorgsansvaret

Utdanning/arbeid /eventuelt uføretrygd:

tidlegare erfaring  
noverande situasjon  
forventa situasjon