

# THE SOCIAL SHARING OF HALLUCINATIONS

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By

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## **Abstract**

In this dissertation, I explore the social sharing of hallucinations and address the primary question of the lived-experience of this phenomenon from multiple perspectives. What is it like to speak about and hear about hallucinated experience outside of professional contexts? I interviewed 23 individuals regarding their experience sharing hallucinations with others (Experiencers) or hearing about hallucinations from individuals who experienced them (Listeners). Data were gathered from community as well as clinical samples. A wide variety of hallucination contexts were present, ranging from sleep paralysis, post-partum psychosis, drug-ingestion, mental illnesses, medically-related conditions (stroke, fever), healing, religious visions, as well as encounters with ghosts, archetypes, and deities. I analyzed these data using a hermeneutic-phenomenological perspective and process, following Max van Manen's style of using this methodology.

Through analysis, four Facets were recognized: Care, Sense-Making, Dual-Processing, and Ontological Cross-Bleed. Care Facet represents the explicit and hidden experiences and expressions of care that Listeners and Experiences share or withhold. For Experiencers, the Sense-Making Facet represents experiences of sense-making related to determinations of whether hallucinations are real, why they occur, and what they mean. Listener experiences of sense-making include shock, confusion, and processes of curiosity and determination regarding the hallucination. Dual-Processing Facet explores the dual experiential response many Listeners described when hearing about a hallucination. This response often involves interior thoughts and reactions that are masked from exterior representation. Finally, the Ontological Cross-Bleed Facet explores the transition that occurs during social sharing in which the hallucination transfers from being an object of consciousness only for the individual having the hallucination, to an object of consciousness for a Listener as well. Results of this study can help clinical psychologists tailor treatments and recommendations to individuals who are involved in related conversations and can also provide useful knowledge to community members who themselves are involved in the sharing, either from Experiencer or Listener standpoints.

***Keywords:* hallucinations, social sharing, hermeneutic phenomenology**

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## **Chapter One: Introduction**

This dissertation is an empirical exploration into the social sharing of hallucinations outside of professional contexts. Specifically, I use the qualitative methodology of hermeneutic phenomenology to explore the lived-experience of social sharing described in two sets of interviews - one with individuals who have experienced hallucinations directly, and another with friends, family members, or others who have spoken to someone about such an experience. My goal is to build a bridge of understanding between these two sets of experiences, to draw out common features of both perspectives, and to make these features and experiences apparent and accessible to a variety of readers, including clinicians, the lay public, and researchers focused on hallucinatory phenomenon.

### **1.1 Outline**

This first chapter introduces the reader to the document, provides a general overview of the social sharing of hallucinations as a focus of study, and reflexively situates my role as researcher and the reasons for my interest in this topic. The second chapter explores common definitions of hallucinations and situates the research within the relevant literature and current understandings of clinical psychology as a discipline. The third chapter elaborates on my methodological commitments and the fourth chapter details the specific methods of sampling, recruitment, interviewing, transcription, and analysis used in the research. In the third chapter, I also include a brief section on reflexivity in which I examine my assumptions for the research, and how these assumptions likely impacted the various stages outlined below. The fifth chapter consists of my interpretation of the four Facets resulting from the analysis of my interviews: Care, Sense-Making, Dual-Processing, and Ontological Cross-Bleed. The sixth and final chapter is a discussion in which I integrate the parts of the dissertation, draw final attention to its main ideas, and explore implications of the research.

### **1.2 Relevance of the Present Study**

Recovery-oriented mental health services widely acknowledge the important role that relationships, families and social networks play in many domains (United States Department of Health and Human Services, Substance Abuse and Mental Health Service Administration, 2012). Yet, to date, there is little in the literature exploring what occurs when individuals share their experience of hallucinations within the context of non-professional relationships. What literature exists seems to indicate that, overwhelmingly, individuals who share their hallucinations with close others feel invalidated by the responses, but this literature overly privileges hallucinations that occur in the context of psychosis or serious mental illness (Faccio, Romaioli, Dagani & Cipollette, 2012; Fenekou & Georgaca, 2010; Shimodera, Inoue, Tanaka, & Mino, 1998). Just as importantly, it does not appear that prior studies have examined the experience of close others in hearing about and responding to hallucinatory experiences.

My research focuses on how close others including friends, romantic partners, acquaintances, and family members understand, respond to, and experience discussions of hallucinations. Further, in that my recruitment is of both a community and a clinical nature, I also provide perhaps the first exploration of listener experiences to non-clinically related hallucinations. This focus extends the growing literature on community individuals who experience hallucinations, but do not require or seek treatment (Baumeister, Sedgwick, Howes, & Peters, 2017; Hill & Linden, 2013; Johns et al., 2014; Laroi & Van der Linden, 2005).

My hope for this research is that individuals on both sides of this interaction (those who perceive hallucinations and those they talk to about these perceptions) can build an informed awareness of where the other side might be coming from and better feel their way into the other's experience of disclosing and responding. To this end, the study has been designed so that, after the analysis and write up, both parties will have access to descriptive accounts of *what it might be like* to be on the opposite end of this interaction. More directly, the results of this study should also help individuals from both sides of the interpersonal exchange who engage in these conversations. This help could come in at least three forms: (1) non-prescriptive recommendations for what to do and what to say during these interactions; (2) a developed empathic understanding of what the experience is like for individuals engaged in these dialogues; and finally, (3) a capturing of this experience in such a way that readers could feel less alone in their (possible) struggle to navigate these interactions. I also hope to enrich the breadth of professional listening so that clinical psychologists and psychiatrists who specialize in the treatment of hallucination-relevant disorders can better hear the diversity of this phenomenon.

### **1.3 Original Impetus for Research Study**

It is important to acknowledge that my inspiration for this research came directly from my clinical work as a master's-level intensive case manager working in community mental health. As an aspect of this role, I initiated and co-facilitated a Voice Hearers group, based on the Hearing Voices Group model (Dillon, 2013; Escher & Romme, 2012). Within this model, group participants are encouraged to reflect on various aspects of their voice-hearing experience, including their history with the voice, who they have spoken with about their voices, any meaningfulness they attribute to the voices, and the overall role of voices in their lives. Through this facilitation, I realized that many of the group members had not shared their hallucinations with one another, despite some of the clients maintaining close friendships prior to forming the group. Further, many clients recalled less than ideal responses from their friends and family when they first began sharing their hallucinations, often in their teenage years. On the other side, I noticed that many friends and family members also struggled at times to know how to respond when hallucinations were present or reported. These situations were all the more complicated when hallucinations were occurring in the context of a chronic serious mental illness, such as schizophrenia, with negative symptoms and disorganization of thought and language also present.

The literature clearly shows that stigma and isolation are common for individuals diagnosed with a serious mental illness (Corrigan & Watson, 2002) and that these features have a negative impact on treatment outcomes (Hendryx, Green & Perrin, 2009). Stigma occurs in both internal and external forms. Internal stigma, also known as self-stigma, involves the

internalization of negative images and ideas related to individuals with serious mental illness. External stigma, also known as public stigma, involves stereotypes, prejudices and discrimination by others in the individual's social world (Corrigan and Shah, 2017). Isolation also involves domains of internal experience and social connection. Wang et al. (2017) described social isolation as involving the quantity of an individual's social network (size and frequency of contact), the structure of an individual's social network (the density of ties between network members and the proportion of kin to non-kin members), the quality of an individual's social network (the number of confiding relationships and the number of social contacts individuals report they would miss if they were to never see the person again), emotional appraisal (the lived experience of loneliness) and resource appraisal (an individual's sense that they have access to resources within their social network, including resources related to expert advice and problem solving).

Research supports that social support increases correlates of recovery (Chronister, Chou, Kwan, Lawton, & Silver, 2015; Soundy, Stubbs, Roskell, Williams, Fox, & Vancampfort, 2015) and three of the ten guiding principles of the recovery model (relationship, culture, and peer support) relate to social support (SAMHSA, 2012). When I saw how meaningful some of the hallucinations were to my clients, I began to wonder if hallucinations could become a point of connection, rather than confusion, for clients and their friends and families. Through my co-facilitation of the Voice Hearers group, and the related trainings, I began to see how immensely meaningful hallucinations could be, the insights they could provide into a person's overall story and values, and the poverty of contact individuals tended to have with others around their hallucinations. Additionally, I saw a missed opportunity for hallucinatory experiences to facilitate social contact and social support outside of the clinical setting. Seeing the potential for research in this area, I decided to return to graduate school for a PhD and to gain advanced training in the qualitative methodologies I knew would best fit an examination of the type of experience I wanted to study—the lived-experiences of the social sharing of hallucinations.

Since I began my graduate training, the field has increasingly acknowledged that hallucinations can be deeply meaningful (Jones & Shattell, 2013; Thomas, Rossell, & Waters, 2015), and that this meaning can be worked with in clinically useful ways (Beavan, Read, & Cartwright, 2011; Coleman, 2011; McCarthy Jones et al., 2013; Rhodes & Jakes, 2009). Thanks in part to the Hearing Voices Movement, which has benefited from the Internet age and the informal networks of service-users and providers formed outside of mainline conferences and publications, it has also become increasingly recognized that many individuals experience hallucinations, including those who never seek or require treatment for the experience (Johns et al., 2014; Krakvik et al., 2015). However, while much of this recent research focuses on attributions that individuals who hallucinate give to their experience, no work that I know of has focused on the lived-experiences of sharing hallucinated experiences outside of clinical contexts.

## **1.4 Situating Myself as Researcher**

Zahle (2018) wrote of the importance of researchers considering their values and being transparent about the ways these values impact their research. At the outset, I acknowledge I have always seen my program of research as being in line with the emancipation of hallucinatory experiences as *purely* pathological. I believe that, as a discipline, clinical psychology, along with

psychiatry and other related professions, must acknowledge the positive and meaningful aspects of these experiences for some individuals, while maintaining a stance of care and treatment for hallucinatory experiences that are painful or distressing.

It should be no surprise that my research findings support acknowledging the neutral or positive aspects of hallucinations, not only because it appears many researchers are finding support for positive or meaningful hallucinations (Bergstrom et al., 2019; Corstens, Longden, McCarthy-Jones, Waddingham, & Thomas, 2014; Heriot-Maitland, McCarthy-Jones, Longden, & Gilbert, 2019; Longden, Read, & Dillon, 2018; Suri, 2010) but also because I was responsible for the research design. Everything, from my research questions to my interview style and the direction of focus for my analyses, was informed by my belief that we must complicate and expand our understanding of hallucinatory experiences beyond the purely clinical. At the same time, we must not ignore the catastrophic consequences that serious mental illness or problematic substance use can bring to service-users and their loved ones, and we must not discount the suffering, terror and discomfort that can coincide with hallucinations for some individuals and their families.

Russel and Bohan (1999) professed that when we study human beings we cannot stand apart from our humanity. This position is consistent with Linda Finlay's notion of relational-reflective research. As one of the leading researchers within phenomenological psychology, Finlay writes powerfully of the importance of reflecting on and claiming our position in relation to the content and the participants of our research, throughout the data generation and analytic phases (Finlay & Ballinger, 2006; Finlay & Evans, 2009). Finlay also advocates for an acknowledgement of the relational nature of the research endeavor, particularly as it appears in qualitative work. To acknowledge the personal influence my assumptions and position have on my work, I have woven myself throughout this document. My aim is not to be an objective omniscient presence writing in the third person and masking my contributions to the analysis and data, but rather to honour and acknowledge my presence and influence on this study. Specific actions I have taken towards this aim will be further explored in my methodology section.

## Chapter Two: Defining, Reviewing and Situating

In this chapter, I provide the definition of hallucinations used in my program of research. I then explore other important elements of hallucinatory phenomena such as their context and modality. Next, I consider relevant qualitative research pertaining to the clinical treatment of hallucinations, including a continuing awareness that hallucinatory phenomena appear to manifest on a continuum with both clinical and non-clinical presentations. Finally, I consider current directions in hallucination research and explore the important contributions that qualitative approaches have made in our understanding of hallucinatory experiences.

### 2.1 Hallucinations

Studying something in science requires the ‘something’ to be defined. Such is also the case in phenomenology, where problematic or murky definitions can derail investigations before they begin (Guts, Halling, Pierce, Romatz, & Schulz, 2016). Yet, to a certain extent, especially from constructionist and interpretive epistemological standpoints, to define a thing is, at least partially, to give it form (Burr, 2015). Thus, definition becomes of immediate importance to the following investigation, both to clarify the domains under evaluation and to avoid the danger of favouring disciplinary meanings of clinical terms at the expense of lay-person understandings. However, prior to defining, the question as to whose definitions should be used must be considered. The answer to this question is wrapped in issues of power (Georgaca, 2000; Harper, 1999; Parker, Georgaca, Harper, McLaughlin, & Stowell-Smith, 1995), with myself as researcher in a privileged position to determine what is allowed, and what is discounted, when considering hallucinated phenomenon.

There is a spectrum of possible directions here. On one side, I could provide a strict definition, serving to limit participation in my study to a narrow subset of experiences that might fall under the umbrella of what clinical psychology typically considers “hallucinatory.” Doing so would potentially discount experiences such as encounters with ghosts, ego-death, religious visions, and extreme cases of déjà vu. On the other end of this spectrum, I could allow participants to define what they consider hallucinations. This option would potentially allow phenomena into the data set that would typically not be considered hallucinatory, muddying the analysis and limiting the clinical applications of the research.

As a clinician, as well as a researcher, I am extremely sensitive to the power of the discourses of research, science, psychology, and medicine to define *for* others and to create the frame by which experiences are understood, with the danger of unnecessary pathologizing ever present. This concern is further complicated by the broad availability of possible definitions within hallucinations research, a set of definitions that as a whole has been described as “unstable and wide-ranging” (Pienkos, 2014, p. 262).

Pienkos (2014), a modern researcher of the phenomenology of hallucinations, has acknowledged that “efforts at classification appear as attempts to impose order over what is in reality a very muddy set of experiences with features that often overlap or shade into one another” (p. 262). Though attempts have been made to better understand similarities and differences for hallucinations occurring across various contexts and presentations (Siddi, Ochoa, & Laroi, et al., 2019; Waters & Fernyhough, 2017) the state of research has led Pienkos to conclude, “there is currently little consensus on how to conceptualize the diverse phenomena called hallucinations, leaving clinicians and persons suffering from AVHs (audio verbal hallucinations) unclear about how best to proceed” (p. 262). This instability poses a challenge when attempting to find consensus on a single definition of hallucination phenomena, but it also allows room for a flexible approach in considering what will or will not be considered “hallucinatory” within my data set. Importantly, the construct of hallucinations as a primary sensory experience has also been questioned, with phenomenological evidence indicating that hallucinations may better be explained as shifts in base layers of subjectivity that eventuate in experience of self and world (Pienkos et al., 2019).

### **2.1.1 The three-part definition**

To clarify how hallucinations were understood in this study, I begin by examining two definitions largely consistent with how I personally view hallucinations and how experts are increasingly defining hallucinations. I then consider other commonly used definitions, examine assumptions underlying these definitions, and address why these definitions are inadequate for the purposes of this research.

To begin, the glossary of The Diagnostic and Statistical Manual of Mental Disorders - Fifth Edition (DSM-5) (American Psychiatric Association, 2013) currently defines hallucination as,

A perception-like experience with the clarity and impact of a true perception but without the external stimulation of the relevant sensory organ. Hallucinations should be distinguished from *illusions* in which an actual external stimulus is misperceived or misinterpreted. The person may or may not have insight into the nonveridical nature of the hallucination. One hallucinating person may recognize the false sensory experience, whereas another may be convinced that the experience is grounded in reality. The term hallucination is not ordinarily applied to the false perceptions that occur during dreaming, while falling asleep (hypnagogic), or upon awakening (hypnopompic). Transient hallucinatory experiences may occur without a mental disorder. (p. 822)

Largely consistent with the DSM-5 definition, Aleman and Laroi (2008), leading neuroscientists in the field of hallucination studies, utilize David’s (2004) definition of hallucinations as “a conscious sensory experience that occurs in the absence of corresponding external stimulation of the relevant sensory organ and has a sufficient sense of reality to resemble a veridical perception. In addition, the subject does not feel he or she has direct and voluntary control and which occurs in the awake state.” This definition is consistent with the DSM-5 definition but adds the additional requirement that the hallucinating subject does not have direct or voluntary control over the experience. Aleman and Laroi’s 2008 definition is most consistent with my own understanding of hallucinations and it was this definition that I used to

establish whether events described by my participants could be considered hallucinatory. I welcomed hallucinations occurring in the context of sleep disorders because, despite the DSM-5 stating these are typically not defined as hallucinations, they appear to be phenomenologically consistent with hallucinations of other varieties, or hallucinations that occur in other contexts, such as drug-assisted, religious, or non-need for treatment hallucinations.

The DSM also acknowledges that hallucinations can occur in culturally sanctioned contexts, and that hallucinations occurring in these contexts should not be considered mental illness related (APA, 2013, p.88). As an aspect of determining whether hallucinations are culturally sanctioned, the DSM-5 acknowledges that cultural formulation may be helpful. Cultural formulation is a process of assessment that provides clarity on the cultural identity of the individual. The cultural formulation interview involves multiple components, including cultural considerations of distress, culture features of vulnerability and resilience, cultural features of the relationship between the individual being assessed and the clinician, and an exploration of who the individual understands their problem, what troubles them most about their problem, and perceived sources of healing (APA, 2013, p.749).

The researcher and clinician are themselves attached to cultural understandings surrounding hallucinations and clinical and research interpretations of hallucinatory experiences must be understood as occurring within the cultural frame of the clinician or researcher (Laroi et al., 2014). One consequence of the medicalized frame of understanding is that non-medicalized understanding of hallucinations become sidelined in our overall understanding of the phenomena. McCarthy-Jones, Waegeli, and Watkins (2013) acknowledge that spiritual accounts of voice hearing go, “beyond misguided molecules, disordered dipoles, and contorted cognitions. This can include understanding voice-hearing as coming from a higher self or a supernatural entity (e.g., angels, spirits, djinn), variously signifying divine favour, demonic wrath, spiritual emergence/emergency or shamanic potential” (p.247). We must be careful as clinicians and researchers to maintain sensitivity not only the degree to which hallucinations could be problematic but also to the language and understanding that client’s hold around these experiences. For example, an individual could understand their experience not as a hallucination, but as a direct communication from God, or an angelic entity. We should consider the historical and cultural baggage associated with the term hallucinations.

Another important aspect of Aleman and Laroi’s definition is that a hallucination has a “sufficient sense of reality to resemble a veridical perception.” This wording circumvents much deliberation in the literature as to whether hallucinations can only be considered hallucinations if they are perceived entirely as real. As explored in Blom (2010), some authors have proposed separate terminology for hallucinations in which the individual has some degree of understanding that the hallucination is a hallucination as opposed to a “true” perception. “Pseudohallucinations” or “transient hallucinations” are among the terms proposed for sub-types of hallucinations in which the perceiver does not perceive the hallucination as similar to concrete objects of sense-perception (van der Sward & Polak, 2001). However, the veracity and utility of pseudohallucinations as a concept has been previously criticized (Berrios & Denning, 1995). By acknowledging that hallucinations have a “*sufficient* sense of reality to *resemble* a veridical perception” [stress added], Aleman and Laroi’s definition allows for hallucinations of the “pseudohallucination” sub-type to be included in my data set without the problematic divisions



that could come by trying to divide pseudo or transient hallucinations with other types of hallucinations in which the perceiver believes them to be fully real and occurring outside the self. Consistent with phenomenological research on the lived-experience of hallucinations, Aleman and Laroi's 2008 definition acknowledges the possibility that hallucinations occur on a continuum regarding how "real" they seem.

Both the DSM-5 definition and Aleman and Laroi's definition of hallucinations are unique in that they drop the typical definitional aspects which tend to appeal to an objective external reality, or to the world as it is socially perceived by others. By using the terminology "a sensory experience that occurs in the absence of corresponding external stimulation of the relevant sensory organ," these definitions center the perceiver without appealing to a social world or an objective physical reality. Rather, these definitions acknowledge (i) that hallucinations are conscious sensory experiences that occur in the absence of corresponding external stimuli, (ii) that hallucinated experiences *sufficiently resemble* a veridical perception, and, as Aleman and Laroi add, (iii) that the hallucinating subject does not feel he or she has conscious control over the hallucinated experience. These definitional qualities are uncommon in other definitions of hallucinations but capture important phenomenal aspects of the presentation.

### **2.1.2 Common definitions - appeal to objective reality or social others**

As examples of commonly used definitions that lack the nuance of the three-part definition presented above, authors in a recent hallucination-focused research and practice handbook (Blom & Summer, 2012) use multiple simple phrases to refer to hallucinations. Below, I have underlined the aspects of these phrases that appeal to an externally objective reality or give weight to the need for perceptions to be available to more than one person to not be considered hallucinatory. The final definition "intracerebral source," on the other hand, allows for an understanding that the hallucination might still be "real" but is coming, somehow, from within the nervous system of the perceiver. This "intracerebral source" definition comes closest to what Aleman and Laroi and the DSM-5 provide.

*"to see or hear things that remain imperceptible to others" (p.2)*

*"perceiving things that are not there" (p.1)*

*"to be the only one able to experience..." (p.1)*

*"that which occurs in perception from an "intracerebral source." (p.3)*

As the four above definitions show, by their nature, hallucinations encourage us to think about material reality, and implicitly, give us a frame to consider the role of social agreement on maintaining the reality structure, in its shared-perceptual form. When a hallucination "remains imperceptible to others" or when a hallucination is defined due to the perceiver being the "only one" to experience the stimulus, hallucinations disrupt the hidden assumption of an entirely shared and unitary perceptual reality.

The variety of definitions listed above also draws attention to the varying ways in which a central focus of the definition can be placed on either the individual perceiving the

hallucination or on others who *do not* perceive it. For example, when a definition focuses on a hallucination being imperceptible to others, it puts the onus on others to have the perception; whereas, when a hallucination is defined in terms of the person sensing the hallucinations being the “only one to experience” the hallucination, the definition is centralized on that experiencing individual. Regardless, in both of these definitions, sociality itself becomes tied into the definition of what will and will not be considered “hallucinatory.”

In all, most of these short-hand definitions of hallucinations typically require a reference to either a “real” world to which the hallucinations are not a part, or to a “perceiving other” or “group of others” for whom the perception is not present. Within these formulations, individuals who hallucinate are positioned as “lone perceivers” against social agreement or an assumed objective actuality. As can be seen, aspects central to many understandings of hallucination strike to the core of human social experience, such as the ways in which human experience is considered to be both perceptual and shared. Thus, hallucinations provide a unique pathway of investigation into the ways in which we understand our world in its physical manifestation and the role that social influences have on this idea of shared physical space.

### **2.1.3 Contexts of hallucinations**

To begin, it is essential that hallucinations be differentiated from illusions and delusions. Hallucinations require a distorted sensory perception in which there is no external stimulus present. An illusion is either a false or mistaken sensory interpretation of an external stimulus that is present. A delusion is a false belief not held by other members of the culture that is maintained despite contrary evidence (Strickland & Gall, 2016). Delusions are typically more *thought-based*, whereas hallucinations are typically more *sensory-based*. However, at times, it can be difficult to differentiate the two.

Hallucinations present within diverse subsets of clinical and non-clinical experiences. These experiences include sensory deprivation, sleep deprivation, fever, organic diseases of the brain, drug-induced experiences of psychosis, psychotic disorders, mood disorders, personality disorders, posttraumatic stress disorder, drug and alcohol withdrawal, drug and alcohol intoxication, stress, captivity, torture, eating disorders, and religious experiences (Aleman & Laroi, 2008; Ames et al., 2013; American Psychiatric Association, 2015; Babkoff, Sing, & Thorne, 1989; Chaudhury, 2010; Crompton, Yael, & Zahava, 2017; Flynn, 1962; James, 1902; Koyanagi, Stickley, & Haro, 2016; McCarthy-Jones & Longden, 2015; McKetin, 2018; Miotto et al., 2010; Pugh, Waller & Esposito, 2018; Siegal, 1977; Soosay et al., 2012; Nygaard, Sonne, & Carlsson, 2017; Sacks, 2012; Waters, Chiu, Atkinson, & Blom, 2018; Ziskind & Augsberg, 1962). There is also a growing acknowledgement among researchers that hallucinations occur within the “normal population” for individuals who are not significantly distressed by their hallucinations. Various terms have been used for these “normal”, “healthy”, or “general population” individuals who experience hallucinations (Baumeister, Sedgwick, Howes, & Peters, 2017; Dissanaikae & Aguis, 2011; Vilhauer & Sharma, 2018). Following (Underwood, Kumari & Peters, 2016) I prefer the term “non-need for care individuals” for the “normal population” group. I chose this phrase to avoid using the term “normal population,” because individuals who seek treatment for their hallucinations, or related disorders, are just as “normal” as those who do not. The terminology “non-need for care” also acknowledges that hallucinations often become

problematic when they become *distressing*. Research has shown that the distress of hallucinations is related to beliefs about the hallucinations themselves (Hill, Varese, Jackson, & Linden, 2012; Varese, Morrison, Beck, Heffernan, Law, & Bentall, 2016). Command hallucinations, in which the individual hears a voice commanding them to complete a task, is viewed as the most concerning. Some research has linked command hallucinations with a higher likelihood of suicide or committed violence (McNeil, Eisner, & Binder, 2000), while other research supported that impulse control has more to do with violent outcomes than the presence of a commanding voice (Bucci et al., 2013).

Hallucinations can also occur in the liminal stages of entering and waking from sleep for all individuals, and when they occur in these stages, hallucinations are not considered abnormal (American Psychiatric Association, 2013; Jones, Fernyhough, & Laroi, 2010). Hallucinations are also well documented as an aspect of bereavement with individuals in many cultures reporting encounters with recently deceased loved ones, often in both visual and auditory modalities (Castelnovo et al., 2015). Hallucinations are frequently reported by persons diagnosed with Alzheimer's disease and epilepsy, and are a signature symptom of Lewy Body dementia (Chaudhury, 2010). Hallucinations have been documented before, after, and during a seizure and as a reaction to medication, or to anesthesia (Nadkarni, Arnedo, & Devinsky, 2007). They can also occur with simple fever (Lewis, 2007). Hallucinations can even happen during high-elevation mountain climbing (Hufner et al., 2018), and in dozens of other contexts and situations. Hallucinations permeate our existence as perceptual-social individuals in the material world and have been documented since the beginning of medical and religious history (Aleman & Laroi, 2008; McCarthy-Jones, 2012;).

#### **2.1.4 Modalities of hallucinations**

The DSM-5 (2013) lists the following sub-types of hallucinations: auditory, geometric, gustatory, olfactory, somatic, tactile, and visual. Geometric hallucinations are best understood as a sub-type of visual hallucinations where the hallucinations involve geometric shapes such as tunnels, funnels, spirals, lattices or cobwebs. Somatic hallucinations can be differentiated from tactile hallucinations in that tactile hallucinations involve the sense of being touched (Berrios, 1982) whereas somatic hallucinations involve a physical experience localized within the body, for example, a sense of not having a stomach while eating (Shahid et al., 2011). Notably, the DSM-5 also acknowledges that hallucinations and emotions are frequently intertwined. The manual includes mood-congruent and mood-incongruent specifiers for hallucinations and other psychotic features. A working group of the International Consortium of Hallucination Research has been devoted to exploring this relation between hallucinations and emotions (Thomas, Rossell, & Waters, 2016).

The perceptual modalities in which hallucinations occur are also an important matter for hallucination researchers. Researchers tend to include the perceptual senses (touch, taste, sight, smell, sound, and proprioception). Hallucinations can also vary in perceptual depth and detail, with fine description being possible with some, and only general over-arching gestalts being available for others. Unfortunately, this variability makes strict definition of hallucinations difficult, with current researchers arguing for both a broadening of our understanding of the phenomenon (Jones & Luhrmann, 2015), and for an increased attentiveness to their subtypes

(McCarthy-Jones et al., 2014). Laroi (2006) considered hallucinations to be “phenomenologically heterogeneous,” meaning they can manifest in a diversity of presentations across multiple aspects, e.g., level of detail, level of certainty, and modality of perception. Laroi acknowledged that,

Although hallucinations are highly complex and rich phenomena, this fact is rarely given the merit it deserves in the scientific literature. This is unfortunate, as taking into account the phenomenological nature of hallucinations has tremendous implication for both theory and for clinical practice. In particular, current (cognitive) theories of hallucinations have exclusively considered hallucination as internal events misattributed to an external source, even though evidence from phenomenological studies indicates that this may be only one of many possibilities. In clinical terms, not taking into account the phenomenological nature and diversity of hallucinations may seriously hamper the therapeutic progress. (p. 163-164)

Definitional issues are further complicated when hallucinations are considered broadly across modalities, as researchers tend to work with hallucinations occurring in a single perceptual modality at a time (e.g. voice-hearing, tactile, visual, olfactory). Recommendations exist for sub-typing hallucinations occurring in specific modalities, such as voices, (McCarthy Jones et al., 2014), but these recommendations are still relatively novel, for the most part are untested, and are unlikely to apply to hallucinations considered at their broadest level across perceptual modalities. In other words, specific definitions for hallucinations appearing as voices are unlikely to work with the same degree of fidelity for somatic hallucinations or hallucinations occurring in other modes of sense-perception.

### **2.1.5 Hallucination experiences excluded from the present study**

Keeping the definitions, contexts, and modalities of hallucinations in mind, and staying within reason, while I maintained a strict focus on the experience of social sharing, I decided to leave the definition of what was considered a hallucination largely up to my participants, so long as their definition was to some degree consistent with the three-part definition provided above. In short, that the hallucination (i) occurred primarily in a sensory modality, (ii) appeared in some degree to be a veridical perception, and (iii) was not under the influence of conscious control. Defining hallucinations in this way made space for various phenomena, not all of which would fall under the clinical definition of “hallucination.” For instance, spiritual entities, ghosts, demons, physical contact with God, and sensory distortions related to self, time or space that were experienced somatically are present in my participant accounts. There were only three instances of participants providing experiences of hallucinations that I did not consider hallucinatory and did not include in the data set. All of these participants mentioned other hallucinations as well, so the interviews were still included in the research. However, segments specifically related to the following three hallucinations were not analyzed with the rest of the data:

1. One participant spoke of an overwhelming emotion he had after ingesting empathogens. Though it is possible this hallucination could be considered somatic, I was unable to accrue enough evidence that this was the case during the interview.

2. Another participant spoke of “day-dreaming” in which he visually saw things in the room but maintained conscious control over what he was seeing.
3. One participant spoke about paranoid delusions that were cognitive and not sensory in nature, i.e., that all vehicles that had license plates with a certain letter were being driven by individuals pursuing this person.

My over-all open stance in regard to definitions of hallucinations has the advantage of working with understandings of hallucinations based on community rather than clinical populations and of not limiting discourses of understanding to purely medicalized experiences. However, it also has the disadvantage of limiting the applicability of my findings to hallucinated experiences associated purely with mental illness, especially serious mental illness.

## **2.5 The Social Sharing of Hallucinations**

### **2.5.1 Qualitative research on social sharing in psychosis and serious mental illness**

Within the last decade there has been a surge of qualitative studies examining experiences of voice-hearing through a variety of analytic methods, including those associated with grounded theory, thematic analysis, interpretive phenomenological analysis, and Q methodology (Hepworth, Ashcroft, & Kingdon, 2011; Hill & Linden, 2013; Longden, Corstens, Escher, & Rome, 2012; Jones, Guy, & Omrod, 2003; McCarthy-Jones, Marriott, & Knowles 2013; Thomas, Farhall, & Sawyer;). Though this research primarily applies to individuals experiencing voices within the context of a serious mental illness or acute psychosis, many of these researchers have found that individuals who hear voices often worry about the social impact of revealing their voice-hearing experience, or that some mental health professionals are dismissive of personal meanings attributed to the experience (Goicoechea, 2006; Kalhovde, Elstad, & Talsen, 2014; McCarthy-Jones, et al., 2013; Stuber, Rocha, Christian, & Link, 2014).

For example, McCarthy-Jones et al. (2013) performed a metasynthesis of 97 qualitative publications related to psychosis. Though the metasynthesis was focused on psychosis in general, rather than hallucinations specifically, these authors found four themes related to the lived-experience of psychosis, which included the loss of relationships and pain related to this loss. These authors wrote, “Psychotic experiences can lead to self-imposed isolation with withdrawal being used as a coping mechanism. However, isolation could also be due to the actions of others. For example, many participants talk about the loss of relationships with friends/family who don’t understand what they are going through ... The loss of relationships causes great suffering and loneliness; ... This pain is felt particularly acutely, since this is typically a time where the need for love and belonging is especially strong” (p. 6). Even more disheartening, many qualitative studies in the review found that service-users have negative interactions with individuals providing professional care, which led researchers of the studies to state that clinicians should be alert to having a destructive impact during treatment.

While interaction with mental health professionals might be an eventual destination for individuals who hallucinate, often the first and longest maintained point of contact in sharing these experiences is with close others, such as family members or friends. Faccio, Romaioli, Dagani and Cipollette (2012) found that all participants who heard voices initially shared the

experience within close, non-professional relationships. Though it is unclear if this finding extends to hallucinations occurring in non-need for care individuals, research has shown that invalidation around hallucinated experiences occurring in clinical contexts can extend to interactions outside of the clinical system (Fenekou & Georgaca, 2010; Shimodera, Inoue, Tanaka, & Mino, 1998). Fenekou and Georgaca (2010) wrote, “The lack of attendance to the patient’s experiences is the source of an overriding feeling of invalidation people with experiences of psychosis describe” (p.140). Regrettably, other researchers have found that not talking about the voices can lead to “idiosyncratic and less socially functional ways of understanding and coping with voices” (Romme & Escher, 1993). Many service-users must then choose between isolation or rejection, as they decide what to communicate and with whom regarding their hallucinatory experiences.

The qualitative metasynthesis also noted that, for individuals with psychosis, the maintenance of interpersonal relationships becomes a challenge. Chernnomas, Clarke, and Chisholm (2000) found in their study that women diagnosed with schizophrenia talked about losing relationships with friends and family who do not “understand their illness and the difficulty they now have ... connecting to the world” (p.139). MacDonald et al. (2005) found that some individuals diagnosed with psychosis-related disorders “felt misunderstood by their friends and preferred not to spend time with them” (p. 139). While it is not clear what role hallucinations specifically play in the challenge to maintain contact with friends, family and the world, the negative impact on verbal exchanges resulting from these perceptions cannot be dismissed.

Furthermore, individuals with schizophrenia have been found to have “impoverished social networks” with fewer friends, and narrower social connections compared to the general population (Wan-Yuk Harley, Boardman, & Craig, 2012). Some participants in this study of social networks even named their mental health providers, or the voices themselves, as the primary source of their social contact, pointing to real difficulty forming and maintaining bonds outside of professional contexts for some individuals with SMI (serious mental illness). What appears to be the case, given the clinically relevant research, is that we know little about the actual *lived-experience* of social sharing. But we do know that it occurs in professional and non-professional contexts, and that individuals with SMI appear to largely feel dismissed from these encounters.

Though it is important not to rely overly on the clinical literature, or hallucinations occurring primarily in contexts of psychosis or serious mental illness, it is also important to understand that individuals experiencing hallucinations in these contexts appear to report feeling isolated from others when they attempt to speak about their hallucination experiences. The clinical literature is also important because it illustrates the relative absence of research directly on close others (“Listeners” for the purposes of my program of research) when hearing about and responding to hallucinations. Yet, as reviewed in the next section, research also clearly supports the important role that close others play in the recovery process.

### **2.5.2 Social approaches to treatment**

Services and programs are increasingly being directed to family members of individuals with serious mental illness, with family psychoeducation groups gaining popularity as an

evidence-based conjunctive intervention for treatment of SMI (Murray-Swank & Dixon, 2004; United States Department of Health and Human Services, 2009). Additionally, in the Western Lapland region of Finland, The Open Dialogue Approach, has been shown as effective in addressing recovery-related measurements in psychosis (Bergstrom et al., 2017; Bergstrom et al., 2018; Buus et al., 2019). The Open Dialogue Approach to treating psychosis involves drawing on informal social networks at the same time that individuals with first experiences of psychosis begin therapy (Lidbom, Boe, Kristofferson, Ulland, & Seikkula, 2015). In this approach, family members, individuals experiencing psychosis, therapists, and other relevant care-workers meet and collaboratively discuss experiences and understandings related to the illness (Seikkula, Alakare, & Aaltonen, 2001). Through this process, individuals experiencing psychosis are able to find words, expressions, and meaning within their symptoms, that are collaboratively formulated with important others in their life (Seikkula et al., 2001). The Open Dialogue approach has also received support as a value-aligned and human-rights consistent approach to working therapeutically with individuals in psychotic distress (Schutze, 2015; von Peter, 2019).

Proponents of this therapy have pointed to the essential need to look not only “at the therapeutic method itself but the ability to see the polyphonic nature of the client’s reality” (Seikkula, Arnkil, & Eriksson, 2003, p. 200). Therefore, an important aspect of these meetings involves clarifying the meaningfulness of the client’s symptoms, including hallucinations. Meaning is examined not only for the client, but for the other important individuals in the client’s life. Stakeholder understandings of the symptoms are shared, and these understandings are then worked with as professional teams formulate plans of care. This trend for inviting family member understandings and input into treatment planning appears to positively impact rates of relapse and degree of recovery. However, these interventions are focused on distress related to hallucinations occurring in the context of clinical disorders, so little is known about the social interactions that occur outside of professional interactions for hallucinations occurring in other contexts.

Cretchley, Gallois, Chenery and Smith (2012) examined differences in accommodation and conversation style between various family members and individuals with schizophrenia living in Queensland Australia. These authors point out that, since the transition from institutionalization to community care, over half of individuals with chronic mental illness reside with a relative and that this relative acts a primary caregiver. These relatives often make up the largest contribution to an individual’s weekly social contact. Understanding the experience of family members of individuals with mental health diagnoses is extremely important, as there is an increased burden of care placed on family members of individuals with a psychiatric disorder (Cretchley et al., 2012). Yet, the lived-experience of family members and close others in hearing about and responding to hallucinations is under-examined.

Other recent trends in the treatment of hallucinations, such as hearing-voices groups, peer support, and the recovery movement more widely, have illuminated the existing dominance of medical language over an individual’s experience. These new approaches have created opportunities for people who experience hallucinations to interact with each other, in a way that preserves their individual views and experiential framework, even if an individual viewpoint clashes with medical norms.

## **2.6 Translating qualitative research**

Within the last decade, qualitative research has made important contributions to programs that center the voice-hearing experience, such as the Hearing Voices approach and the Network Therapy approach previously mentioned. Qualitative studies exploring the lived-experience of voice hearing have been on the front-line of shifting the views of researchers and clinicians in understanding that voices can be meaningful, positive and important aspects of a voice-hearer's life. For example, Fenekou and Georgaca (2009) conducted a study exploring the lived experience of voice hearing and made recommendations regarding how we can better understand the frameworks that voice-hearers have for their voices outside of our clinical models. Qualitative research has been integral to our understanding of the phenomenal presentation of hallucinations as well. For example, phenomenological approaches have been helpful in elucidating sub-types of hallucinations as well as the various ways they can present to consciousness (Woods, Jones, Alderson-Day, Callard, & Fernyhough, 2015). In addition, discourse analytic approaches have investigated conversational aspects of institutional settings or psychiatric care that disempower clients with serious mental illness (Goicoechea, 2006; Harper, 1999).

Davidson (2012) acknowledged that personal experiences of psychosis and research examining subjective experience has increasingly been integrated with more quantitative or clinical understandings to come to better understandings of psychosis experiences, and to increase the efficacy of our treatments. Another important aspect of qualitative research is that some qualitative research is immediately accessible to service-users, voice-hearers and other individuals who experience hallucinations. This feature dovetails with a recognition that it is important that service-users are collaboratively involved with research as much as possible (McCarthy Jones et al., 2012). Inviting service-user collaboration and experience into our clinical research missions has led to important realizations regarding the social networks of individuals who experience hallucinations. For example, Flanagan et al., (2010) utilized qualitative methodologies to better understand the lived-experience of schizophrenia. The welcoming of service-user experiences in this study allowed the authors to learn that their participants "worried that if they told other people they would be dismissed as 'crazy'" (p. 151). Thus, qualitative research into psychosis, serious mental illness, and related experiences such as hallucinations, has brought new light to the role of social connections in these disorders.

## **2.7 The Call to Expand Hallucination Research Beyond Clinical Contexts**

The initial meeting of the International Consortium of Hallucination Research (ICHR) occurred in 2010 (Thomas, Russel, & Waters, 2015). This consortium has a meeting every year, and continues to hold annual general meetings, often accompanied with public conferences welcoming individuals with lived-experience of hallucinations. Out of these conferences and the general meetings of the ICHR, multiple working groups have been formed to advance our understanding of hallucinations. Starting in 2015, the ICHR began to bring sharper focus to the need to expand our understanding of hallucinations beyond individuals who experience hallucinations in the context of mental illness, and to expand the exploration of hallucinations beyond auditory verbal hallucinations, which are the most common for individuals with psychosis. As such, there has been a growing interest in "healthy voice-hearers." In 2017, a



systematic review of the healthy voice-hearer literature found 36 manuscripts meeting criteria for inclusion (Baumeister, Sedgewick, Howes, & Peters, 2017). In reviewing the literature, the authors found that the subjective experience of voices (presentations such as loudness or localization inside or outside the head) was consistent across healthy and clinical voice hearers. However, the clinical voice hearers had more frequent voices, more negative voice content, and an older age of onset. Authors of this systematic review also found differences between healthy and clinical groups regarding belief about voices, degree of control over voices, and distress or difficulty related to the voices (Baumeister, et al., 2017). They concluded, “Ultimately the results of the present systematic review support a continuum view rather than a diagnostic model, but cannot distinguish between “quasi” and “fully” dimensional models. Healthy voice-hearers may be a key resource in informing transdiagnostic approaches to research of auditory hallucinations” (p. 125). As such, it is important that we work to expand our research to include hallucinations occurring outside of clinical contexts, as well as in modalities beyond audio verbal hallucinations (AVH).

It is also important to acknowledge that even some hallucinatory experiences which would be considered “clinical” should be seen as within the range of the normal human perception continuum. For example, the Hearing Voices movement website, Intervoice (2018), states, *“We understand ‘voices’ to be real and meaningful, something that is experienced by a significant minority of people, including many who have no problems living with their voices. Our research shows that to hear voices is not the consequence of a diseased brain, but more akin to a variation in human behaviour, like being left-handed. It is not so much the voices that are the problem, but the difficulties that some people have in coping with them.”* This statement assists in foregrounding the view that, whether individuals seek treatment for their hallucinations or not, even hallucinations that are distressing should be seen as “akin to a variation in human behavior.”

## **2.8 Grounding the Current Research**

While this call has been made to expand research to include hallucinations occurring in non-need for care individuals, particularities of the social sharing of hallucinations occurring in both clinical and non-need for care individuals has yet to be examined. Further, while research has shown that family members and close others play an important role in recognizing hallucinations as an aspect of early psychosis and of supporting individuals with schizophrenia as a main support system (Caqueo-Urizar, Rus-Calafell, Urzua, Escudero & Gutierrez-Maldonado, 2015), I was unable to find research of the lived-experience of close others when hearing about and responding to hallucinatory experiences. As such, my program of research answers the call to continue inviting and incorporating the lived-experience of service-users and their families into our understanding of hallucinations and the way we approach clinical treatment of hallucinatory experiences (Bergstrom et al., 2018).

In addition to the above, the current program of research is in line with the recommendations from the international hallucination research community in a number of ways. First, I collected rich descriptive detail rather than questionnaires in considering whether participants originally experienced or heard about hallucinatory experiences. Second, I expanded participation in my study to include participants who shared hallucinations in both clinical and

non-need for treatment contexts. Third, by dedicating a subset of my participants as “Listeners”, I have incorporated research on close others and on social context and connections for those who are hallucinating. These actions match the recommendations of the International Hallucination Research Consortium (ICHR) to expand our research on hallucinations to include ever-broader sets of experiences, including hallucinations for which individuals are not distressed and never seek treatment. ICHR authors write that critical and in-depth methodologies are needed that “... devise new ways to understand how conceptual frameworks, available cultural scripts, and biographical and embodied experiences might help structure and constrain both the subjective experience and communicated phenomenological form of AVHs.” Woods and his co-authors (2014) acknowledge the benefits of “analytic frameworks that attempts to understand how language, narrative and embodied experience can both structure experience over time and provide potential tools for healing” (Woods et al., 2014, p. S249).

Given the above, the following research contributes to our understanding of the social sharing of hallucinations in multiple ways. First, it examines hallucinations at a broad level, allowing for hallucinations occurring in both clinical and non-clinical contexts to be considered together. Second, by focusing on the social sharing of hallucination that occurs *outside* of professional contexts, the present program of research draws focus to important non-professional relationships. Third, though qualitative research has focused on the lived-experience of psychosis, hallucinations and recovery (Cogan, Schwannauer, & Harper, 2019; Davidson, 2003; Hansen, Stige, Davidson, Moltu, & Veseth, 2018; Pienkos et al., 2019; Windell, Norman, Lal, & Malla, 2015;) the current program of research adds to these understandings by specifically considering the *lived-experience* of the social sharing of hallucinations. Finally, the research dually considers both Listeners and Experiencer standpoints and considers both sets of experiences together.

## Chapter Three: Methodology

The following chapter addresses the over-arching methodological framework in which my research questions were formed and the specific research methods used to address these questions. I begin with a general introduction to phenomenology as a qualitative research methodology within the discipline of psychology, continue with a comprehensive overview of van Manen's hermeneutic-phenomenology as a subtype among phenomenological approaches, and conclude by elaborating the specific methods and processes of sampling, recruiting, interviewing, transcribing, analyzing, and interpreting used in this program of research.

### 3.1 Phenomenology

Phenomenology focuses on an individual's life-world, described as, "the realm of immediate human experience existing prior to the abstractly conceived world of the natural and the social sciences, including psychology" (Halling, 2008, p. 155). As such, phenomenologists attempt to acknowledge and, as much as possible, put aside social science concepts as well as their own assumptions and preunderstandings prior to and during their investigations (Halling, 2008; Willig, 2013). Even with this intention, most phenomenologists choose to recognize that their preunderstandings are constantly being forced upon the topic of their research, with Halling writing, "... one can focus on an experience even while one imposes upon it (often without knowing it) one's preconception of what it is and how it should be understood... one inescapably proceeds from some already existing perception or *preunderstanding* of a particular question or issue. If one did not have some notions about the issue, one would not attend to or ask questions about it" (p. 169). Likewise, Crotty (1998), explicating the process of hermeneutic phenomenological research, wrote "... in order to understand something, one needs to begin with ideas, and to use terms, that presuppose a rudimentary understanding of what one is trying to understand. Understanding turns out to be a development of what is already understood, with the more developed understanding returning to illuminate and enlarge one's starting point" (p. 92).

This being the case, phenomenologists are encouraged to be mindful of their preconceptions and biases. They attempt to acknowledge and then, when possible, put these assumptions aside, or 'bracket' them, during the investigation. Though inescapable, language itself must also be considered a site of interpretation, with Gadamer (2004) writing "...language is a medium where I and world meet, or, rather, manifest their original belonging together" (p. 469). Thus, my prior understandings of the phenomenon, including my significant clinical work as an intensive case manager, my background in humanistic approaches to therapy, and my position within the discipline of clinical psychology played an important role in my overall understanding of the research topic.

At its most basic and cryptic, phenomenology can be understood as the study of what appears. As Husserl (2001, p.168) wrote, "we must go back to the things themselves." Phenomenon means "that which appears," and logos means "word" or "study" (van Manen,

2014). Phenomenology can be understood, then, as the study of that which appears as an object, experience, feeling, relation, and so on, within consciousness. Jan Patocka (1998) wrote that phenomenology brings out “the originary personal experience. The experience of the way we live situationally, the way we are personal beings in space” (p. 172). This statement is an acknowledgement that as materially, temporally and socially situated conscious beings we exist in a pre-reflective mode in which we are, for the most part, swept up by the successive moments of our lives.

### **3.1.1 The living now and the mediated now**

In *Phenomenology of Practice* (2014), the primary guide for the present analysis, van Manen explained the difference between the *living now* and the *mediated now* by encouraging the reader, as I would like you to do now, to picture a scene. You are sitting outside a café on a summer day sipping coffee and day-dreaming as you wait for an old friend, whom you have not seen in years. You see a large red ball rolling into a busy street and your body charges as you instinctually begin to rise from your seat out of fear that a child will follow the ball into traffic and be hit by a car. Fortunately, the child catches the ball before it leaves the sidewalk and you relax. Your friend arrives soon after and you lose yourself in conversation as you catch up on one another’s lives and reminisce about old times. After coffee, you walk the neighbourhood together, stopping for a while on a bridge to lean against the railing and watch the water flow below (van Manen, 2014).

Perhaps you have experienced an afternoon like this, or something similar. If you recall now, at the time you were likely lost in the occurrences, you were living, rather than reflecting on, what was happening in each moment. To varying degrees, you were immersed in each moment: sipping your coffee, instinctually rising when you see a child’s ball rolling towards the street, enjoying the company of your old friend. Perhaps you were aware, as we can be in such moments, that something special was happening as you stood silently beside your friend on the bridge watching the water below. During the flow of these experiences, you likely stayed in the moment, in the *living now*. You *lived* these experiences, rather than *reflected* on them.

Reflecting back on those moments, you might have a certain sense of what these experiences were like, and how they differ from one another. What is it that makes the experience of sipping coffee on the patio of a café different from seeing a red ball roll into traffic? What gives each of these experiences their unique identity? What distinguishes these experiences, as lived, from one another? Phenomenology aims to answer these questions by seeking elements of experience that appear, as present, when the phenomenon is investigated through accounts of lived-experience. Investigation of experience does not mean that participants are consciously aware of these elements during the moment, during the *living now*. It means that in reflection, through the process of interview, explication, and getting descriptive detail of the moment as lived, that these elements come to the fore-front and their impact on the originating experience is seen.

With the present research, I have asked: what is the experience of speaking to another person about a hallucination; what is the experience of hearing from another person about a hallucination? Phenomenological methodological understandings, paired with relevant methods of data generation and analysis, allow questions of this type to be asked and answered in an

empirically grounded way. Phenomenological approaches acknowledge the distinction between the living now and the mediated now. These approaches provide a philosophical framework and methodical guidance on how to access the living now. Understanding of the living now is accomplished, in part, through the process of bracketing and an attunement to concrete lived-experience during the interview and throughout the analysis. The phenomenological research process aims to minimize the degree to which the mediated now interferes with our conception of the original experience with the recognition that, to some degree, interference from the mediated now as well as interference from the researcher's pre-understandings are unavoidable.

### **3.1.2 The natural attitude**

A final differentiation within phenomenological approaches involves separation of the scientific attitude from the natural attitude. In the natural attitude, we aim to get at life as it is lived in the originary moment. The scientific attitude layers on top of the natural attitude and shields it partially from view (van Manen, 2014; Halling, 2008). Phenomenology aims to move past scientific language and scientific understandings to get at natural language and everyday experience *as it is lived prior to a layer of scientific interpretation*. As explained in the introduction, one reason I decided to leave it up to my participants to define 'hallucination' was to reduce the degree to which this layer of scientific understanding would constrain the experiences brought forward from the recruitment and interview prompts. Phenomenological description is meant to *describe* rather than *interpret* or *explain*. The results of phenomenological analysis should avoid, as much as possible, drawing on scientific theories or disciplinary jargon. Yet, even description must be acknowledged as an interpreter task (Gadamer, 1975; Willig, 2013), as the quotes in the introduction regarding the necessity of pre-understanding to any understanding indicate.

Descriptions generated from the perspective of the natural attitude are useful because they help us better understand experiences as they are lived by individuals during the course of their everyday life. Focusing on the natural attitude allows the results of the analysis to be understood by the non-specialists, to the "lay-reader." Within clinical psychology especially, this understanding is useful in that it informs and enriches our understanding of the experiences under study. It helps us tailor our programs, interventions, and conversations by drawing attention to important features of speaking about, and listening to, hallucinatory phenomena. At the same time, we must never lose our willingness to explore what hallucinatory experiences, and the social sharing of these experiences, mean for those who have them.

Importantly, getting at the originary moment is not only about getting at what that moment feels like. Some phenomenologists expand their questioning to consider the total context in which such moments exist (Halling, 2008). For instance, rising to stop a child from racing into the street is interrelated with aspects of being human that are directed toward caring for and protecting children, as well as sensing danger and being reflexively summoned to respond. These aspects are not experienced as such in the moment, they are not reflected on in the action; yet, they likely inform the action as someone instinctually moves to keep a child safe. Though the following dissertation focuses primarily on the lived-experience of moments of social sharing, contextual elements, such as the context of the relationship or the etiology of the hallucination, are also considered.

### 3.2 Interpretive Phenomenological Approaches

Descriptive and interpretive threads run through phenomenology and it is necessary for me to state to which of these I most align. Descriptive methods, the best example of which is Giorgi's descriptive phenomenological method (Giorgi, 2008), maintain the Husserlian orienting of phenomenological philosophy towards transcendent structures of experience. Transcendent structures are understood as existing beyond the sole perception of the individual and to never be perceived in their entirety. Phenomenology understands items to exist in transcendence *beyond* consciousness, but to only be known *through* consciousness. However, consciousness does not create the items of perception, but rather consciousness reveals limited vistas of the objects on which it shines. Due to the paired structure of consciousness with phenomenal *items of consciousness*, some researchers would state that these structures have a real independent existence outside of the experiences themselves. Davidson (2003) wrote, "We come to realize that this thing is not contained in, not merely a part of, any one experience for it remains the same as its appearances may vary. It may only be viewed through our experience of it, but through these experiences it is experienced nonetheless as a thing that transcends these experiences themselves; as that which is other than our experience of it" (p. 20).

Within transcendental phenomenological methodology, there is a search for the "general structures" that *necessarily* make up components of the experience as lived. Phenomenological research focused on these general structures can be framed as the search for essences, and in the move toward essence, this sub-methodology moves beyond individual cases to examine their necessary commonalities. Through research on general or essential structures of the lived-experience, extensions into universality are made when possible. This process of moving from the individual to the universal is termed "eidetic intuition" (Langridge, 2007).

In this movement, the analysis, which begins as a description of individual experience, transitions to saying something more generally about the phenomenological structure of the experience under examination. Many descriptive/transcendental phenomenologists, including Husserl, maintain that because what is essential will be necessarily present in every description of that experience, a phenomenological analysis is possible with a single account (Langridge, 2007). The presence of essential elements in every instance is one reason phenomenological researchers often have smaller sample sizes than some other qualitative methodologies. On the other hand, by collecting multiple accounts that center on the experience under study but differ on a variety of other dimensions, the central features of the phenomenon are more likely to come to light. One of the underlying reasons for maximum variation sampling, which was the sampling method used in this research, is the belief that by collecting extreme variations in diverse domains of the accounts, these "essential" aspects will be better revealed.

As opposed to descriptive phenomenological approaches, as an interpretive approach, the outcome of hermeneutic phenomenology is inconsistent with claims regarding general laws (Ashworth, 1997). The primary goal is rather to describe an experience in sufficient depth that it captures the essence of the life-world for those studied (Ashworth, 1997). In this usage, essence refers not to a philosophical essence without which an object or an experience can no longer be what it is, but rather a *relatability*, an understanding, an insight into aspects of the core elements (van Manen, 2014). Relatability is developed, in part, through the experience of resonance,

which is accomplished when a reader encounters a piece of phenomenological research and is moved by it to either recognize similar features in their own personal background, or to feel, quite directly, a new empathic understanding for the experiences being described.

Another core difference between transcendental/descriptive and interpretive/hermeneutic subtypes of phenomenology is that, in hermeneutic phenomenology, description is acknowledged as an act of interpretation. Although the researcher makes every attempt to stay empathically in tune with the life-world of participants, the researcher's active role in deciding what is deemed relevant and what is emphasized within the data is acknowledged (Ashworth, 1997). Further, though some phenomenologists speak of "uncovering" or "revealing" aspects of an essential structure through their process of data generation and analysis, Van Manen's hermeneutic phenomenology acknowledges that the findings of research are co-generated between the researcher and research participants. This position is consistent with my own view regarding the research process as well as many other leading phenomenological researchers (Finlay 2009; Kvale & Brinkmann, 2009).

To acknowledge the distinction between the results of my analysis and what would typically be considered essences in phenomenological research, I have used the term "Facets" to describe my resulting categories. A full review of this term and its meaning within the present research will follow, but in brief, a Facet is an aspect that seems in some way interesting, striking and central to the accounts. Facets, singly and together, provide a framework through which the phenomenon of social sharing hallucinations can be viewed. They enrich our understanding of the accounts and create an awareness for important features of the experience of the social sharing of hallucinations in our personal lives which may prove useful in our clinical work and program development as well.

In sum, I will not be making claims regarding essence, as my project more closely aligns with interpretive phenomenological approaches, rather than transcendental phenomenological approaches. Interpretive approaches generally give greater acknowledgement to the role of the researcher in the process of interpretation and move away from language that involves an assumption of general structures outside of consciousness.

### **3.3 Phenomenological Data Analysis**

There are a variety of analytic methods and techniques available to phenomenologists, with different phenomenological researchers sometimes utilizing similar techniques in different ways. Halling (2008) described three levels of phenomenological analysis that can serve as a rough guideline of the analytic movements used in the present research. I elaborate specific analytic movements in the next section.

*First*, the researcher closely examines individual accounts of the concept under investigation. The researcher pays attention to descriptive detail and attempts to learn something about the phenomenon as reported by the particular individual to which the account belongs.

A *second* level of analysis involves a search for themes (in my case Facets). At this level of analysis, the individual descriptions are compared and contrasted with one another. During these comparisons, the researcher tries to get a sense for what makes the lived-experience of the

phenomenon under study unique from other experiences. For the present study, this analytic movement enables me to say something about how individuals participating in my study described the social sharing of hallucinations and what some of the common features, or possible contours of this experience, might be. Inconsistent features among the accounts should also be noted.

Finally, the phenomenological researcher engages in a *third* level of analysis that is more philosophical. At this level, the researcher reflects on what it is about humans that gives rise to this particular experience. For the topic of social sharing of hallucinations, this reflection could possibly centre on ideas of mutuality and perception and the ways in which we, as human beings, at least in certain cultural contexts, assume the perceptual manifestations of physical reality to be shared, as well as the ways in which we respond to violations of this assumption.

While data are analyzed thematically during some of these movements, the specific steps of analysis are not prescriptive and should grow out of the interrelationship of the researcher, the accounts generated, and the subject of the study (Halling, 2008). The analysis can be understood as movement through hermeneutic cycles of understanding in which parts are understood relative to the whole and new understandings are understood relative to prior understandings. The analytic movement should involve repeated cycles of: saturation in the data, comparing accounts, reflecting, writing, and engaging with the available literature on the topic. Finally, during all parts of the analysis the researcher should reflect on how their role, as researcher, interviewer and interpreter, contributed to the results of the study.

Among phenomenological approaches, hermeneutic phenomenology is one of the least restrictive regarding process. The hermeneutic (interpretivist) method of van Manen (1990), like many phenomenological methods, should be seen as a “heuristic – as a guide to practice – rather than as a set of rules determining the method” (Langridge, 2007, p. 122). Phenomenology is widely acknowledged as fluid, not fixed, and it is expected that individual researchers will make the approach their own. It is also expected that the researcher will be adaptively responsive to the phenomenon under study (Fischer, Laubscher, & Brooke, 2016). There is a call to be flexible with the specific methods of data generation, data analysis, and writing up the results, so that these aspects can responsively match the phenomenon of interest. However, in other phenomenological approaches, line-by-line coding, specific processes of thematic collapse and expansion, or guidance regarding combinations and sequences of deductive and inductive coding are recommended (Smith, Flowers, & Larkin, 2015). In hermeneutic phenomenology, priority is given to the researcher’s flexibility in responding to the phenomenon at hand (van Manen, 2014) and the accounts as given.

Ultimately, there are six basic steps for hermeneutic phenomenological research:

1. Turning to a phenomenon which seriously interests us and commits us to the world;
2. Investigating experience as we live it rather than as we conceptualize it;
3. Reflecting on the essential themes which characterize the phenomenon;
4. Describing the phenomenon through the art of writing and rewriting;



5. Maintaining a strong and oriented relationship to the phenomenon;
6. Balancing the research context by considering parts and whole (van Manen, 1990, pp. 30)

### 3.4 Facet, Theme, and Essence

For this research, I wish to differentiate the results of my analysis from the words “theme” and “essence.” Essence risks association with philosophical essence, meant as a requirement or an *essential* centrality. The word ‘theme’ can take on many meanings, depending on the author and research. Therefore, I have chosen to use “Facet.” This term, I believe, is appropriate because it allows flexibility—results of my analysis do not need to be considered as essential components of the phenomenon of social sharing. Beyond this, it allows me to speak not only directly to the lived-experience of my participants, but also to address aspects of context and language that seem relevant within the data set. A primary goal of these Facet categories is that they will provide both an expansiveness into general considerations and an anchoring in relation to the phenomenon as described concretely by my participants in the accounts. By this, I mean that they will anchor the reader in the accounts, and the accounts within the phenomenon, while simultaneously allowing for *new hearing* or a *new openness* regarding these experiences.

Van Manen (2014) wrote that analysis is a “complex and creative process of insightful invention, discovery and disclosure” (2011). The researcher maintains openness to the phenomenon, and to the concrete details of the phenomenon of lived-experience and desires to make sense of the phenomenon (van Manen, 2014). Through this process of analysis, the researcher collapses the descriptive details of the accounts into a brief symbolic form (essence, theme, or here, Facet). Unavoidably, this process of collapse leads to some loss of richness, individuality and detail. Research, descriptive writing, and Facet attribution are never “fully adequate to the mystery of the phenomenon and the experience” (van Manen, 2014). Though Facets “give shape to the shapeless” in that they should allow a new understanding for the phenomenon, it is important to acknowledge that my Facet categories are inadequate for capturing the lived-experience of the social sharing of hallucinations entirely.

### 3.5 Ontology and Epistemology

It is important for researchers to acknowledge the epistemological and ontological framework in which the research is performed. Epistemology can be understood as the branch of philosophy concerned with the possibility and nature of knowledge itself. Willig (2013) wrote that epistemology, “attempts to provide answers to the question, ‘how, and what, can we know?’” (p. 4). On the other hand, ontology involves the “philosophical study of capital ‘B’ Being and addresses not what can be known, but rather existence and the structures of existence (Langridge, 2007, p. 29). Ontological and epistemological claims justify the choice of particular methodologies and acknowledge that research methods and the results of any analysis reach into the assumptions regarding reality that are brought to the work (Crotty, 1998).

Most phenomenological studies are framed within an interpretivist ontology that understands the existence of objects of study, as well as results of the analysis, as generated in interaction between the individual researcher (or any perceiver) and the object (or concept) as it exists in the world. This interaction is represented in phenomenological philosophy, in part, by

the idea of *intentionality*, whereby consciousness is always consciousness-of-something and the duality of world and subjectivity collapse into a unity that can be understood as human experience (Langridge, 2007). Thus, ontologically, phenomenology understands two aspects of being - the perceiving consciousness, and the thing consciousness perceives. However, this co-existence of consciousness and items of consciousness is not a pure dualism, as consciousness and the items of consciousness can never be fully separated.

Consistent with the understanding of the inseparable duality of consciousness and items of consciousness, interpretivists do not acknowledge a 'reality' or 'existent ontological structure' *alone from* the experiencing individual and, as such, results of hermeneutic-phenomenological studies must always be framed as contextual, local, and generative. Further, the importance of language, human relatedness, and social structures in creating an intersubjective world is often stressed in interpretive or hermeneutic phenomenological approaches. This aspect of hallucinations as being defined, of being *brought into existence*, through the discourses that create them, makes the social sharing of these objects particularly fitting for interpretivist and hermeneutic approaches, in which the conversational act, the discourses, and the historical situation of understanding is acknowledged alongside the phenomena.

In relation to the specific questions of this research, epistemology considers what it is that can actually be known about the social sharing of hallucinations, what degree of certainty the knowledge generated from the research holds, and how new knowledge related to the study can be generated. Ontologically, within an interpretivist framework, the social sharing of hallucinations cannot be considered to have an existence separate from the perceiving consciousness. The participant descriptions that form the data of this research do not merely provide access to the phenomenon of social sharing as it exists outside of their descriptions. Rather, the phenomenon of social sharing and the conscious availability of this sharing to my participants are co-created and to some degree inseparable, as consciousness must always be *consciousness of something*, and the phenomena of consciousness would not exist without the conscious awareness.

### **3.6 Quality and Validity in Phenomenological Research**

There are developing, conflicting, and cautious viewpoints within the field regarding assessments of quality in qualitative work. Phenomenology is unique among qualitative approaches; as such, a subset of recommendations regarding standards of quality relevant to phenomenological research must be considered. Elliot, Fischer and Rennie (1999) proposed various criteria by which qualitative publications might be judged. These criteria generally include the researcher owning their perspective, being explicit about their theoretical orientation and personal assumptions, situating the data within their occasional context, using direct examples from the data to support claims, not generalizing beyond what seems reasonable given the breadth of data collected, and writing up research in a way that stimulates understanding of the topic. Similarly, Wertz (2011) wrote that appropriate questions when evaluating phenomenological research include, among others, the degree to which data were broad enough to provide sufficiently varied lifeworld examples, the author's acknowledgement of contextual influences on the data, and that the results of the analysis can be widely applied to other instances of the phenomenon.

Addressing validity in phenomenological research is accomplished through a variety of methods. Some researchers increase validity by cycling the results of their analysis back to their participants for feedback (participant validity) (Willig, 2013). Other researchers have more than one researcher perform the analysis (researcher corroboration), with validity increasing with the degree to which results correlate. In light of the above recommendations for measuring the quality for qualitative research and in combination with my own consideration of how the aims, scope, and content of this study interact with these recommendations, I have held myself to standards of validity as judged by the following:

1. Excerpts clearly support the Facet categories.
2. Facet categories form a cohesive whole, speak to one another in meaningful ways, and, on the surface, seem to capture important aspects of the phenomenon of social sharing.
3. Facet categories are broad enough to have wide application.
4. Facet categories can be applied to new occurrences of the phenomenon in immediate and meaningful ways.
5. I have explored and accounted for, as much as is reasonable, my own assumptions regarding the research and the ways the context (interview, university setting, etc.) might have had an impact on the data.
6. Consistency is maintained between my research process, analytic results, theoretical orientation, and the language used to make and support my claims. Generalizability is considered, but not overstated.
7. Facet categories draw the reader into thoughtfulness rather than telling the reader how to think. Readers are able to make their own connections between Facets, and Facets inspire readers to ask their own questions about the phenomenon.
8. Facet categories are not masked in jargon, but are easily understandable and relatable to the lay reader.
9. Finally, there is a sense that something worthwhile and substantial has been said with the data and contextualizing chapters.

## **Chapter Four: Defining, Reviewing and Situating**

### **4.1 Defining Hallucination in the Study**

By widely allowing my participants to self-describe what they would consider hallucinatory, I generated a data set of accounts with participants who were able to maintain their naturally occurring and non-clinical understanding of the phenomenon. As stated in the previous chapter, an important aspect of phenomenology involves the “natural reduction” in which the researcher attempts to move away from scientific understanding and language, to capture the phenomenon as it presents in the flow of every-day life prior to the lens of science. My reason for not rigidly defining hallucinatory phenomena was two-fold. First, I wanted to distance myself from medicalized understandings so that I could invite non-professional frameworks into the data set. Second, I was dedicated to the experience of social sharing as the focus of the analysis, rather than to the hallucinations themselves.

Van Manen used an example of the experience of “fatherhood” in which he provided a description of the lived-experience of riding bikes around the neighbourhood with his adolescent son on a sunny afternoon (1990). In this example, “fatherhood” is not defined as a genetic relation, but rather as an experiential bond between a man and his son or daughter. A foster parent, a step-parent, even an older brother, uncle, neighbour, or teacher can all inhabit the experiential space of “fatherhood,” as phenomenologically the central defining element involves the relationship rather than the genetic link. Similarly, in the phenomenon of the social sharing of hallucinations it is largely the belief of the individual sharing or hearing about the hallucination, regarding whether what they are sharing is a hallucination that is of central importance to the experience itself, rather than the degree to which hallucinations would fit strict medical criteria.

This open stance regarding hallucinatory experiences invited a data set of social sharing that grew directly out of community understandings of what hallucinations are and the contexts and relationships in which they are shared. I believe this decision is well grounded in phenomenology as it creates an experience-near aspect to the phenomenon. In addition, it allows me to explore the various sets of understandings that cluster around hallucinations, from multiple viewpoints and frameworks.

Another reason I wanted variety in the hallucinatory experiences for my study was so that I could use this variation during the phenomenological analysis. Wide variation enabled me to compare different subtypes of experiences to one another, as well as to look for what maintains commonality across situations of sharing from the different experiences of the participants. There are criticisms to this approach. For example, purity of my data set is disrupted from a clinical perspective—I end up with a diverse data set of experiences that limits applicability to clinical populations. In addition, I risk diluting the experience so much that I am unable to say anything of specific meaning at all. To address these concerns, I begin my analysis section with a lengthy consideration of how these various contextual elements are important, and how context

itself, in some instances, seemed to be a central revelation to the social sharing. While I deem it appropriate to have invited multiple definitions and understandings into my data set, I aim to offset some of the criticisms related to that choice by exploring the impact it might have had on my data. An argument against this “purity” argument is that in phenomenology a sampling of maximum variation is desired, and that I enriched the variation in my sample by inviting multiple understandings and contexts.

As for the criticism that I lose some aspect of clinical applicability by inviting both need for care and non-need for care participants into my data set, a central goal of this program of research has always been emancipatory. I made a committed effort to frame hallucinations *outside* of the pathologizing lens they are vulnerable to being framed in. To have invited only experiences that could be considered mental health-related would have been inauthentic to this stance. I believe the benefits, as well as consistency with my values and assumptions regarding the phenomenon, outweigh the goal of having purity and singularity around strictly defined hallucinatory experiences.

#### **4.2 Research Setting, Sampling, and Recruitment**

I conducted this study in Saskatoon, a mid-sized prairie city in the province of Saskatchewan, Canada. Canada, along with the United States of America, can be considered a developed and westernized North American nation and participants who are recruited can be said to be living within this context, regardless of their cultural beliefs and practices. However, Saskatoon is culturally and ethnically diverse and many different geographical backgrounds are represented in the accounts, as are multiple religious affiliations, including Christian, Indigenous, Pantheist, Taoist and mysticism. I acknowledge, however, that generating data in Saskatoon as opposed to elsewhere on the globe, led to data that primarily represented western religion and disease models.

The method of sampling was *purposive maximum variation sampling* (Langridge, 2007), in which the researcher seeks out participants who have a common experience but who vary on a wide range of other characteristics such as demographics and diagnosis. This sampling method fits with a phenomenological analysis that depends in part on having diverse accounts to compare. Sampling also attempted to employ the *snowball recruitment* procedure in which participants are encouraged to notify others who they think might be interested in participating in the study.

Recruitment materials were personalized for each of the interview groups. (Experiencers and Listeners). Adverts introduced the study as a qualitative exploration of different accounts of the social sharing of hallucinations outside of professional contexts. Examples of adverts can be seen in the Appendix (Appendices A and B). Participants were excluded from the study if they were currently hospitalized, currently experiencing an acute stage of psychosis, were under the age of 18, or did not speak English well enough to complete a phenomenological interview. Towards the end of recruitment, participants were also excluded if their hallucinations happened primarily in the context of drug-intoxication due to an unexpected and overwhelmingly large presence of this specific context of occurrence in my data set.

I recruited participants in two groups—those who had experienced hallucinations and then spoke to someone else about it (a group I termed “Experiencers”), and those who received the sharing of the experience (a group I termed “Listeners”). I based these titles, in part, on Clark’s publication on the social sharing of sympathy (1997). For this research, Clark conceptualizes her participants into “sympathizers” (givers of sympathy) and “sympathizees” (sympathy recipients). I thought it necessary to maintain distinct titles for these separate positions, though they overlap, and many participants speak from both Experiencer and Listener perspectives.

I recruited participants from clinical and non-clinical populations, to maximize variation and expansiveness within the data set. On-campus recruitment occurred through a PAWS announcement, flyers posted in buildings, and word-of-mouth. PAWS is the University of Saskatchewan’s digital student platform, through which students access their emails, register for classes, and review their grades. A feature of this platform is that announcements can be placed on the opening page when students initially log into their university web account. On-campus recruitment led to study participants that included undergraduates, graduates and professional staff. Off-campus, recruitment occurred via flyers posted on street-boards and within small business in multiple neighbourhoods of Saskatoon. A recruitment partnership was also formed with the Mental Health and Addiction Services (MHAS) arm of the Saskatoon Health Region, where flyers were posted in the waiting room for individuals receiving nursing, case-management, or therapy appointments in the central office. Clinicians at MHAS were also provided a brief write-up of the study and were able to distribute this write-up to individual clients as appropriate. Table 1 identifies the number of participants recruited from each source.

I attempted to recruit Listener participants through the Early Psychosis Intervention Program (EPIP). I participated in a meeting with the family group of this organization to provide a description of my research, answer questions, and welcome participation. However, no family members participated, though the session itself was extremely informative, as will be described in the discussion section. I also met with the program manager, social worker, occupational therapist, and psychiatrist of the EPIP. Although these conversations are not included in the data set, they were extremely helpful in increasing my understanding of how catastrophic early psychosis can be for individuals and their family members, as well as the pervasiveness of cannabis in initiating and maintaining psychotic symptoms (Marconi, Di Forti, Lewis, Murray, & Vassos, 2016). These conversations also drew attention to the co-relatedness of emotions and hallucinatory experiences, a relatedness that pervades my data set. Finally, I recruited through the Schizophrenia Society of Saskatchewan (SSS), Saskatoon Chapter, which operates the Partnership Program, a local stigma-busting program in which individuals with mental illness, family members and professionals give presentations to groups in the community about the experience and impact of serious mental illness. The Schizophrenia Society distributed a description of my study through their email list and many participants were recruited through this channel.

Table 4.1

Recruitment Channel	Number of Participants	Format
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University Campus	9	PAWS, Flyers
Saskatoon Neighbourhoods	7	Flyers
SSS	4	E-mail to listserv
EPIP	0	Meeting with Family Group
MHAS	3	Flyers, Clinicians
Snowball Recruitment	3*	Word-of-mouth

**Note:** *SSS* – Schizophrenia Society of Saskatchewan; *EPIP* – Early Psychosis Intervention Program; *MHAS* – Mental Health and Addiction Services; \*indicates these participants are double-counted and included in the other categories.

### 4.3 Process of Consent and Data Generation

Potential participants who encountered recruitment materials and were interested in the study left a message on a confidential voice mail or emailed my university email address. I returned this phone call or email and provided more a detailed description of the study, such as risks and benefits, the purpose of the study, and what participation would entail. Any questions regarding participation were encouraged and answered. A preliminary and brief consent process was undertaken during this initial phone call if the participant expressed an interest in being involved in the research. A full in-person consent process occurred immediately prior to the interview.

After this initial phone call, I scheduled an interview. Interviews took place primarily in my own office, but on three occasions they took place at either a long-term care facility (n=1) or in private university offices belonging to study participants (n=2). One interview took place over the phone, due to a participant being in another province. Prior to the telephone conversation, the unique aspects of telephone interviews were reviewed, and verbal assent was given to participate. Unique aspects of the telephone interview included that I was unable to see who was present with my participant in the room, would be unable to read body language, and would be using verbal consent rather than a signature. Two interviews were completed with two participants simultaneously - Gunnar/Allistaire who are married and Nicole/Naomi who are roommates. All other interviews were completed individually.

All interviews were audio recorded with the participant's consent. A short debriefing occurred after the interview that included questions about the participant's experience speaking with me on this topic. I made a list of resources for professional assistance and community support available in the event that a participant expressed serious distress. No participants expressed distress at the end of interviews, though one participant did indicate she intended to reinstate counseling with a previous therapist. A brief follow-up with this participant suggested no further resources were desired and that the distress was not long-standing.

At the end of the interview, if participants were interested, they were given flyers for the study and welcomed to invite others to contact me regarding participation in the research. When passing along flyers, participants were firmly told that they could not give me the names of potential participants, but that these individuals needed to contact me directly so that their privacy was maintained. After the interview, participants were compensated \$50.00 cash for their time.

Interviews were transcribed and de-identified by me. Pseudonyms were used during de-identification. At my request, a few participants picked pseudonyms after the interview; I picked pseudonyms for the rest of the participants. I emailed a password-protected and de-identified transcript to participants who indicated they wanted to review their transcript. These participants confirmed the written account as an accurate representation of the interview exchange. As social sharing was the focus of the interviews and individuals not consenting to the research were often mentioned during the interview, significant time and care was spent in ensuring identities were appropriately masked in the transcripts. Many of my Listener participants checked with the individuals they talked about during the interview to receive their permission and consent for the interview, as well as to confirm some of their understandings regarding the hallucinations. This checking was done without my prompting. Overall, the extreme care and sensitivity that my participants illustrated for the individuals we were speaking of was remarkable and I made every attempt to match this same care and sensitivity throughout the transcription.

#### **4.4 Interviews**

Following Kvale and Brinkman (2009), the data generated in my interviews must be seen as relational, produced, contextual, linguistic, narrative, and pragmatic; claims made from the data must acknowledge these aspects of interview accounts. This stance means that my role, as researcher, in the generation of the accounts is acknowledged, as is the social and cultural context of the interviews. Hermeneutic phenomenology as a methodology also supports this view of interviews as relational, contextual, linguistic and produced, and there are multiple ways I acknowledge this stance throughout the research. One is by explicitly stating it as I do here. Another is the frequency with which I include my own contribution to the interview in the excerpts, so that the reader can see the temporal and relational context in which participants' answers were given. During analysis, I considered the ways in which my presence and contributions led to the generation of the data set, and, in the discussion chapter, I include a section exploring the impact I believe I had on the data I generated together with my participants and on the results of the research. A researcher's impact on data can never be fully known (Willig, 2007), but I have attempted as much as possible to acknowledge, rather than mask, my presence throughout the research process.

I conducted interviews around the research question—how do participants describe the experience of participating in instances of social sharing of hallucinations? Interviews focused primarily on eliciting as much descriptive material as possible about these experiences. Interviews focused on generating accounts of this experience as it was lived. However, interviews also explored contextual factors related to the moment of social sharing. Examples of external factors related to the social sharing of hallucinations included: the decision to share or not to share, emotions or worries related to the sharing, experiences of support or non-support



that were an outcome of the sharing, transitions in beliefs about the hallucinations as an outcome of the sharing, specific details about the hallucination that was shared, and understandings of why the hallucinations occurred.

Interviews were semi-structured with extra stress placed on the flexibility to follow paths that surfaced during the conversation and on allowing the participant, as well as myself, to guide the interview. I often told participants that my goal was to “invite them into curiosity around the topic.” All participants were also told briefly about the Hearing Voices Group approach to hallucinations and that I hoped to provide something of use to both the discipline and non-professionals engaged in conversations about hallucinations. I also expressed my own belief that hallucinations are inherently a “normal” aspect of human experience, though they can be, and often are, distressing for those who have them. I believe this open stance, and the degree to which I was explicit with my participants about my own assumptions, helped some individuals be more open about their experience than otherwise would have been the case. Also, without doubt, by pre-emptively telling participants my stance and assumptions I likely had an impact on the content of the data I generated in multiple ways, such as increasing the chance of non-medical understandings.

I oriented participants to phenomenological interviewing by letting them know I would be trying to elicit descriptive details regarding the experience of social sharing, and that I would likely be returning to any concrete instances they mention of the phenomenon multiple times throughout the interview. I also informed all participants, both during the consent process and immediately prior to the interview, that if they did not want to answer something they could tell me “I don’t want to answer that,” and we would immediately move on without questions being asked and with no impact to their payment. No participants declined to answer any questions. Participants were also informed that they could stop the interview at any time, without penalty, and that, once the interview began, they would get their compensation regardless of any decision to halt the interview. No participants left the interview prior to the end. My aim during the interviews was strictly phenomenological; I tried to elicit rich, descriptive detail about the conversations, the experience of the conversations, and contextual or elemental factors that stood out for my participant. Interviews ranged from 47 minutes to 2 hours and 9 minutes. The mean interview length was 1 hour and 12 minutes.

The terms *accounts*, *occurrences* and *extracts* are central to the organization of my data. *Accounts* refer to the interviews themselves and each participant is considered to have provided an account, such that a simultaneous interview with two participants is equal to two separate accounts. *Occurrences* refer to each separate mention of the social sharing of hallucinations. Some occurrences were the primary focuses of the interview and others were mentioned only briefly. *Extracts* refer to specific sections of the accounts, typically focused on a single occurrence. Thus, each account involves multiple occurrences of social sharing and each occurrence likely involves multiple extracts.

Immediately after interviews, I free-wrote in Evernote (a journaling application I kept on my phone and personal computer) my reactions and thoughts so that I could later reflect on possible impacts my presence and questioning had on the interview moment and the data set as a whole. After interview notes were primarily used for personal processing of the interview encounters, but these notes also provided a paper trail to re-read when considering the steps of

my analysis, or writing up details of the interview encounters. While self-reflection is important, and increases the quality of my research, I also acknowledge that we, as researchers, are incapable of fully seeing the impact we have on our research. And, although reflexivity draws into awareness channels and content of our own impact, it can never account entirely for the role we have played as interpreters and generators of meaning within the research.

#### **4.4.1 Number of interviews**

There is a tremendous range in the number of interviews recommended by experts in the field of qualitative research. The consensus tends to be that this number ‘depends.’ It depends on the topic of research, the research question being asked, the method of analysis, and the theoretical underpinning of the methodology (Baker & Edwards, 2012). Many phenomenological research projects utilize only five or six interviews and it is rare for phenomenological research to use more than ten. However, due to my desire to collect accounts from a broad array of hallucination contexts, I completed 15 interviews with Experiencer participants and eight interviews with Listener participants for a total of 23 participants, in 21 interviews.

Significantly, many participants were able to speak from both the Listener and Experiencer perspectives, and many participants provided multiple moments and relationships of social sharing. Phenomenological research holds the moment of experience as the unit of analysis, rather than the participant (Langridge, 2007), so each of my participants were able to speak to multiple occurrences of social sharing, often from different perspectives.

#### **4.4.2 Participant list (in order of interviews)**

**(1) Marcel:** (age range: 25-40), [Experiencer] Male. Hallucinations in the context of dysthymia, alcohol withdrawal, marijuana use and one instance of mushroom use. (56 minutes)

**(2) Aurora** (18-25), [Experiencer] Female. Hallucinations in the context of sleep paralysis. Shared with her mother, boyfriend, religious friends, and secular friends. (1 hour 22 minutes)

**(3) Zack** (25-35), [Listener] Male. Student. Grandmother experienced religious hallucinations during a progressive dementia while in a nursing home. Zack was not able to stay in the room with her. (1 hour 15 minutes)

**(4) Esther** (60-75), [Listener] [Experiencer] Female. Telephone Interview. Friend experienced a hallucination of a ghost in her house. Esther herself experiences hallucinations in the context of her every-day life, including a brief but extremely meaningful encounter with her “inner-child.” (1 hour 35 minutes)

**(5) Simon** (25-35), [Experiencer] Male. Experienced hallucinations during mushroom use. Shared his experience with a girlfriend, his parents, a roommate, and a friend. (1 hour 35 minutes)

**(6) Park** (18-35), [Experiencer] [Listener] Male. Experienced and listened to hallucinations during nights of drug use with a small group of friends in which multiple individuals in the group experienced hallucinations. (1 hour 31 minutes)

(7) **Gunnar** (25-35), [Experiencer] [Listener] Male. Married to Allistaire. Taoist. Experienced and listened to hallucinations in the context of mushroom and LSD use. Interviewed simultaneously with Allistaire. (2 hours 9 minutes)

(8) **Allistaire** (25-35), [Experiencer] [Listener] Male. Married to Gunnar. Pantheist. Experienced and listened to hallucinations in the context of Salvia, mushrooms, and LSD as well as religious hallucinations that included conversations with gods. Interviewed simultaneously with Gunnar. (2 hours 9 minutes)

(9) **Gail** (45-60), [Listener] Female. Multiple members of her immediate family have experience with serious mental illness. A community advocate. (1 hour 8 minutes)

(10) **Olivia** (45-60), [Experiencer] [Listener] Female. Experienced hallucinations in the context of mushroom use, DMT use, and medical fever. Listened to hallucinations for a friend with serious mental illness who was committed involuntarily. Listened to her son's imaginary friend hallucinations. Her own hallucinations included seeing her boyfriend turn into a demon. (1 hour 32 minutes)

(11) **Keanu** (45-60), [Experiencer] [Listener] Male. Experienced hallucinations after LSD and PCP/Hash use. Listened to hallucinations in small groups of individuals who have used drugs. Hallucination involves believing he is in the movie *Speed*. (1 hour 43 minutes)

(12) **Cleo** (35-45), [Experiencer] [Listener]. Female. Recently converted to Mormonism and has started seeing demons and lizard-eyed individuals, as well as ghosts in her home. Also experienced being physically touched by the Lord. Listened to hallucinations from a friend who also sees lizard-eyed people. Heavily involved in the Church of Jesus Christ of Latter-day Saints and recently spoke to the congregation about her new experiences. (1 hour 41 minutes)

(13) **Euk** (25-35), [Listener] Female. Has listened to hallucinations from her close friend who is diagnosed with Schizoaffective disorder. They are involved in the Schizophrenia Society Partnership Program. (1 hour 9 minutes)

(14) **Matt** (18-25), [Listener] Male. Has heard about hallucinations in the context of screening participants for a research study as well as in the context of working in community mental health. The only "professional" interviewed in the data set. Speaks from case management and research assistant standpoints. (1 hour 24 minutes)

(15) **Ally** (45-60), [Listener] Female. Listened to hallucinations after her father and grandmother experienced medical issues, extended interactions with both family members in the hospital. (47 minutes)

(16) **Nolan** (25-35), [Listener] [Experiencer] Male. Experienced hallucinations after ingesting mushrooms and watching a NASCAR race on television. Listened to hallucinations from a friend who had extreme experiences of déjà vu during a baseball game in which he was unable to tell what reality occurred. (47 minutes)

(17) **Drea** (25-35), [Experiencer] [Listener] Female. Experiences hallucinations in the context of her work as a spiritual healer and Reiki practitioner. Voice Hearer. Has heard and seen hallucinations from individuals with whom she has worked and has shared what she has seen with them. (1 hour 12 minutes)

(18) **Joseph** (18-25), [Experiencer] [Listener] Male. Experienced hallucinations in the context of a psychotic episode while hitchhiking. Has romantic feelings for a woman whose ex-boyfriend, a friend of his, died in a house fire. Sometimes sees his friend dying and believes his hallucination was telling him not to become romantically involved with the woman. (47 minutes)

(19) **Hermione** (18-25), [Experiencer] Female. Experiences hallucinations during sleep paralysis. First experienced them as an adolescent traveling in Europe with her family. (1 hour 6 minutes)

(20) **Naomi** (25-35), [Experiencer], [Listener] Female. Experiences hallucinations in the context of serious mental illness as well as drug use. Interviewed simultaneously with Nicole. (1 hour 8 minutes)

(21) **Nicole** (35-45), [Experiencer], [Listener] Female. Experienced hallucinations in the context of a post-partum psychosis. Interviewed simultaneously with Naomi. (1 hour 8 minutes)

(22) **Katie** (25-35), [Listener] Female. Husband experiences hallucinations in the context of an anxiety disorder. His hallucinations including bugs, shadows, a bear charging his car while driving and a woman appearing in the middle of the free-way. (1 hour 12 minutes)

(23) **Luke** (45-60), [Experiencer] Male. Has experienced hallucinations in the context of serious mental illness as well as substance use. Symptoms currently well-controlled. (45 minutes)

#### 4.4.3 Transcription

I performed the transcription myself. The aims of the research did not necessitate full Jefferson transcription (Jefferson, 2004) which captures detailed nuances in speech such as inflection, volume and length of time between speech segments. I used only those notations that assisted the readability and understandability of the transcript, e.g., italics for emphasis, double dashes for interruption, and paralinguistic elements such as pauses, gestures and laughter. See Appendix P for a summary of the notations used in this transcription. Transcription took place concurrent with recruitment and interviews, and was one of the most labour-intensive aspects of this study. All transcripts underwent four cycles of creation—two listenings and two readings. On first listening, I transcribed the interviews. On second listening, I checked the transcripts for accuracy against the recording. As a third step, I read all transcripts for grammar and made small edits as necessary for clarity. Finally, before sending transcripts to participants for review, I read all transcripts searching for identifiable characteristics that were not adequately masked. Thus, prior to initiating the open-reading stage of my analysis, I had reviewed all transcripts at least four times.

## 4.5 Analysis - Specific Actions in Seeking Facets

Within hermeneutic approaches, specific actions of analysis are flexibly deployed in response to the phenomenon and data from a stance of held-orientation to the experience at hand – in the present case, the social sharing of hallucinations. As mentioned in the previous chapter, the hermeneutic (interpretivist) method of van Manen (1990), like many phenomenological methods, should be seen as a, “heuristic—as a guide to practice—rather than as a set of rules determining the method” (Langridge, 2007, p.122).

The following specific actions have been identified as appropriate and were utilized in this research: Facet recognition; Facet collapse; Facet aggregation, separation and deletion; open reading, immersion in data; highlighting key phrases; writing ideas in the margins; considering parts in relation to the whole; creating and shifting components of the framework; explication, querying relationships between constituents; interrogating evocative excerpts for the source of evocation; shifting perspective; free-writing; outlining; and reframing. All this activity was anchored by sustained immersion in the accounts. I spent nearly two years immersed in the data engaging in cycles of writing, outlining and reading. The eventual four Facets emerged from this process and are as much a result of my own processes of engagement as researcher, as they are “inside” these experiences of social sharing.

Ultimately, the process of analysis aimed to investigate the experience of social sharing as it was lived concretely by my participants rather than conceptualized by our discipline. I attempted to reflect on Facets that characterize this phenomenon and to increase our understanding of experiences of social sharing hallucinations. Throughout all stages of analysis, I maintained a strong orientation to the phenomenon, with parts and whole being considered in tandem and co-considered both within and across transcript accounts.

### 4.5.1 Pre-Analysis

I must acknowledge that I entered the analysis with significant prior engagement with my data. Having independently conducted, transcribed, and “washed” the interviews of identifying data, my first “official” analytic reading was my fifth or sixth immersive interaction with each account.

As such, analysis must be seen as ongoing throughout the research study, occurring at the interview and transcription preparation phase, cementing during the analytic reading phase, and receiving added nuance as I wrote. The analytic phase, detailed below, had three main components: open reading; active Facet structuring; and a final deductive reading. In the final deductive reading, I returned to the transcripts one last time with the Facet categories in place to seek remaining examples of these categories that were missed on first and second readings.

In an effort to minimize the degree to which Listener and Experiencer accounts were analyzed as separate, I mixed the accounts together during analysis. During analysis, I picked a transcript at random from a pile of mixed transcripts and I ensured that no more than three transcripts of any participant category (Experiencer or Listener) were analyzed before I switched to a transcript from the other category. Also, to maximize the degree to which accounts were analyzed by *occurrence* rather than by *participant*, I frequently studied multiple accounts

concurrently during the second analytical phase. This approach is consistent with hermeneutic analysis, which seeks to consider parts in terms of the whole and to actively engage the degree to which parts and parts, and whole and parts, illuminate one another (van Manen, 1990; van Manen, 2014).

#### **4.5.2 Step one: Open reading**

First, transcripts received an “open” reading during which I attempted to refuse note-taking, thinking about Facets categories, or actively looking for similarities. This open reading was done individually for each transcript to get a feel for the account *as account* rather than as phenomenological data. This activity was done for individual accounts as well as for the group of accounts together. I took minimal notes during this first reading, although areas that seemed to pronouncedly illustrate a potential Facet were marked. Immersion in the data is a fundamental requirement of phenomenological analysis (Halling, 2008; Langridge, 2007; van Manen, 2014). As such, I constantly looped back to reading the transcripts as wholes, even during stages of the research focused on writing. Eventually, these readings became more template oriented as patterns and Facets developed through this process, and I returned to previously read accounts to see if instances of the same could be found. For example, I re-read all accounts specifically looking for Ontological Cross-Bleed, after this Facet category became clear.

#### **4.5.3 Step two: Active seeking and accretion into Facets**

Second, I entered an *active Facet seeking* phase in which accounts were read specifically for: i) commonalities; ii) sections which seemed evocative of the phenomenon; and iii) items that seemed striking or unexpected. The software Evernote was used as the primary organizing device for this step. Lengthy “snippets” (my term) of interview data were captured as examples of aspects of the phenomenon that held promise as centralizing features of the social sharing. These lengthier snippets eventually became the extracts included in this document.

Facets function in several ways. They frame the experience of social sharing and assist the description of what could be occurring in these experiential states. They are also ways of thinking about the presence of social sharing in the accounts, and ways of grounding the concrete occurrences reported by my participants to the overall idea of the social sharing of hallucinations.

As appropriate, I tended to include my own question or contribution to the interview in the snippets, even beyond what has been included in the extracts of the final document. Doing so helped me position myself in relation to the data at the analytic stage and forced me to keep an eye on the degree to which my own interests, questions, and beliefs had an impact on the interview data that were generated. In terms of length, snippets ranged from a few lines to spans of pages. When they lasted more than a page, I attempted to break them down, often by selecting smaller sections for transfer to other relevant Facet categories.

During this second analytic phase, subcategories of the Facets were written on post-its, located on a wall in my home, and organized to develop an outline for the writing stage. This “wall-organization” was an active process with elements of the data being moved around and grouped together temporarily as I determined their relationships.

Many types of qualitative research collapse or expand given themes into sub-ordinate or super-ordinate variations (Thematic Analysis, Interpretive Phenomenological Analysis) (Braun & Clarke, 2013; Smith, Jarman and Osborn, 1999). In the current research, rather than consider how various Facets could fit inside of one another, or expand to include more components, I thought of ways that they could inform and enrich our understanding of possibly more central concepts. For example, DEMONS was a preliminary focus category appearing in many accounts. When thinking about this focus, I considered how to maximize the degree to which an encounter with the demonic could inform the experience of the social sharing. I also considered the ways it could enrich other Facet categories and our overall understanding of this phenomenon.

To extend this example, part of the preliminary Facet section Having Care Expressed and Expressing Care (eventually CARE Facet) included many Experiencers stating that they were less likely to share demonic or frightening hallucinations due to concern that it could be upsetting—a choice reflecting a care for the others. Similarly, demons also appear in the accounts as an explanatory concept and as an aspect of how some individuals from religious backgrounds account for the presence of hallucinations. As a result, the DEMONS category also fits in with the SENSE-MAKING Facet. In this way, Facets and their subcategories are not mutually exclusive, but rather serve to draw attention to components of the experience that appeared central in the accounts.

Figure 1 captures an example of the form of data from which I worked:

Figure 1

**Aurora: (15) I THINK THEY WOULD EXPLAIN IT IN A BODY WAY {religion} {sense-making} {demons}**

Adam: What do you think ... they ... like your mom or your friends — not just describing it, but if someone was to ask them what was going on at the time how do you think they would explain the hallucination?

Aurora: They would probably try to explain sleep paralysis first and then they would say, “a lot of times in sleep paralysis the brain will project.” I think they would explain it in a very ... body way. I think that is what they would believe, that it is the brain. I think they would be brain focused. If I ever told a religious friend and they were to tell you about my hallucination they would probably tell it from a different perspective, they would say like ... there was evil in her room. I guess it would be very different. I don’t know.

Example Evernote “Snippet”

In the above, Aurora is the participant designation. Numbers in the parentheses represent the transcript page number(s) in which the excerpt appeared. The all-capitalized titles represent a brief (less than one line) representation of what was meaningful about the excerpt. This format provided a quick way for me to identify snippets during the analysis. The final words in brackets, {religion} {sense-making} {demons}, were used when snippets fell into multiple potential categories. I used the term “foci” for this preliminary group of categories. These foci categories eventually stabilized into Facets. Snippets were cut and pasted into each Evernote page

representing that focus category. In this way, I was able to see a snippet in every possible foci, while also acknowledging that it could be used for more than one focus category. With the example in the figure above, the snippet title for the focus category {Demons} was changed to **THERE WAS EVIL IN HER ROOM**. I found this to be a functional, yet flexible, way to organize my data during the analysis.

Eventually, after completing 13 of my 25 interviews I realized that this process was a time-consuming way to organize the data and that the data were difficult to manage in this format. In addition, I was no longer finding new focus categories or enriching my current Facets. So, I began marking the front of each transcript with the page numbers and brief summaries of the most useful extracts for each Facet. However, the Evernote pages were a pivotal point in the analysis, as they allowed me to organize the snippets and to account for single extracts representing multiple focus categories. Eventually the process of sorting and accretion of snippets and foci resulted in the formation of the four Facet categories. A fifth Facet category: ASPECTS OF THE UNFORMULATED was abandoned during the editing stage of the document. The final four Facet categories are (i) more central to the phenomenon, (ii) evocative of the phenomenon, and (iii) simple, and readily apparent in the accounts.

Besides direct engagement with the accounts, this phase was marked by a process of growth in which I questioned how these ideas might be connected together. I asked how various aspects of the experience of social sharing could be pointing towards similar and increasingly fundamental Facets of the experience. During this accretion, focus was on concrete instances and descriptions in the accounts, and what I thought was most generally helpful or useful in understanding, or thinking about, these experiences of social sharing.

#### **4.6.4 Step three: Facet support and deductive reading**

After the above steps, I transitioned into an active structuring phase. I examined how the collected Facets related to one another. I then reduced the number of Facets to a representative set of what appeared to be most common, evocative, or unexpected within the phenomenon. Through refinement and accretion, five Facets were recognized: Care, Sense-Making, Dual-Processing, and Ontological Cross-Bleed.

At this point, I created a list containing every occurrence of social sharing within the accounts. Some of these occurrences were considered as primary occurrences and some as secondary occurrences that were only mentioned briefly. *Primary occurrences* can be understood as instances of social sharing that were explored at significant length during the interview, meaning there were multiple questions asked about these occurrences and the transcript contained decently rich descriptions of these instances of social sharing. *Secondary occurrences* were occurrences of social sharing that were only briefly mentioned or alluded to, such that significant time was not spent exploring these occurrences and rich descriptions were not collected.

During this third step, I also re-read all accounts, deductively searching for examples of the Facets I had chosen to work with. It was not uncommon for examples to be missed in accounts that were read early on simply because some examples of specific Facets did not appear until after multiple readings.



The analysis continued during the writing and editing process. This activity is in line with van Manen's (2014) understanding that phenomenological analysis continues into the writing stages. Writing is seen as an important part of the over-all analysis. What follows in the next chapter are the Facets which resulted from the analytic procedures outlined above. I begin the next chapter with a section briefly introducing each of the four Facets, continue into a consideration of important elements of my participants' descriptions of the social sharing of hallucinations that informed the resulting Facets, and finish with a section exploring each of the Facets at length.

## Chapter Five: The Four Facets

### 5.1 Setting Up

#### 5.1.2 Context

Context has an impact on the occurrences and experiences of social sharing in multiple ways. First, there is the cause of the hallucination itself. Individuals participating in my study who experienced hallucinations as part of a long-term psychosis shared their hallucinations in different ways than somebody who had a single brief visual hallucination during an episode of sleep paralysis, or someone who has intentionally sought out hallucinations through drug use.

For my participants, the social and relational context also played a role. Descriptions of sharing with a stranger were different than sharing with a close family member, a romantic partner, or a long-term friend. Similarly, the timeline of the hallucination mattered. Hallucinations that had been chronic for many years were spoken of and heard differently than hallucinations that were newly occurring. Likewise, the contexts in which the hallucinations are understood and framed, and the reasons for their occurrence, have an impact on the lived-experience and other components of the sharing. Individuals who are heavily involved in religious life are likely to interpret and share hallucinations in different ways than individuals who understand their hallucinations in purely supernatural or medical ways. Age, religious belief, chronicity, relationship and overall context of the hallucination are all likely to have an impact on the social sharing. As one participant said in our interview, “*It is the situation. It is the context. It is the person*” (Ally). This recognition of situatedness is one reason I collected accounts from such a wide variety of situations, contexts and people, so that I could try to speak beyond the various contextual factors.

Another important aspect of context is the extent to which revealing the experience of a hallucination nearly always divulges something *else* about the individual having the hallucination. The person sharing their hallucination might also reveal that they have sleep paralysis, or that they have experienced a period of psychosis, or that they have tried mind-altering substances, or that they have inspiring and terrifying religious experiences, or that they are a spiritual healer, and so on. Often my participants spoke of the “outing” of this other contextual factor as equally, if not more, at play than the revelation of the hallucination itself.

#### 5.1.3 Normalcy

Though some occurrences of social sharing are clearly distressing and stand out from the normal stream of social conversation, I was surprised by how often social sharing seemed to be an accepted commonplace within a relationship. Many of my participants spoke of hallucinations as existing within the normal course of social talk. This revelation was one of the more surprising findings of my research, and something I noticed early in the interviews. My

assumption that it would be difficult for individuals to speak about their hallucination experiences was false. It appears that many individuals who have hallucinated have friends or close others whom they trust, and with whom they feel extremely comfortable sharing these experiences. This was particularly the case with individuals whose hallucinations were frequent and within the context of relationships that were supportive, open, and close.

The relational context appears to play a role in the degree of normalcy present in the sharing. Individuals were overall less likely to share their experiences with others they did not know well or trust. It should also be noted that, at times, sharing hallucination experiences, even within the context of a close relationship, led to a catastrophic fall-out. One participant, Simon, lost a girlfriend immediately once he revealed to her that he had taken mushrooms in his past. Related to the “outing” element described above, this loss was more the consequence of mushroom use than of the hallucination.

In my data, hallucinations tend to be more distressing to the individuals who are hearing about them than they are to those who experience them, but there is a large degree of variance. Most Experiencers have certain people in their life they would not tell, due to the possibility of a catastrophic reaction. Yet, catastrophe is not always the expected outcome. For example, Gunnar and his husband had taken mushrooms at a music festival and were lying down, looking at the sky. When a friend approached and asked what they were doing, they told him they were tripping out and looking at the stars, to which the friend replied, “*cool, let me go get my telescope.*” This reaction is vastly different from that of Simon’s girlfriend, who left him the day he revealed he had taken mushrooms, though mushrooms were the substance responsible for the hallucinated experience in both accounts.

When the social sharing of hallucination occurs in its normalized form, it appears to involve an exchange of stories “over beers” or in a small group of peers who have experimented with psychedelics or have had similar mental health experiences. Many of my participants who experienced drug-assisted hallucinations stated that they are more likely to share their hallucination experiences with others who have used similar substances. In the same vein, individuals with mental health diagnoses acknowledged a greater likelihood that they will share with other service-users. I was attentive to this aspect of the accounts, but also tried to move beyond these unique sub-sets of social sharing so that I could speak about the experience of social sharing more broadly.

#### **5.1.4 Drugs as context**

Regarding substances, the following drugs are mentioned in my interviews: psilocybin (magic mushrooms), LSD, Marijuana, Alcohol, PCP, Hash, Salvia, Methamphetamine, Crack and DMT. Magic mushrooms were the most frequently mentioned (N=6)

Notably, there was a social aspect to the drug use that plays a significant role in the four Facets I have analyzed and in the phenomenon as a whole. Participants joined others to use psychedelics, and they joined others in speaking about their trip experiences. There were social rules and situational set-ups specific to drug experimentation, such as the importance of a trip-sitter, the unspoken understanding that someone might need to go off and be alone for a while, and the preference for settings that are familiar. In some ways, it appeared that hallucination

experiences occurring in the context of drug use have better ingrained social conventions than hallucinations occurring in other contexts. Many participants also spoke about the social ties that formed between themselves and other individuals who they knew to have used similar substances, such that they were more willing to share their experiences with these individuals.

Equally important, individuals seemed to seek out psychedelics in part due to their ability to bestow hallucinated experiences. The relationship of psychedelics and hallucinations, and the spiritual seeking that occurs around psychedelics has been dealt with at length in other works (Metzner, 2017, Pinchbeck, 2003; Pollen, 2018; Yaden et al., 2016) and is not a focus of this dissertation so I will not spend time on it here. However, there is a social aspect to drug-taking, drug-sharing, and speaking about drug-related hallucinated experience that weaves its way through the following chapters. Similar to schizophrenia, schizoaffective disorder, and bipolar disorder (serious and persistent mental illness), drug intoxication as a context of hallucinations creates its own subset of experiences. Examples from within this subset of experiences related to drug-intoxication include that it is often sought and initiated; it is typically brief; it comes with a set of stigmatizing variables; and that use can exacerbate psychotic symptoms.

Even within drug-related experiences there are further divisions based on substance. For instance, most of my participants who took magic mushrooms had pleasant experiences that changed their life in meaningful ways. However, the few who mentioned methamphetamines or “street” drugs (PCP, Crack,) often had serious life consequences (jail, institutionalization). These aspects of the context undeniably had an impact on the social-sharing that occurred. Revealing to someone that you have experimented with magic mushrooms while in college is very different than revealing that you have injected heroin later in life. However, phenomenology aims to get at the most fundamental layers of these experiences, a layer that should be present despite contexts of occurrence. Thus, I have analyzed occurrences related to use of drugs alongside one another, as well as occurrences related to a mental health diagnosis, sleep paralysis, religious visions, and non-need for treatment everyday hallucinations.

### **5.1.1 Overview of Facets**

The four facet categories resulting from the analytic activities are: Care Facet, Sense-Making Facet, Dual-Processing Facet, and Ontological Cross-Bleed Facet. For participants involved in my study, the social sharing of hallucinations was, to varying degrees, an experience of caring, sense-making, dual-processing, and cross-bleeding. These four Facets provide a lens by which we can see the social sharing of hallucinations, and build connections between the Listener and Experiencer sets of lived-experience during the moment of sharing. Of note, all these Facets are to some degree inherent and essential components of our human sociality. Care and sense-making are not unique to the phenomenon under study. Yet, these aspects of our being-with-others clarify important parts of this phenomenon. My intent is not for the reader to see these as “discoveries,” but rather as interchangeable lenses through which we can expand our view of experiences related to the social sharing of hallucinations. Through these lenses, I invite readers to broaden their curiosity on the topic as they read the following sections. And, if appropriate, I encourage readers to apply the results of this analysis to their personal or professional lives.

## 5.2 Facet One: Care

### 5.2.1 Introduction to Care

The Care Facet is developed from the experiences of receiving and expressing care, as well as failures or misfires of care reported in the accounts. All participants touched, in some way, on care as a facet of their experience of social sharing, noting both the presence and absence of care. That care is pervasive in my data is not surprising, as care is foundational to our social existence, both in the ways that we “take care” of one another, and in the ways that we “care” about and take interest in one another’s lives, worlds and stories. Listeners express care for Experiencers who are distressed or confused by their hallucinations; furthermore, care is an important element of consideration for Experiencers, as they make decisions about what to share, and with whom. Expressions of care can take verbal or behavioral forms such as statements of understanding and offers of concrete assistance. For Experiencers, when care is present, it is received as a feeling of being taken seriously or of being reassured. Correspondingly, when care is not provided, Experiencers report feeling dismissed or abandoned. For some Listeners, care is described as an experience of listening or focused sensitivity, as they hear about the hallucinated experience. For other Listeners, care is associated with frustration because they cannot do more to help. Some Listeners also express regret that they did not take more of a caring stance when the hallucination was revealed. Regardless of whether care is provided, many Listeners indicated needing to work through aspects of fear, surprise, shock, curiosity, and confusion when they hear about hallucinations. For some Listeners, the need to process the shock or confusion internally while expressing care externally can lead to a duality between internal experience and external response, which will be further explored in the section dedicated to Dual-Processing.

### 5.2.2 Not being dismissed

The experience of not feeling dismissed appears to involve a sense on the part of Experiencers that they are being taken seriously and heard, while at the same time experiencing an undercurrent of the *possibility* of being dismissed regarding their hallucinations. To begin, I examine multiple instances of social sharing from a single participant, Aurora, to illustrate how the Care Facet is relevant in a variety of situations. Aurora is a young woman with chronic sleep paralysis in which she is sometimes unable to move her body briefly after waking. In the year before our interview, she experienced her first visual hallucination during her paralysis and awoke to see a woman in a yellow dress, hair covering the face, walking slowly at her in a mirror facing her bed. Not being able to move her body, and not recognizing the woman, or knowing why the woman was in her room, Aurora described a sense of terror. Fortunately, as she shared this experience with others in her life—friends from university, her mother, and her boyfriend -- she experienced comfort, reassurance, safety and support. At the end of our interview, Aurora reflected on how lucky she considers herself that the individuals with whom she shared this story were so immediately supportive, as she knows this is not always the case. Indeed, not all participants were able to speak to positive receptions.

In the following extract, Aurora reports telling a friend during a study session at a coffee shop about having her hallucination the night before. Knowing that Aurora is scared and will not

sleep if she returns home, her friend expresses verbal support and concrete help by inviting Aurora over to stay the night.

***Care Extract 1: Aurora***

*Aurora: We were sitting at Starbucks studying and I told her that I was worried about not getting a good sleep because I was going to be home alone again, and I was going to get pretty stressed out. And she said, “you know what, we will go back to your place and you can pack a bag and then you can come stay at my place because we are going to stay up late studying anyways. It’ll be fine.” So, I said, “sure.” And she was very supportive. She met me at my place and she waited outside for a good fifteen minutes for me to grab all my stuff. She is really good at helping out and not making you feel like a burden. She is very helpful. She will always be like, “do you want a ride home from class?” Do you -- yeah, so she is really good about it. ... I had a good sleep that night and then I told my friend that I had a good sleep (both laugh).*

*Adam: It worked!*

*Aurora: Yeah. Yeah.*

In the extract above, Aurora introduces the idea that part of the experience of social sharing for Experiencers involves receiving expressions of care from others. This extract also evidences that decisions about who to share with and whom not to share with are made partially from previous knowledge about the individual with whom the hallucination is shared. Aurora notes her friend has previously helped by offering a ride home after class and that this friend has a way of helping Aurora out without making her feel like a “burden”.

This potential for Experiencers to become a burden to those with whom they share creates a two-sided danger. On the one hand, Experiencers might worry that the Listener could respond judgmentally. On the other hand, even if the Listener responds positively, the Experiencer must worry about being a “burden” while the care is expressed. Experiencer worry that Listeners could experience difficulty when hearing about the hallucinations is explored at the end of this section when I consider how Experiencer expressions of care are partially driven by decisions of who to tell and why. Two other things to note about the extract above are that Aurora does not deliberate at length about whether to tell her friend, nor does she worry about what the response might be. This kind of understood trust for *certain* individuals was frequent among my participants. Aurora’s friend responds in such a way that it is clear she takes Aurora seriously - she does not dismiss Aurora’s experience, nor does she become dramatic about the event or make Aurora feel badly about putting her in a position to offer care. Her friend even minimizes the help being offered, “you know, what, we will be up studying all night anyways, it’ll be fine” and waits for Aurora outside of her apartment for fifteen minutes while Aurora gathers her things despite both students being under a time-crunch to study for an impending exam. Aurora feels she is being taken seriously by her friend, she experiences her friend’s response as supportive, and is able to accept the offer that she sleep at her friend’s house so that she is rested for the exam.

Similarly, Aurora characterizes her mother's response as one of support and care. Aurora explained that she called her mother the morning after the hallucination. Out of consideration for her mother, Aurora waited until it was later in the morning so that she would not disturb her mother's sleep. Aurora described an established relationship of warmth and closeness with her mother. I ask her what was supportive about her mother's response.

### ***Care Extract 2: Aurora***

*Aurora: Well, she doesn't try to tell me that I didn't see it. She doesn't try to deny that I might be struggling with something like that. She doesn't just dismiss it as, "oh, you just had a bad dream." But she believed me when I told her everything that I saw.*

*Adam: Did you expect her to believe you? Did you get the response you expected?*

*Aurora: Yeah. Yeah, she usually believes me. She doesn't shut me down (laughs). She's good. She just basically told me how scary it would be if she saw something like that and just kind of tried to talk me through and calm me down. Because she knew I was home alone. So, she was like, "if you need to have a friend over, or go and do something, don't stay in the apartment by yourself."*

Again, we can see that Aurora does not deliberate about telling her mother, and that this decision might be partially due to her mother previously supporting Aurora in other situations. She states that her mother "usually believes me. She doesn't shut me down." Aurora feels acknowledged by her mother, "she just basically told me how scary it would be if she saw something like that" and she is open to her mother talking her through the experience, calming her down, and offering advice. Aurora does not feel dismissed by this response and she follows her mother's direction to spend time with others - by studying with her friend and eventually staying the night at her friend's house. Aurora's network of support cooperates, unknowingly, to provide Aurora with what is needed - a good night's sleep and a sense of being taken seriously in her distress. Aurora's experience in these extracts is marked by the absence of potential negatives - the absence of feeling she is burdening others and the absence of being denied, dismissed and shut down. Rather, she feels recognized, supported and cared for. Aurora's hallucination provides a connective experience for Aurora, her mother, and her friend.

Aurora gets a similar response from her boyfriend, who makes sure she is okay and gives her an easy out for a sporting event happening later that night if she is too distressed to play. I asked Aurora to reflect on what might be different if she had been dismissed, rather than supported, by the individuals with whom she shared. The threat of being dismissed is clear in this extract, as well as the distress it would cause Aurora if this response was a blanket reaction from others.

### ***Care Extract 3: Aurora***

*Adam: Well, you said your boyfriend recognized that it was a traumatic experience for you?*

*Aurora: Yeah, again, he wasn't someone that was dismissive of it. He wasn't like, "Oh grow up, stop being such a baby." That wasn't him at all. It was - - every time I tell someone I feel like they are going to tell me that. Like I feel almost childish talking about having this because it reminds me a lot of nightmares. And I feel like nightmares are a thing that children have (laughing). That is kind of how it makes me feel. So, every time I share it I'm expecting them to be like "what is the big deal," type of thing, "everyone has nightmares."*

*Adam: Well what do you do — what would happen for you if that was the — say you talked to your mom and that is how she responded? Or, you talked to your friends and that is how they responded? Your boyfriend responded like that too.*

*Aurora: If everyone responded like that?*

*Adam: Yeah.*

*Aurora: That would be really hard (she laughs). Because it would probably make me feel that there was something wrong with me... I guess them accepting it doesn't change the fact that it does happen but it kind of changes my perception of it. It makes me think that this is something that other people can understand. I am not an anomaly. And there are supports for me. I do have a support system for this, I guess. I'm not sure if it makes sleep paralysis any more normal, maybe it does. It just makes me feel like I'm not ... imagining it all. I guess, if -- if they believe me too then it's, yeah, I'm having a hard time describing that.*

*Adam: ... I'm trying to sort out like — it's interesting that uhm (deep breath) like if you have the experience and then people believe that you had it, it doesn't feel like there is something wrong with you?*

*Aurora: Yeah!*

*Adam: But if you have the experience and people don't believe that you had it, it feels like ... there could be something wrong with you?*

*Aurora: Yeah, and I don't know why I have that feeling but I do.*

*Adam: What do you think would happen to your stress level and stuff like that if people -- like if your mom hadn't believed you when you talked to her on the phone, and like nobody believed you?*

*Aurora: (long pause) Uhm, I really don't know. I might start to link it more to a spiritual thing because then I would feel like I was being targeted by something. If no one else could relate to this. The fact that they all believe me makes me think more that it is my body having little glitches and stuff. But if I was getting a negative reaction from other people I would think that this is something targeted at me. Orchestrated at me. You know what I mean? Like attacking me. I would feel alone, and I would feel very isolated. It would make me feel that way. I don't know.*



This extract makes clear that, as Aurora shares her hallucinations with others, the sharing has an impact on how she views the hallucination. As others hear her, support her, and take her seriously, it solidifies her perception of the hallucination as her “body having little glitches”, which makes her feel less like an anomaly, less like “there is something wrong with me.” Aurora states that if she had not been taken seriously, she would not only feel like a child, but it might change her perception of the hallucination from a medical understanding (sleep paralysis) to a spiritual understanding (something targeting her). Aurora states that without supportive and understanding responses she would feel isolated and alone. However, with supportive responses she feels comforted and connected to her mother and friends.

The distinction between *not being dismissed* and *being reassured* is important when considering the lived-experience of the social sharing as Aurora, and others, describe it. The negative assumption contained within the language of ‘not being dismissed’ acknowledges the undercurrent of feeling that a dismissal could happen at any time. For Aurora, she worries that others will tell her she did not really see the woman, that it was a nightmare. Even with her friend, mother, and boyfriend, whom she trusts and has established relations of caring, she still acknowledges that she worries they will respond in a way that could make her feel infantilized, perhaps even rejected.

Aurora’s fear that others might discount her experience is not unfounded. For example, another participant, Nicole, describes a different type of response when she shares her hallucinations. Nicole experiences her hallucinations in the context of a schizoaffective disorder that, in the past, has been exacerbated by substance use. She describes a rocky relationship with her mother overall, even prior to the onset of her mental health symptoms.

#### ***Care Extract 4: Nicole***

*Nicole: And other times when I’ve hallucinated I’ve told my mom. She doesn’t really know how to handle it. About ten years ago every time I shut my eyes I’d see faces. Different faces. Someone would be there for a while and then it would flash to a different face. Sometimes it would be a little more of the body, but it was usually just faces I saw. And I don’t know what it was or what it means. They weren’t people I knew.*

*Adam: You told your mom about it?*

*Nicole: Yeah.*

*Adam: What did she say?*

*Nicole: She was kind of like ... “well, you need a med change.” With her it is always either, “you need a med change,” or “go to the psychiatrist,” or “talk to somebody else.” She doesn’t want to deal with it, you know.*

*Adam: What are you hoping she will say when you talk to her about it?*

*Nicole: “It is okay. And I love you and accept you.” I’d hope she would let me express at least what I am saying to her. Be kind of like, “Oh, okay I understand.” And then later,*

*once I realize it is not real, then I can come to her again and say, "I guess it's not real." But I just wish people would accept the hallucinations and delusions and stuff when you experience them. But everyone is like (loud) "IT'S NOT REAL! IT'S NOT REAL!" But for that person, at the time it is so real. For me anyway. And I think other mental people, it seems so real at the time. So real that you would bet money. You would bet your life that it is real. That is how real it seems.*

In this extract, we see that the context of the relationship between Nicole and her mother informs aspects of the sharing. Nicole had previously in our interview described a more contentious relationship with her mom, stating that their astrological signs do not align. Nicole and Aurora provide opposite reflections from one another around their lived experience of care. Nicole's mother "doesn't want to deal with it," and Nicole wishes "peoples would accept the hallucinations and delusions and stuff when you experience them." Aurora, on the other hand, feels accepted by those she tells. However, even Aurora acknowledges that she always worries that someone will tell her "Oh grow up, stop being such a baby." Despite the positive responses Aurora receives, she continues to worry that others will write her experience off as nightmares, as not a big deal. Aurora's experiences with those in her life illustrate that even when care seems likely, even when the relationships are close and trust is implicit, the potential for dismissal remains a possibility. Nicole, on the other hand, receives such a discounting response. This reaction causes her frustration, and she experiences a disconnection from her mother and a desire that her mother would take her more seriously.

Thus, in sharing their hallucinations Experiencers are faced with the possibility of their hallucination experience being discounted, becoming dismissed and not being taken seriously. Yet, if, as Nicole describes it, the hallucination is "so real at the time that you would bet money. You would be your life that it is real," a response of dismissal creates an opening for a separation between the individual who experienced the hallucination and the person with whom they are sharing. The individual experiencing the hallucination is either cut-off from their own veridical sense of perception, or cut-off from the social world of meaningful others for whom that perception is not real. In this way, Care Facet can be seen as either a bridge or a crevice.

Yet, we must be careful not to vilify Listeners. Though Nicole feels dismissed by the response from her mother, from the mother's perspective it is possible she is in some ways trying to take a caring stance by referring Nicole to her psychiatrist for a medication change. Nicole mentions that her mother "doesn't really know how to handle it." Nicole's mother's response possibly illustrates the difficulty some Listeners face when someone shares a hallucination with them. To a degree, it is the Experiencer's *perception* of care that matters, rather than the Listener's *expression*. As can be seen, Experiencers tended to report their lived-experience of care as existing on dimensions of acceptance and reassurance. Experiencers were particularly sensitive to indications that they would be dismissed, and even those who received affirming responses spoke of worry that their hallucinations would not be taken seriously. Fortunately, most Experiencers described a sharp intuitive sense regarding who could be trusted to respond well to their hallucination.

Ultimately, from the Experiencer perspective, the act of listening appeared to be viewed, in part, as acceptance of their hallucination *as real for them*. Experiencers spoke of "not feeling dismissed" when a listening stance was taken by their counterpart. Specific expressions

consistent with listening included asking questions, encouraging more talk, and providing feedback to show engagement. At times, listening also involved recommendations or offers of concrete assistance, such as prayer, a healing ritual, inviting someone over to stay the night, or driving into town to be with someone who has had a negative experience.

In the extracts that follow, though the Experiencer does not feel dismissed by the interactions, it is possible that the reactions could have been interpreted as dismissal. In the extract below, Aurora expresses how even her religious friends, who have more spiritual explanations for the occurrence, do not dismiss that the hallucination really happened. I asked whether she would still feel supported by a more religious understanding, even if it is not in line with her own understanding of the hallucination.

#### ***Care Extract 5: Aurora***

*Aurora: I think I would still appreciate it. Because they are taking the time to really search within what they believe and trying to formulate what was happening.*

*Adam: Yeah, that is cool.*

*Aurora: Yeah, I think whether or not I believe that what they were saying is true, I would still appreciate them for listening to my story and not dismissing it and being like, “you are joking.” Because that is all I can really expect is for them to come up with their own understanding of it.*

In this extract, Aurora indicates that her experience of not being dismissed is related to the serious response of her religious friends, and that the serious response is more important than her friends sharing her specific understanding of the hallucination. In other words, Aurora illustrates that it is possible for Experiencers to share their hallucinations with others who do not have the same understanding of the hallucination, and as long as the individual or group has “searched within what they believe” and tried to “formulate what was happening” then it is still possible they will not feel dismissed.

Of note, listening and sensitivity do not always require extended verbalization. Aurora tells how her friend’s sister indicated that she is taking Aurora seriously through a simple “Whoa!” This exchange occurred during the conversation from the previous extract, while Aurora was studying with her friend at a coffee shop. Her friend’s sister was listening to the conversation while talking on the phone. The friend verbalizes a “whoa!” while on the phone, to acknowledge Aurora’s description of the hallucination as Aurora speaks to her sister.

#### ***Care Extract 6: Aurora***

*Adam: What do you think that “whoa” that — what — like I’m trying to figure out what it communicates. Like what does it ... what happens to you when someone has that response like that? What would that ...?*

*Aurora: I think it means — I think it means that they do believe me. Like they are reacting in a way that is not in disbelief, but they are very, I guess, surprised. And it kind of tells me that this is something new for them, something that they don't have a lot of experience with. Because they say, "whoa." I don't think that they are like, "I don't believe you." I think they are like, "that is really interesting, and I don't quite know what to say."*

In this extract, neither an offer of help nor a statement of understanding is present. Rather, Aurora's friend's sister communicates a simple "whoa" which Aurora interprets as supportive in that it does not discount her experience. In fact, Aurora sees this reaction as the sister taking her hallucination seriously. She receives the "whoa" as an authentic communication of surprise, as well as a statement that the hallucination is something new for the sister, something she might not have a lot of experience with. Ultimately, Aurora feels believed by the sister; she feels *not dismissed*.

In contrast to Aurora's experiences of telling her mother, boyfriend, friend, and friend's sister, she states she would never tell her father about her hallucinations. Aurora considers that he is likely to be dismissive of the occurrence.

#### ***Care Extract 7: Aurora***

*Adam: Are there people you don't tell specifically because you think they would be more likely to be dismissive?*

*Aurora: Yeah, my dad. I don't think I have ever told him about this just because ... I don't know, he dismisses a lot of things. I don't think I have told him about it because he just tends to have that type of personality where it is ... I don't know how to describe it. If it doesn't have some sort of fact behind, it can't be ... Mm, I don't know, this is really hard to articulate. I think he would see me as being theatrical about all of it and making it out as something more than it was. I think, if I told him.*

*Adam: (Pause) Do you want to tell him?*

*Aurora: (quickly) No. ... I don't see him often enough that it would probably come up. I wouldn't consider him someone who is a main support for me.*

*Adam: Okay*

*Aurora: So, when I do see him we don't talk about dark things like that (she laughs). I have a lot of other people that can support me in the way that I think that I need. In the way that he can't. So, I think it just makes him someone that I don't go to for that kind of thing.*

This type of statement was fairly consistent across participants. There seemed to be little deliberation regarding who, and who not, to tell. Many participants spoke of knowing that certain people were unlikely to be supportive. Still, as Aurora shows in her concern that someone might be dismissive of the experience, the danger of being disregarded is ever present, even when individuals are telling someone whom they trust, feel close to, or expect not to dismiss them. Aurora's experience in the extract above is one of restraint, of hiding the hallucination from her

father, whom she states would not support her in the way she thinks she needs. As Aurora describes sharing, or not sharing, with multiple individuals in her life (her friend at the coffee shop, her mother, her boyfriend, her religious friends, her friend's sister and her father), she illustrates a diversity of responses, many of which she interprets and experiences as caring. Even in situations when the understanding of those with whom she shares differs from her own, Aurora described that she experienced validation and care, as long as the individuals take her hallucination experience seriously. Even when the response is brief or comes from someone who is unsure what to make of the experience, such as with her friend's sister who says "whoa!", the response can still be interpreted, and experienced, as an expression of care.

At times, participants described care that was communicated in ways that could be interpreted as less supportive. Naomi, a woman in her forties who experienced hallucinations in the context of a post-partum psychosis and has been diagnosed with bipolar disorder, speaks about how her grandmother expresses care, but can minimize Naomi's experience at the same time. Naomi describes being very close to her family and speaking with her grandmother and father often on the phone. During her psychosis, Naomi believed that someone or something was going to murder her, her family, and her newly born infant. The grandmother's response is both supportive and dismissive, illustrating that the wall between these two experiential states is thin and is at least partially informed by how the Experiencer interprets the Listener's response.

### ***Care Extract 8: Naomi***

*Adam: Is there anybody that you told about the post-partum psychosis and the hallucinations that you wish you hadn't?*

*Naomi: (very long pause) Just ... no. Because everyone was like, "Oh Naomi is just ill right now." Like, she is getting the help she needs, which is good.*

*Adam: That is how they would respond?*

*Naomi: Yeah. Nobody believes me -- Or I'm like "I don't drink anymore" I haven't drank for about three or four years. And I don't smoke cigarettes anymore. I vaped and I hardly vaped at all.*

*Adam: And people -- your family doesn't believe you? Or people don't believe you?*

*Naomi: My grandma just thinks I am on crack. (laughs briefly) My grandmother is in her eighties. I talk to her every day. She is like "Naomi you are looney." (laughing)*

*Adam: That is what she says? (chuckling)*

*Naomi: She just says -- she laughs at me. (She laughs while she says this.) She is just like "Naomi, everything is okay."*

In this extract, Naomi states that her family attributes her hallucinatory experiences to being ill and that Naomi interprets this, at least partially, in a positive light. Though Naomi states that her family does not believe her when she talks about her abstinence from alcohol and

vaping, her overall interpretation of her family's response is that they do care for her and are trying to reassure her, for instance by saying "Naomi, everything is okay." Naomi is even able to take the phrase "Naomi, you are looney" as an expression of care, perhaps in part because of the endearing way the phrase was stated. These counter-examples illustrate, to a degree, that care is sometimes in the eye of the beholder and that statements that some might view as uncaring can still be received as caring by the individual sharing their hallucination.

With the exception of Nicole, the extracts above contrast to extracts from Experiencers who feel *outright* dismissed when they share their hallucination. Pointing to the importance of the relationship in how hallucination experiences are received, Luke describes acquaintances at a bar being extremely dismissive of him when he tells them about a meaningful hallucination he had of an angel. Luke's hallucinations occur in the context of schizophrenia, but he stated that drug use exacerbated his hallucinations.

### ***Care Extract 9: Luke***

*Luke: Most of my conversations about hallucinations were with people that were in my life who really didn't care. Or care about me. I hitchhiked a great distance once and on the way back I thought I saw an angel sitting on a cloud with a massive book. This is something I visually saw. Something I experienced. And I came back and said, "I saw all these angels and it was really cool." And the people I was hanging around with were like, "No you didn't. You are lying. No, you didn't see that." Because at that point in my life when I was sick I didn't have a lot of friends. A lot of the friends I made during high-school and stuff when I got sick they didn't want anything to do with me. So, I had all these people around me that were just acquaintances, or enemies, or not really friends at all. And a lot of them I talked to about delusions or hallucinations and they really just didn't care. They just thought, "he is crazy," or whatever.*

In this extract, Luke has a hallucination that is meaningful to him - an angel sitting on a cloud with a massive book, something he visually saw, something he experienced. He is accused of lying by his acquaintances at the bar. He has lost most of his friends because of his illness. He experienced that others did not want anything to do with him, that they did not care about him. He *felt* dismissed as crazy. Luke encounters this dismissal while still ill and he comes to expect that others will not take him seriously when he shares these experiences. We can again see the degree to which the Experiencer is set to choose between the reality of their own perception ("this is something that I visually saw") and their connection with others. Fortunately, Luke is able to speak to individuals in his life such as his mother and girlfriends, who are more accepting and curious about his positive hallucination experiences. Regardless of whether being dismissed actually happened or not, it was an ever-present risk for the persons I interviewed.

### **5.2.3 Reassurance**

Reassurance can be thought of as a sub-type of both the Care-Facet and checking which is explored at length in the Sense-Making Facet. In reassurance, the question has less to do with "what is happening?" or "is this real?" and more to do with reassuring the internal state of the Experiencer directly. Thus, reassurance is experienced as being put at ease, or comforted.

Importantly, experiences of being reassured and experiences of not being dismissed are separate experiential domains. Individuals might have their hallucinations dismissed by some individuals they tell, while also reporting reassurance in finding out that the hallucination is part of a mental illness, or that they are not bad people. In other words, it appears possible to be reassured and dismissed at the same time, or to be dismissed and still experience reassurance. For example, by framing hallucinations of the demonic as aspects of a psychosis, a person might experience reassurance that they are undergoing a mental illness rather than being hunted by demons. However, in the reassurance, the hallucination itself is dismissed as part of a mental illness rather than as a real demonic entity in the world. In the extracts above, when Naomi's family tell her she is looney and that everything will be okay, this action is a dismissal of Naomi's sense that tragedy would befall her infant. However, Naomi was able to experience these expressions as reassuring, at the same time that they dismissed what she was experiencing.

Although many participants spoke about negative interactions with professional care and that professionals could be dismissive of their experience, many also acknowledged feeling reassured when they found out their hallucinations were part of a mental illness. In the extract below, Luke describes his mother responding with reassurance when he would ask her about the negative voices.

***Care Extract 10: Luke***

*Luke: I would tell her things like, "Mom, am I evil? Am I ugly? Am I a loser? Am I this? That?" She would say, "No, Luke. I know you – you are not. You are a beautiful human being." But I can remember one time I said, "Mom, am I Satan?" And she said, "No, you are a beautiful human being." And that was the voice. And me and my mom did presentations together for about four years. And we evolved – we got really good at it. And she helped me with the voices. Am I ugly? Am I – Am I –, we talked about the things I heard and stuff. And she would always be supportive. "No, no, you are not ugly, you are fine." Do you know what I mean? She was just reassuring.*

Similarly, in her interview, Naomi speaks about the reassurance she received from others during her post-partum depression when she was hearing voices that someone was going to hurt her and that bad things were going to happen to her baby.

***Care Extract 11: Naomi***

*Adam: So, when people would tell you, "Naomi, it is going to be okay," and then you would say, "Is it though? I don't really know." Would you actually experience some comfort from them telling you that it is going to be okay?*

*Naomi: Yeah.*

*Adam: What was it like for you to have that comfort in the moment?*

*Naomi: It is good.*

*Adam: It is good. Can you describe what that felt like at all?*

*Naomi: It is reassuring, and it is good to hear.*

In the extracts above, participants experience reassurance as they share their hallucinations with others. This reassurance is comforting and positive for the participants. Luke is told by his mother that he is a beautiful human, that he is not Satan, and that he is not ugly. He was able to check with his mother about the negative things the voice was communicating and hear from her that the voice is wrong. Naomi similarly heard a voice telling her that terrible things would happen to her and the people that she cares about. Her family reassures that “everything is okay” and, even though Naomi questioned whether things would actually be okay, she described her family’s response as “good to hear.”

The experiences of reassurance mentioned by Luke and Naomi in the extracts above need to be differentiated from the experiences of not being dismissed mentioned previously. In Luke and Naomi’s extracts, the Listeners are disagreeing with the content of the hallucination. Luke’s mother tells him that he is “a beautiful human being” and that he is not evil. Naomi’s family tell her that things are going to be okay. Though these statements oppose the content of hallucinated messages Naomi and Luke received, they do not dismiss the hallucinations themselves. Luke and Naomi are able to experience this opposition as something reassuring, though they do not believe them entirely. This lack of complete belief is represented in the continued checking behavior both Luke and Naomi reported engaging in. These conversations occurred frequently between my participants and those they cared about. The reassurance was a constant necessity and the participant’s trusted connection with their close others was able to diminish their belief that the voice’s message was true (i.e., that Luke was Satan and that bad things would happen to Naomi and her child.) Previously in our interview, Naomi talked about how she would respond to her family by asking “is it though? Will it really be okay?” and that she struggled to believe what they were saying. Likewise, Luke continues returning to his mother to ask if he is innately evil and an ugly human being. These participants experience a connection with those they speak of that allows them to at least question, if not entirely override, the content of their hallucinated voices.

Cleo, a wife and mother of two who has recently converted to the Church of Jesus Christ of Latter-day Saints, also speaks about receiving reassurance and care from her sisters at church when she speaks to them about the demons she has started seeing since her baptism. The church sisters let her know that, due to her baptism, “the adversary” (Satan) will try to scare her and bring negativity in her life. In this extract, the blessing can be seen as the expression of care, and reassurance can be understood as the coinciding experience. In addition to sensing the influence of the adversary in those close to her, Cleo has begun seeing people with faces of demons as she is out in the community. She also reported an ability to see individuals who are “walking in God’s light.” She describes these abilities as related to her new set of eyes since choosing to walk with God.



### ***Care Extract 12: Cleo***

*Adam: I have a whole lot of questions here. Uhm, (long pause) what is — when you were talking about — so can I go back to the church family [mmhmm] and sort of talking about these experiences with them?*

*Cleo: Yeah.*

*Adam: I can't even think of a question I just want to know more about that. Like it sounds like they are not surprised [nope]. They are just saying this is part of what happens [yep].*

*Cleo: Well, they are like, "this is completely normal. So, don't worry about it or stress out about it." And then they will give a blessing or something. If it is bad stuff going on. They will do a blessing and then it seems to make it better.*

Cleo is able to experience solidarity with her church sisters and a sense of reassurance that they are not surprised she has begun having these experiences. The church sisters provide a concrete expression of care, a blessing, but also provide Cleo a sense that there is no need to worry and stress about these experiences. They normalize the experience for Cleo. Cleo is then able to integrate these experiences as aspects of her new religious life, as an outcome of her new set of eyes. Cleo experiences a resolution to her questions regarding why these experiences are happening and this resolution serves to further connect her with the sisters at the church as they do not discount her visions. In taking the visions seriously and connecting them to her religious belief, Cleo feels less alone in her distress.

This sense of reassurance among my participants was not isolated to family members or religious communities. Some participants also described receiving reassurance through interaction with medical professionals. Joseph, a Métis man in his late twenties, speaks about receiving reassurance when hospitalized for a psychotic episode occurring in the context of schizophrenia.

### ***Care Extract 13: Joseph***

*Adam: So, while you were there in the psych ward you were telling somebody about the hallucination? What did they — do you remember what they said in response?*

*Joseph: The guy was like. (pause) Let me think here. He just said like, "You are having an episode of like a schizophrenic episode. Things happen like that to people. It's okay Joseph, you are in the psych ward, you can calm down now."*

*Adam: Did that help you?*

*Joseph: Yeah. It helped me because someone acknowledged me and told me— like they weren't ignoring me. I was thinking well if he is a doctor and he tells me this then everything is fine. He is at least acknowledging that I am not like some stupid guy that just sees things.*

Joseph is acknowledged and he experiences this acknowledgement as reassurance and as not being ignored. Joseph begins to understand that he is “not some stupid guy that just sees things.” He hears that he can calm down, that he is in a psychiatric ward and, in hearing these words, his distress is reduced. Joseph hears that “things like this happen to people” and, similar to Cleo being told by her church sisters that after baptism some people will begin to see things, he understands that he is not alone in his experience and that there is an explanation for the hallucination he experienced.

#### **5.2.4 Listener experience of Care: Listening and focused sensitivity**

Experiences of acceptance and reassurance appear to be directly related to Listeners’ stances of listening and curiosity regarding the hallucination. Experientially, Listeners described this stance as one of listening and focused sensitivity. Listeners also described experiences of frustration and regret related to hearing about hallucination experiences -- frustration that they were not able to do more to help with the distress caused by the hallucinations, and regret that they did not act as caring as they might have liked in the moment of the sharing.

Importantly, listening and focused sensitivity are not the same thing as agreement and understanding. By this, I mean that Listeners can be curious about the hallucination experiences without completely agreeing with, validating or fully understanding what has happened. It also is important to note at the outset that listening and focused sensitivity are both *expressions* and *experiences*. Specifically, listening and focused sensitivity are actions, or stances, that Listeners take, but in these actions of attunement to the Experiencer sharing the hallucination, the Listener *experiences* the person they are listening to and focused on, and this *experience* of the other person contributes to their expressions of care. A connection can be seen between Listener expressions and experiences of listening and focused sensitivity and the Experiencer descriptions of not being dismissed and feeling reassured that I examined in the previous section.

As a final note, listening and sensitivity often extend beyond the content of the hallucinatory experience itself to capture aspects of the Experiencer’s mood, general distress, or other attributes. We have already seen this extension beyond listening and sensitivity in the extract above in which Aurora’s friend not only listens to the hallucination content but perceives Aurora’s worry that she will not sleep and Aurora’s concern about being alone. Thus, Listener responses to a hallucination experience, extend beyond responses to the hallucination itself to take in a wider view of what is happening for the Experiencer and what the Experiencer might need in the moment.

The idea of care being in the eye of the beholder can extend to Listener experiences as well. It is possible that it is not the expression of care that matters, but rather the degree to which a Listener is listening and focused on the experiencer and able to flexibly adapt their expressions to that individual. For example, when Nicole’s mother (Care Extract #4) refers her to a psychiatrist and states that she needs a medication change, this *action* could be interpreted as caring, or could be intended as caring on the part of the mother. However, in that there is a lack of true listening, and a sensitivity to Nicole’s needs at the time, this possible expression of care is experienced by Nicole as dismissive. Thus, listening and focused sensitivity as experiential states for Listeners might be more likely to lead to expressions of care that are interpreted as care by

Experiencers. In this sense, listening and focused sensitivity might be valuable orienting targets for Listeners who are trying to take a caring stance but are uncertain as to how to do so.

### 5.2.5 Listening

Multiple participants in the Listener group stressed the importance of simple listening for showing support when hearing about the hallucination. In the extracts below, Olivia, Nolan and Esther all acknowledge that they entered a state of curious listening when hearing about hallucination experiences and that an aspect of this stance involved asking questions rather than shutting the experience down or dismissing it. It is important to differentiate the *experience* of listening from *expressions* of listening. While listening is the experiential state these participants describe, their expressions of listening include verbalizing interest, illustrating they are listening with their body language, asking questions, encouraging the other person to talk, and not challenging the other person in a strong way. This difference in listening is one primary difference between Aurora (Care Extract #2) and Nicole's (Care Extract #4) mothers in the extracts above. Aurora's mother appears to let Aurora talk about the hallucination as much as she wants, until it has been processed, whereas Nicole's mother immediately directs her to a psychiatrist for a medication change and "doesn't want to hear it." The differences between the way these two reactions are experienced are clear – Nicole feels dismissed and Aurora feels heard, which she then experiences as reassurance.

In the following extract, Olivia mentions that she tries to take a receptive and curious stance when someone she knows tells her about hallucinations, supernatural entities, or something outside her belief system—something that is "far-out".

#### **Care Extract 14: Olivia**

*Adam: Just in general what do you do—or what are the types of things you do, or think, or say, to be supportive, when you think something is far out?*

*Olivia: I think I tend to listen and try to make sure that my body language is such that I'm being open and all those things. I really want to encourage people to talk. My sister had some mental health issues (swallows) over the years. And I had a friend that I had to sign papers to commit for mental health. Just she was having lots of delusions and not eating and all this sort of stuff and not sleeping and it was just (inaudible). So, I just feel like I really ... it is important to just be really—to make people feel really comfortable. So, it would be like—just more listening, and agreeing, or asking more questions if it seems like someone is wanting to talk about it more. And just trying to be sort of attentive... Having been someone that I felt growing up was very lonely and judged and (long pause) I just—part of me never—I never want people to feel that way (eyes begin to water). I'm sorry I get teary.*

*Adam: That's alright.*

*Olivia: I just don't want people to feel that way. I've just always felt that I never want anyone to feel as shitty as I was made to feel. So, I just try and—I want people to feel valued and loved... Does that make sense?"*

In the extract above, Olivia describes that she enters a particular mode when listening to someone speak about their hallucinations - she asks questions, she lets them talk as much as they want, she tries to be attentive, and she tries to make them feel comfortable. In some ways, what Olivia describes is a setting aside of her own agenda, world-perceptions, and need to speak or challenge the other. Her primary aim does not involve trying to insist to the other person that the hallucination is not real, but rather to make the other person feel "valued and loved." Olivia relates this listening stance back to prior experiences in her life, including her experiences growing up and her encounter with others who have struggled with mental illness, including a friend for whom she signed papers for hospitalization. In a way, Olivia draws on her own prior experiences, personal and social, to enter an experiential state of attentive listening. She appears to give immense value and personal meaning to the importance of this state, as her tears during this extract indicate.

Esther relays an occurrence of interacting with a friend, Sarah, many years ago, who claims to have seen a ghost multiple times in her home. The ghost is often seen upstairs sitting on a bed where the woman, Sarah, folds laundry. In the extract below, Esther recalls a memory of Sarah telling Esther about the ghost and showing her where he likes to sit on the bed. Esther recalls the way she tried to illustrate to her friend that she was listening by asking pointed questions.

#### ***Care Extract 15: Esther***

*Esther: I was mostly listening. But listening and providing enough feedback to show that I was engaged and following her. And curious about it.*

*Adam: Right. Right. Do you remember – again I know a lot of this is reconstruction and I'll completely acknowledge and honour that. But while you were giving her feedback and showing her you were engaged and curious, what are the things you might have been saying to communicate that to her?*

*Esther: Uhm (long pause) well things like, "So, when you are folding clothes does he just watch?"*

*Adam: Oh! Nice!*

*Esther: "How does he come and go? Does he just disappear suddenly? Are there regular times? Are there times that you can be confident that he would likely be here? Is he in other areas of the house?" Which he was. That wasn't his sole location it was just the most common place she would find him. And yes, he would be down sometimes in the kitchen. And then I – her in-laws lived not too far away and I suspect that I did ask her, "How does your mother-in-law relate to that?"*

*Adam: (brief laugh) Yeah.*

*Esther: Or, “can you have conversations with your in-laws about that?” You know? “Is it hard to have conversations about this because it is unusual?” And then the other ways eventually are like at some point saying something like, “I’ve never had an experience like this but I’m curious about it – you must view yourself as being fortunate to have had this kind of experience.” But that is just all speculation, Adam.”*

In Esther’s extract, she describes not a *passive* listening, but rather an *active* listening - a listening that involves “providing enough feedback to show that I was engaged and following her.” This active stance of listening is present in Olivia’s stance as well. Both of these participants mention energy and thoughtfulness being directed towards the act of listening, of inhabiting an experiential space that involves not only silently hearing what the other person is speaking about, but providing responses and demonstrating body language, that lets the other person know they are paying attention and interested. For Esther, one key feature for this demonstrated attentiveness involved pointed questions that demonstrate a real curiosity, as well as an understanding, such as, “Does he come and go? Are there times he is in other areas of the house?”

Nolan also relays how he uses questioning to show interest in his friend who has been hallucinating. Nolan describes his friend’s struggle to distinguish between real events in his life and hallucinations. Specifically, his friend is unable to recall if he has hallucinated arguments with his girlfriend or if they have really occurred. In the following extract, the two buddies, life-long friends, are playing cards and talking.

#### ***Care Extract 16: Nolan***

*Adam: When you are just like listening to him or you are just comforting or whatnot, can you give examples of the type of stuff that you are saying or doing that illustrate to him that you are listening and comforting?*

*Nolan: I try to maintain eye contact as much as I can. And I guess, ... I don’t want to interject or SHARE. You know, especially with him. When he is telling a story and he goes, “and then I went to Peru,” I don’t want to say, “Oh! I was in Argentina one time!” I just, “Okay, you were in Peru,” and then keep asking. Sitting there listening. And he if gets hung up on something I try to remind him of where he is in the story.... “So how did that effect –?” “Why are you bringing this up?” I guess is something I have said a lot. “Why is this important?”*

*Adam: Great. Okay. Yeah. Yeah. Yeah. ... (long pause) You are a good listener!*

In Nolan’s case, as with Esther and Olivia, his experiential state during the sharing involves an active curiosity for the other’s experience, as well as a temporary putting aside of his own agendas and judgments. Nolan’s focus is not only on ensuring that he opens space for his friend’s story, and stops himself from interrupting with his own stories and ideas, but also to remind his friend where he is in the story. Nolan’s questions also thoughtfully indicate that Nolan is paying attention and interested in the experience his friend is speaking of. Though

Nolan's inflection for the phrase "Why is this important?" is not present in the transcription, this phrase was not spoken with dismissiveness, but rather was stated as an expression of genuine interest in the meaning the experience held for his friend.

Thus, from the viewpoint of Listeners, not surprisingly given the designation I chose for this participant group, the lived-experience of the social sharing of hallucinations can be an act of *listening* and of engaging in curiosity with the person. Though not always the case, when this stance is taken it may be experienced as an act of care by the Experiencers who are sharing their hallucination. Specifically, this listening stance can lead to an experience of feeling accepted and not dismissed.

However, listening is not always straight-forward, or easy. There are multiple barriers to engaged listening, with contextual elements of the relationship and reason for the hallucination having an impact. Furthermore, even for individuals who engage in listening, there is sometimes more to the story, with unspoken thoughts in their minds. In the Dual-Processing Facet, I explore the many parts of the listening process. For example, while Listeners are expressing curiosity and interest, they might also be working internally to determine what is going on, whether they need to be worried and whether they have misjudged the person talking about the hallucination entirely, though this is not always the case, and a singular process of *pure listening* is also described by some participants.

Coupled with listening, another experiential component Listeners described was a careful attunement to the individual experiencing the hallucination. Relational context is important here, with this attunement developing out of histories of close-relationship or friendship. I consider this attunement "focused sensitivity."

### **5.2.6 Focused sensitivity**

For Listeners, care can also manifest as a focused sensitivity to the individual experiencing the hallucination. This stance of sensitivity appears as an openness to hearing about the other person's experience, as well as a keen awareness of how the other person is taking the conversation, or the distress that they might be experiencing. It seems to be fueled not from a position of outright acceptance, but of interest and listening that includes close observation, sincerity, and verbal and gestural cues. These positions of focused sensitivity are described by Listeners as an "attunement" to the Experiencer and their recounting of the hallucination. This attunement often extends beyond the experience of the hallucination itself, to include other aspects of the Experiencer's presentation, such as the valence and intensity of their emotional presentation, and the degree to which the Experiencer appears distressed by what they are describing. Katie illustrates focused sensitivity in the extract below. Her husband has a long history of hallucinating bugs and shadows. While driving, he recently encountered his first complex hallucinations. One consisted of a bear charging his car from a ditch. Another one involved a woman dressed in white appearing suddenly in the road.

#### ***Care Extract 17: Katie***

*Katie: I've been with him for so long that I can kind of peg when he is starting to get agitated. So, it was just -- it was just an emotional response. Not that he said anything*

*other than he did express that it freaked him out. But he didn't say like, "Oh this is freaking me out talking about it," or, "I don't feel good talking about it," but you could definitely tell that he kind of ... you know, increased his breathing. And it seemed to have caused a response.*

*Adam: And how did you respond to that aspect of it?*

*Katie: I kind of backed off once I knew that it was really distressing.*

Overall, many Listeners spoke evocatively of their sensitivity to the Experiencer. They seemed to have a compassionate and nuanced understanding of what the other person might be experiencing, and they spoke of adapting their questioning and response to fit where the other person could be at in the moment. Many Listeners also provide a great deal of empathic observation for the Experiencers in their accounts, with Katie stating, *"We are really open, and we talk about it a lot. Sometimes if I notice he is over-tired or acting a little bit more withdrawn and obviously having a hard time I will ask if he has been seeing stuff too."*

Katie's description illustrates an attentiveness to the other human and a close sensitivity to variations in that person. Euk describes this sensitivity as well. When asked if she notices differences in her friend when he is hallucinating, she answered:

#### ***Care Extract 18: Euk***

*Euk: I would notice a difference between whether just in general he is having good or bad days. Yeah, so if he is having a bad day his emotion goes down. He is less likely to want to be touched. He is actually a very affectionate person but when he is having bad days he usually doesn't want to be touched, or if I am going to touch him I have to warn him so he doesn't get surprised. And he has trouble making eye contact. So, it is just hard for him to make eye contact. He might have trouble speaking, like maybe stuttering a bit. And words that might not make sense... he might have to... try a couple of times before he is able to get out what he wants to say.*

This same attentiveness to the other's internal state is described by Nolan as well.

#### ***Care Extract 19: Nolan***

*Nolan: I notice the few times that we get to see each other mostly now he is more jovial. But when I do come see him or if he sees me if something is bothering him I guess I can just feel that something is off. So that is a big break. Okay, I know he wants to have a real talk about something... We are GOOD friends (laughs). That is the only thing I can really say. You can kind of pick up on a guy's mood and tone.*

Similarly, Gail, a mother of a young woman with schizoaffective disorder who frequently experiences delusions, is describing how she maintains sensitivity to her daughter during a conversation about a rape. Her daughter reported she had been raped and Gail is trying to figure out what happened, if the rape could be related to a hallucination, and how she can help. Although Gail states she feels disconnected from her daughter during the conversation, it is clear

that she is attuned to her during their encounter and trying to do what she can to ensure the daughter feels comfortable, adjusting as needed to maintain the space of simultaneous closeness and distance that the conversation requires.

***Care Extract 20: Gail***

*Adam: Did you make physical contact at all with her? Like rubbing her back?*

*Gail: I think I tried to over the rape and she was like, "Don't touch me." She is very physical don't touch me. So, you can't put a hand on her. She will clench away. So, it is no touch. I might have – I remember being able to sit on the bed with her. But not close intimately. There is no touch. I might be two or three feet away but if I flex the bed and she feels it she might move over away from me.*

**5.2.7 Frustration**

Yet, direct expression and experiences of care are not the whole story. For some Listener participants, care also manifested as feelings of helplessness and frustration at their inability to help a loved one in distress. Frustration as an indirect aspect of care seemed to be especially true if the cared-for-other has hallucinations occurring in the context of a more severe or chronic mental illness. For example, Euk talks about her frustration at not being able to do more for her friend who is diagnosed with schizoaffective disorder when he experiences disturbing hallucinations.

***Care Extract 21: Euk***

*Euk: I think the only difficult part is that I can't help him. There is really nothing I can do to improve his state of mind. So that would be the only difficult thing about seeing him in that state.*

*Adam: (long pause) What is that like to not be able to help him?*

*Euk: Horrible.*

*Adam: Can you describe it?*

*Euk: I feel helpless. I feel like a failure. Because I know what he is going through -- like I couldn't imagine going through what he is going through. To always have to deal with this day in and day out. He has had times when he has had to take a test and he is experiencing an active psychosis so the voices in his head are telling him all these horrible things about himself - that he is stupid, and he is a failure and he has to sit there and try to focus on a test. I couldn't imagine. And you know I constantly do ask him -- I've kind of stopped asking because I know the answer. But I always ask him if there is anything I can do. What I can do to help him, and there is nothing. I can't take away his pain. I can't take away his hallucinations. I can't ... I really can't do a damn thing. And it is hard. And you know all I can do is just be his friend, but sometimes that doesn't feel like enough.*



Euk's sensitivity for her friend's distress is not only manifested in experiences of listening to her friend, but also in a terrible feeling that she is "helpless," "a failure" and that she cannot do more to help. In this extract, she expresses great detail regarding her friend's hallucinations and the disturbance the hallucinations can cause to his functioning, for example by distracting him during a test. Euk conveys an image of care that is not only experienced and expressed in the moment of the social sharing, but that expands beyond this moment to involve empathy, compassion, and understanding for her friend, along with frustration that she is not able to do more to help. In the end, she states, "all I can do is just be his friend, but sometimes that doesn't feel like enough."

### **5.2.8 Regret**

Listeners also seem aware of the degree to which care might have been needed but was not provided. This awareness was especially true for Zack, a Listener who was unable to be with his grandmother who was having religious hallucinations in the context of a progressing dementia. He expressed regret at not spending more time with her.

Regarding the relationship, Zack reported that his grandmother was not someone he felt especially close to and that her religiosity in particular had often been a barrier in their relationship. However, she was a part of his life and a part of his family, and he indicated he regretted not acting differently while she was in the nursing home. A description of his grandmother's hallucinations will be helpful for context. Though he reported she was not distressed by her hallucinations, as she saw them as an indication that she would soon walk with the Lord, what she was describing was viscerally alarming for Zack: *I remember visiting her at the hospital and she was telling us about the night before and no one was around and she was saying that she was looking out the window and she said the sky turned red and all of the trees became pillars of fire. She said people with charcoal coloured skin were coming up to the window and looking in at her.*

I ask him how he responded to his grandmother. His regret and self-blame are palpable.

#### **Care Extract 22: Zack**

*Zack: Uhm, I honestly – shame on me as a grandson, I didn't spend nearly as much time with her as I probably should have given the circumstances. But I also found it very upsetting at the time to be around her when all of that was happening because it ... I don't know if you would say I just didn't have the ...wisdom, social wherewithal, experience, to handle that appropriately. It was just something that I didn't want to be around.*

*Adam: Can you say more about that – so that is kind of the focus for me, is that there is a challenge here for people. What ... how did you handle it? Like what....*

*Zack: I kind of just dismissed it. Like I didn't want to think about it and I was pretty satisfied with that decision for quite a while. It was only years after her death where I felt like I should have been there. But at the time I was, you know ... I had said my piece and done my part and I found it too uncomfortable to be around her when she was not all there*

*... as far as how I was handling it? Yeah, I would say I probably just removed myself from the situation.*

*Adam: Like you would just leave essentially?*

*Zack: Mmhmm.*

Zack identifies how he would go sit in the waiting room of the nursing home while his mother and grandmother continued their visit. Later in the interview he continues.

*Adam: Do you think about that experience often? Or at all?*

*Zack: I don't think about the hallucinations. I think about being ... I have regret with how I handled the situation. Just being disengaged and not wanting to visit her because it was uncomfortable. It was a very selfish way to approach it. At least thinking about it now. If it were to happen again I would hope that I would just bite the bullet and socialize with her because I think that would bring her joy. Despite how uncomfortable it would no doubt make me. I suppose that is the only part that I dwell on is how poorly I handled it.*

Zack states that this regret is all the more pronounced because his grandmother passed away soon after. The inclusion of Zack's experience in my data set is important in two respects. First, it lends support to the idea that it might sometimes be more difficult for the Listener to hear about a hallucination than it is for the Experiencer to have one. Second, when care of the other is not initiated in the moment, it can be regretted. Yet, by retreating from an uncomfortable or confusing situation, the Listener is still showing care-of-self, and it is unreasonable to think that everyone will be able to respond with understanding all the time.

Though perhaps not immediately apparent, Zack's extract also indicates an experience of care, though one that did not occur until long after the conversation. In many ways, Zack's description can work as a counter-example to some of the other extracts explored in this section, for example the Listening and Focused sensitivity described by Nolan, Euk, Olivia and Esther above. Here, Zack, a teenager at the time, who was not especially close to this particular grandmother, and who found the content of her religious hallucinations off-putting, does not put his own agenda aside during the encounter in order to take a stance of invited curiosity and acceptance for his grandmother and her reported hallucinations. Rather, Zack provides a word that perhaps captures a Listener-focused aspect of the dismissal that some Experiencers report - Zack uses the term "disengaged." Yet, years later, he expresses a wish that he had worked through his discomfort in the moment to spend more time with his grandmother, to "bite the bullet and socialize with her because I think that would bring her joy." Though it is not clear if Zack knew that engaging with his grandmother would bring her joy in the moment of the sharing, in hindsight, he must have had some degree of awareness and sensitivity to her experience for him to believe there might have been benefit to engaging rather than disengaging.

### **5.2.9 Experiencer to Listener Care**

One of the more intriguing aspects of this Facet is the number of Experiencer participants who spoke of choosing *not* to tell someone about their hallucinations due to their care for the

other person. This variation was not always the case and, as expected, many participants also spoke of decisions not to tell others because of fear that they would be judged, or that there would be other interpersonal consequences. Keanu describes his reservations about sharing, explaining that it is as if some people have a “*peanut allergy*” to hallucination experiences. However, a number of participants spoke as well of not telling certain individuals due to caring for these other individuals in their life. Frequently, they worried these individuals would not be able to handle, appreciate, or relate to what they were talking about. There were two primary sub-sets of this feature of care: (1) not telling others for fear of scaring them (with a tendency to share positive or neutral hallucinations over scary ones), and (2) not telling others because of a concern that the other person would not know what to do with the information.

### **Care Extract 23: Gunnar**

*Gunnar: I haven't told my mom. I don't think I would. Not because I think she would reject me or feel weird, but I think because she wouldn't have the ability to appreciate what I went through or to really understand how profound it was ... I know she really wants to be at that point in my life, but I don't think it's a capacity she has. And so, I kind of don't want to put her in an awkward position where she would have to fake trying to understand. If that makes sense. You know it is a little bit -- and this sounds patronizing -- it is a little bit that you are trying to protect them. Because it seems like a cruel thing to say to somebody, "I've had this profound experience and this is what it was like." And they have no frame of reference to try to understand it. It seems kind of like dangling a carrot in front of them while they are hungry and then saying, "Nope, you can't have it." Because they have no connection. That is another reason why I don't always share it with everybody. Unless they can really connect with it I feel like I am doing more harm than good."*

Experiencers also talk about taking a caring stance for Listeners by being less likely to share hallucinatory experiences featuring the demonic. There appears to be some sort of conscious restraint at times to protect the individuals they are sharing with from how horrifying some of these hallucinations are. Unfortunately, Listeners might never be aware of this expression of care since it is marked by absence.

Luke describes seeing both angels and demons during one his psychotic episodes, and that he believes he was more likely to share the angels than the demons, because the demons were “too much off.”

### **Care Extract 24: Luke**

*Luke: And THEN when I got to the bus depot I started seeing demons, and ... not ... well maybe they were real demons, or my hallucinations. But they were in the wall too. And they looked like people. Men. But they were really like – how do you explain it? Like fire – not like us. Not like us. DEMONIC. And talking to me. And they were in the wall too, right? And I could see them. And they were taunting me and it was really flesh to me. It was in the flesh. Do you know what that means? Carnal. I was feeling really carnal and – and – and it was scary. It was a nightmare. You know how they say Schizophrenia is like having a nightmare while you are awake? Well it was like that.*

*Adam: Did you talk to anybody about that at that point in time?*

*Luke: I talked about the angels to those people at the bar.*

*Adam: What about the demons in the wall?*

*Luke: No, I didn't tell anyone.*

*Adam: Why not.*

*Luke: I don't know. I guess I knew it was just a little too much OFF.*

Olivia also speaks about reluctance to share more frightening hallucinations. She elaborates on how she shared her positive experiences of her new “God eyes” with the church but she is reluctant to share her visions of the demonic.

### ***Care Extract 25: Olivia***

*Olivia: Yeah. I had a whole speech actually on Sunday at church where I shared my whole testimony with them and I talked about getting this new set of eyes and like—I never talked about the ... seeing the demon side of things. (brief laugh) But I talked about how bright things were. How joyful I felt. Stuff like that.*

*Adam: Why don't you think you talked about seeing the demons?*

*Olivia: I guess I don't — if anybody is new at the church there I don't think I necessarily want to—because it is kind of scary when you are first coming out of it, when you first see those things. I don't want to turn anybody off from God's world [yeah]. God's world is perfect. It is awesome. But it is kind of scary seeing the other side of things too, right? (brief laugh)*

*Adam: Yeah. Some of this stuff sounds really frightening.*

*Olivia: Yeah. (brief laugh)*

Even those who have experienced hallucinations can be frightened by others' disturbing stories, perhaps even more so. In the next extract, Aurora talks about how she sought out testimonials on YouTube of others who had experienced hallucinations during sleep paralysis but had to stop watching due to fear. In the long run, she found these testimonials not helpful because she began getting scared that what others were describing would begin happening to her. Aurora's description can also be considered an example of the “infection” idea from the Ontological Cross-Bleed Facet explored at the end of this chapter.

### ***Care Extract 26: Aurora***

*Adam: ... When you say you do research on sleep paralysis is that like on the Internet or do you do lit reviews using like...*

*Aurora: ...no, just the Internet.*

*Adam: Just the Internet, okay.*

*Aurora: Mmm (both laugh). Which I don't know if that's a great thing because it seems to scare me more than it helps.*

*Adam: Where do you end up getting information from?*

*Aurora: Mmm, .... It sounds really bad but maybe like web-MD (both laugh). Anything really that pops up. I've watched a few testimonials from other people who have sleep paralysis and I think that makes it worse for me.*

*Adam: Oh really?*

*Aurora: Because hearing them talk about it I feel like its planting ideas in my brain that like, "oh maybe I should do this." (She laughs.) Like maybe my brain should give me that hallucination next time. So, hearing about it is interesting. I like watching other people talk about it but at the same time I get scared. Because they are basically describing a nightmare to me and I don't think that is going to help at all.*

*Adam: Yeah. No. (Laughs)*

*Aurora: No, I don't think it will.*

*Adam: Because they are having more extended, scarier hallucinations?*

*Aurora: A lot of times, yeah. Like I watched this one girl, it was on a YouTube video and she talked about it and her hallucination was absolutely terrifying. And now when I think about getting a hallucination I fear getting what she had because it just sounds terrible.*

*Adam: What was her hallucination?*

*Aurora: It was like an actual I guess you could describe as like a demon. It was an actual face right in front of hers, yelling at her, and she couldn't move. Uhm ... I don't know. I can't remember what it was yelling. But just a very intimidating voice, just screaming at her until she could wake herself up.*

*Adam: Scary.*

*Aurora: Yeah.*

*Adam: Is this on YouTube?*

*Aurora: Yeah.*

*Adam: How many of those videos did you watch?*

*Aurora: Probably like five or six.*

*Adam: Okay, and then you ...?*

*Aurora: And then I was like, "I'm done." (both laughing) "This is not helpful."*

### **5.2.10 Conclusion to Care**

Care appears to be a pervasive component of lived-experience in relation to the social sharing of hallucinations. However, there are differences between the presentation of care within Listener or Experiencer descriptions. For Listeners, care appears primarily to involve a surrendering, or setting aside, of any negative reaction or strong questioning of the reality of the Experiencer's hallucination so that they can enter a state of listening and focused sensitivity as they hear about the other person's experience. For some Listeners, the stance of listening and focused sensitivity is achieved through a conscious effort to make sure the other person feels heard, understood, and comfortable. For some Listeners, the stance of open listening appears to be a natural response, with little intention required to achieve the listening stance. Yet for other Listeners, care not given in the moment of listening can come back to haunt them, as they look back in their memory and wish that they had taken more of a caring stance in the moment.

Listener experiences of care are quite different than the Experiencer experiences of care. While the Listener's *experience* of care involves a focusing on the individual they are listening to, the Experiencer's *experience* of care involves responding to the expressions of care that are secondary to the Listener's sensitive and welcoming stance. In response to these expressions of care, Experiencers reported feeling not dismissed or reassured. The nuanced difference between "not feeling dismissed" and feeling "reassured" is important, as it indicates that Experiencers often expected to be dismissed, while at the same time knowing that the individuals they chose to tell were likely to be supportive.

Finally, some presentations of care are hidden between Listeners and Experiencers. For example, Experiencers reported not telling certain individuals because they were worried they could upset the other person, or that the other person would feel burdened from hearing about the hallucination. Similarly, some Experiencers spoke of not sharing *certain* hallucination content with others. Multiple Experiencers specifically described not wanting to share hallucinations involving the demonic, and that they were more likely to share positive or neutral hallucinations.

## **5.3 Facet Two: Sense-Making**

### **5.3.1 Introduction to Sense-Making**

Sense-Making is a broad Facet experienced by both Listeners and Experiencers. Experiencers must make sense of their hallucinated experience, while Listeners seek to understand the experiences about which they are hearing. Though the Sense-Making Facet is a general one with wide applicability, I focus on the following areas - participant descriptions of non-social checking, and three forms social checking: (1) reasoning if the hallucination is real, (2) reasoning why the hallucination has happened, and (3) seeking meaning behind the

hallucination. For many Experiencer participants, sense-making was marked by an incomplete certainty. When sense-making is paired with other human actors, this doubt is overridden by trust in others and a questioning of one's own direct observations. Experiencers must deal with the perception that the hallucination is real while at the same time understanding that perhaps it is not. Even for the answer "why," certainty is rarely a given or an ultimate conclusion. Multiple explanatory factors are possible and the real reason for the hallucination might never be known. For Listeners, encountering a social other who is experiencing hallucinations can bring one's own assumptions about the shared perceptual world into doubt, leading to shock, confusion and disturbance. Their reactions might invite curiosity about hallucinations more generally, as well as alter their relationship with the experiencer.

### **5.3.2 Checking: Non-Social**

To begin, Experiencer participants spoke of a variety of ways in which "checking" was done *without* others. These reports demonstrate that, although social checking is part of the sense-making experience, checking also exists in non-social forms. I consider three instances of non-social checking: (1) Aurora checking in with her paralyzed body while she is hallucinating during sleep paralysis; (2) Marcel checking to see if YouTube is playing in another room when he hears sounds coming from another part of the house; and (3) Nolan anchoring in a TV-remote during a mushroom experience in which visual hallucinations of colour were over-stimulating. These three examples show how non-social checking can serve as an anchoring to the non-hallucinated world.

In the extract below, Aurora describes checking in with her physical body during the "woman in the yellow dress" hallucination. She realizes she is paralyzed, and this realization aids her understanding that she is, to some degree at least, seeing a hallucination. *"I think the hallucination itself looks like it could be real. Literally I can see her coming towards me, but I'm still getting the physical sense of being tied down and I've come to recognize that as this isn't normal. So, this isn't quite reality."*

In another situation, Marcel hears sounds coming from another room and "checks" if his hallucination is real by looking into the room to see if he has left his computer on.

#### ***Sense-Making Extract 1: Marcel***

*Marcel: I wasn't really upset or freaked out I was just "what is going on?" And it occurred to me for a minute that maybe because—you know how it is on YouTube where you watch a music video or song and then if you don't close the browser or whatever it flips you onto another song? Something related to what you just watched. And I thought "did I leave that on downstairs?" So I went downstairs and checked and realized, no, I turned the computer off. But that was my thinking, "Oh, I left the music on or something."*

Finally, Nolan speaks about anchoring himself with his TV remote during a mushroom trip to check in with stabilized reality.

### ***Sense-Making Extract 2: Nolan***

*Nolan: I .... had consumed a good deal of psilocybin mushrooms, a bunch of them. And I like music. I like sounds when I am hallucinating. My hallucinations are very auditory driven. So I was watching a NASCAR race with surround sound on and it was really fun. The sounds would actually make colours and whatnot swirl as the cars would come around the racetrack the surround sound would go “Vroom” and they would come roar behind your head. And then they would roar off in that direction (motions), and you would get the doppler effect as they drive away. And you would get the swirling colours doing the same thing as they come up to you they would speed up, slow down, come around. It was a giant circle of swirling colours and sounds. It was really pleasant.*

*Adam: So you are like sitting at a big screen TV? Surround sound around you? Were you alone or were you with others?*

*Nolan: Just me.*

*Adam: Were you alone the whole time?*

*Nolan: Yeah. I was working and living on my family farm so I was—well, I was miles away from the nearest human... So, like the television was right in front of a wood paneled wall. So, I could watch the cars swirling. And you would lose perception that they were cars on the television or anything. It was just a swirling mass of colour. And if I moved my focus from the television to the wall the swirling mass of colours would now be the wall. And it would be the wood grains, it would be—the different knots in the wood, they were all swirling.*

*Adam: Did you have a hard time -- like how were you making sense of all of that at the time that it was happening?*

*Nolan: I would always try to keep something nearby that I knew was real. And that way you could—if things got too intense or too weird you know that this whatever that I kept over beside me was real. For me really I would just use the TV remote. I knew that the television remote was a real thing. And I could pick up the real thing. Focus on the real thing. Say, “This is the television remote. Alright. Chill out.”*

In this extract, Nolan is carried away by his hallucination; he requires a grounding object to re-center his experience as what it was - viewing a NASCAR race after ingesting mushrooms. He keeps something by him that he *knows* to be real, something to check in with if and when things get out of hand. Note that both Nolan and Marcel speak to *themselves* during the checking: “*Oh, I left the music on or something,*” and, “*This is the television remote. Alright. Chill out.*” Thus, there is still an element of dialogue to independent checking. But the dialogue happens internally for the individual experiencing the hallucination.

In a similar manner, many Experiencers mention checking with Listeners at some point to see if a hallucination is real or not. In these cases, a social other serves the same purpose as found in the examples above. Experiencers describe checking with others, and Listeners are able



to provide reports of being checked-in with, or as serving as a grounding presence during hallucinated phenomena. At its most simple, this type of checking is a version of “what is going on” and a way others can get involved in that question. The experiential state of this checking is difficult to determine and remains elusive within my data, yet I believe this experience of checking is important and at times foundational to the social sharing of hallucinations. Checking seems most likely to occur when the hallucinations are perceived “with a sufficient sense of veridical perception” rather than full veridical perception. The Experiencer must have a sense that something requires checking. Though the checking does not entirely rid the sense that the hallucination is or could be true, it appears the checking impacts the social sharing of hallucinations by shifting the reality structure for the individual experiencing the hallucinations towards the social world.

Another feature of checking as an experiential component of the social sharing of hallucinations is that it happens precisely in the moment of the hallucination perception. In other words, checking occurs *while* an Experiencer is hallucinating. This aspect differentiates it from other types of social sharing that involve revealing or describing hallucinated experiences to others.

### **5.3.3 Checking: Real**

Ally and her father provide an excellent example of the feature of this Facet that involves checking in with a social other regarding what is real. Ally’s father recently had a stroke and is in the hospital. She describes their conversation while he is hallucinating in the hospital room and how she offers to help him differentiate what is an hallucination and what is in the room.

#### ***Sense-Making Extract 3: Ally***

*Ally: And I said, “yeah and what else do you see?” And he says, “Well earlier I saw those guys from church and couldn’t figure out why there were here.” And I said, “Well Dad that is not real.” And he said, “What do you mean it is not real?” And I said, “Well you are seeing things. They are not here. That is not real.” And he was like, “What do you mean?” (laughter) So I told him, “Well, I’m real.” And he goes, “Okay so how — what you are telling me is—if some of the things I am seeing are real, and some of the things I’m seeing aren’t, how do I know that you are real?” (pause) And I go, “Well Dad you know I am real because you can reach out and you can touch me.” And I took his hand and I put his hand on my face and I said, “See you can touch me that is how you know I’m real.” And then my sisters walk in the room and he goes, “Okay. Are they real?” (both laugh) And I go, “Yeah Dad they are real.” And he goes, “Okay so if you are real, and they are real, but this other thing is not real ... how do I know what is real and what is not real?” And, and I go, “well” ... so I told him what wasn’t real, and he responded that it seemed real. And how do you now if it was real nor not? How do you know if anything was real? How did he know if I was real? And I told him he could tell I was real because he could touch and feel me, and I took his hand and I ran it over my face. I told him he could ask and I would tell him what was real or not.*

Ally’s father reports to her that the hallucinations *seemed* real as he was experiencing them even as she told him that they were not real. He was unable to determine if his daughters

(Ally's sisters) were real when they entered the room. Though we do not have access to a description of Ally's father's lived-experience, his verbalization to her that the hallucinations seem real, and his uncertainty regarding if what he is observing is really in the room or not indicates an experiential uncertainty. To remedy this uncertainty, Ally and her father form an alliance, with Ally serving to observe the perceptual situation and to report to her father what is "real" and what is not. Ally reaches for her father's hand and holds it against her face, making tactile contact. This move is similar to Nolan's reaching for the remote. In this extract, Ally experiences herself as a grounding perceptual presence for her father.

In moments like the description of Ally and her father in the hospital room, the Listener will also sometimes reflexively check to see if the thing is real. Ally describes how her father kept talking about a sign he saw outside his hospital room, and that her sisters kept checking to see if they could find the sign. At the same time, Ally herself would sometimes turn to look behind her back when it seemed her dad was looking at someone standing in the room behind her. Depending on the situation, Experiencers and Listeners will also check in with one another together, to make sense of odd occurrences. In the extract below, Simon speaks briefly about checking in with his roommate during a mushroom trip to determine if what he was seeing is real or not. This checking occurs in the context of the first time he has taken mushrooms. He and his roommate are in their apartment together.

#### ***Sense-Making Extract 4: Simon***

*Simon: We mostly kept to our own rooms. But the first time I definitely entered his room a few times and asked him questions. I was like, "I'm seeing things. I'm hearing things." And he said, "Yeah that is normal; that is kind of what happens when you are on them." And I knew I'd see and hear things but I just never realized how until I experienced them for the first time. Mostly we kind of just went our separate ways. After about two or three hours he would come out of his room and we would just hang out on the couch. Just (pause) just kind of sit there usually and then if I had questions I would ask them. And most of them just had to do with you know (laughs), "Are you seeing that?" and he's like, "No, but you are." Just kind of like it was just our own individual hallucinations.*

*Adam: He would say that, "No, but you are?"*

*Simon: Yeah. Well he's like, "I'm not seeing that, it is probably the mushrooms in your mind," kind of thing.*

*Adam: What would that do for you?*

*Simon: It just made me realize that everybody sees things differently. And I thought perhaps maybe people see things different when you are not on them.*

In this extract, Simon's roommate serves a similar purpose for Simon as Ally served for her father. The roommate listens to Simon's experience and lets Simon know it is the mushrooms causing his hallucinations. Simon seeks his roommate out to make sense of this, and in the moment of the sharing Simon realizes that individuals see things differently, and that perhaps this occurs even when people are not taking mushrooms. Later in the interview, Simon mentions

that this experience with the hallucination and the related conversation with the roommate had a large impact on how he views the world and others, as it helped him realize the degree to which we all perceive the world differently. Note as well that Simon's roommate does not dismiss his hallucination. His response, "No, but you are," acknowledges that the roommate does not see the hallucination, and that it is a veridical perception for Simon, a real experience. Simon and his roommate are physically represented in separation and connectivity - they both "go their separate ways" but come together also at times to either share the trip experience or so that Simon can make sense of what is happening. This combination of separation and connectedness was mentioned by many of my participants who experienced drug-assisted hallucinations.

Many participants report seeing insects and many Listeners report bugs or small spiders as being typical of the minor, more chronic hallucinations that their friends, family members, or romantic partners experience. In the extracts below, participants speak to how others can be recruited into checking for the existence of bugs, which could conceivably be real.

***Sense-Making Extract 5: Nicole and Naomi***

*Nicole: So once a month or every two months I think I have bugs and then my roommates they like pick on my bed, "Okay that is a fuzz." (laughing a bit) "That is a—."*

*Adam: —So they come in and—*

*Nicole: Yeah. Because I am like "Whoa," you know.*

*Adam: They assess the facts?*

*Nicole: Yeah, they assess the facts. And that is one thing I learned years ago when I got real paranoid. I am like, "Okay, I am assessing the facts." I've learned to talk to people that you trust that aren't going to lie to you or mess with your paranoia, or your delusions, or anything like that. And then decide, "Okay, maybe I am ... maybe this isn't real." But it is really hard to find.*

*Adam: What is hard about it?*

*Nicole: Well because—remember I told you, you would truly honestly bet ANY money at the time that it is real. Isn't that right Naomi?*

*Naomi: Yeah.*

*Nicole: Is that how you feel?*

*Naomi: Yeah.*

*Nicole: Is it though how you feel? Or do you know?*

*Naomi: I think it is real sometimes. That bad things are going to happen.*

In this extract, Nicole mentions that her experience during the checking is also one of a continued uncertainty. She does not describe checking in with others and then realizing that the bugs are not entirely real. Rather, she checks in with others because she is uncertain if the bugs are real, and after the checking she is reluctantly able to surrender the veracity of the bugs, “Okay, maybe I am ... maybe this isn’t real.” It is also important to note that Nicole highlights the importance of finding individuals she can trust, and who will not lie to her about the hallucinations. As with Nolan and his roommate and Ally and her grandfather, the relationship of trust appears to be a central component in the individuals being able to question their hallucinations.

Nicole also speaks of an experience of “assessing the facts” and of turning away from her own lived-perception to partially rely on the assessment of others in how she makes sense of her world. Despite the assessment of others that the bugs are not real, Nicole still states it is hard for her, that she would “bet any money at the time that it is real.” What this means is that in the cases explored so far, after the checking the experience for the individual hallucinating does not appear to be one of surrendering with ease the hallucination that they are perceiving. Rather for Ally’s father and Nicole there is still some uncertainty as to whether the hallucination is real. Yet, they appear to be able to ground in some ways into the perception of the individuals with whom they check.

At times, the experiencing individual might also struggle to determine if a “real” object in the shared material world is a hallucination. One of the clearest examples of the struggle to determine if something is actually real is when Katie’s husband has her look to see if there was really a colony of ants in their kitchen. She says that he will often have her check to confirm whether a bug is real or not when he sees one. Sometimes, even without him asking, she will direct her attention to the area of his focus, if she notices that he jumps or startles, as though seeing one of his shadow bugs.

### ***Sense-Making Extract 6: Katie***

*Katie: He would talk about—he knew they weren’t real. He was never like, “Oh, there is a bug on the ground.” He would be like, “Yeah, I’m seeing bugs I think,” is how he described it. And I was like, “What do you mean you are seeing bugs?” Like he would see them at the grocery store—not that he could really describe their look. But his brain just recognized it as a bug. And those were fairly common for years. But yeah it is just kind of like crawly things. Shadows crawling. He has mentioned seeing spiders before. And I think those are kind of slow. And I think it was spiders in the grocery store, skittering. But I think they are either like little, shadowy bug-like ... uhm, herds, hordes? I don’t know. Hordes of bugs. And then the larger ones are like spiders and stuff. Those are what he would attribute to a spider movement. I don’t know. So, there was a time when we had a legitimate ant infestation in our porch. And it was ants flying away in the spring where they grow wings and go and disperse. And he is like, “Is this real?” (both laughing) “Is this happening?” And I was like, “No, I see those too.” So, he wasn’t sure if that was reality. And then we found this ants’ nest and that was great.*

Katie’s extract provides a mirror image of the other extracts because in this situation the bugs *are* real, but her husband is unable to fully recognize this. He checks in with Katie to

determine if the bugs are real, and she determines that they are. At least before he checks, her husband is “not sure if that was reality” and Katie, as the Listener, voices the representation of “reality”.

### 5.3.4 Checking: Why

In contrast with the checking described above, which involves understanding whether or not the hallucination is real, this subtype of “checking” does not occur during the moment or immediately after the hallucination experience. This subtype has more to do with making sense of the specific hallucination, either why it occurred or its meaning. As clinical psychologists, this kind of social sharing is what we are most likely to engage in professionally, but religions also offer explanations for hallucinations.

Aurora, who experienced her woman-in-a-yellow-dress hallucination during an episode of sleep paralysis, elaborates on the variety of explanations others in her life gave her for why the hallucination occurred. Recall in the Care Facet section that Aurora mentions her hallucinations to three groups of individuals and gets three different answers. Her religious friends tell her she is being haunted by a demon (Care Extract #5). Her mother, who knows her sleep paralysis already, attributes the hallucination to Aurora sleeping on her side or to the fact that she is experiencing more stress than normal (Care Extract #2). And her secular friends point to her sleep paralysis (Care Extract #8).

Aurora speaks about the terrifying possibility of the religious friends being right, and that, to some degree, she chooses medicalized understandings due to this fear. Again, note the presence of uncertainty. Multiple participants remain uncertain about their hallucinations, whether they were real, where they come from, and what they mean.

#### *Sense-Making Extract 7: Aurora*

*Adam: Did you—you mention kind of like as far as interpreting what it meant like it could be spiritual [mmhmm]. It could be mental illness related [mmhmm]. Could you just talk more about that?*

*Aurora: Uhm... I... when I used to get sleep paralysis I used to confide in some friends and they were pretty religious and they thought that it was... like a spiritual thing. And usually when it happens to me I kind of like go back to that and I pray usually when I have sleep paralysis and I think what it does is it gets my mind off of it and it goes away and it helps me wake up. I don't know, but like... In the history of the sleep paralysis stuff, people used to think it was a demon coming in and sitting on you actually. I don't think that's what it is, but... there is still a part of me when it keeps happening over and over again, I wonder from a religious side of things, am I being punished? (laughs)*

*Adam: Yeah, yeah, yeah. That is really interesting. Do you talk to anybody about that?*

*Aurora: Uhm, I stopped talking to my more religious friends about it because I really don't believe that is what it is at all and I think that them telling me that stresses me out a lot more than—I really like to look at it from like the scientific point of view that it is your*

*mind going through the different stages of sleep and what is actually physiologically happening in my brain; I like to think of it that way better. (laughing)*

*Adam: Yeah. (laughing) Why?*

*Aurora: I think it is more comforting. I don't like the idea that there is evil (laughs) associated with it.*

*Adam: Yeah, yeah. So, I guess we are talking about sleep paralysis now, in which the hallucinations are kind of wrapped up, but what are those conversations like with your friends when they are coming from that perspective and you aren't?*

*Aurora: Uhm... well I guess... they kind of tell me like, "When this happens you should pray," and I say, "Yeah I do." Uhm... (long pause) It seems to go... it seems to go kind of like any conversation. Like whether they are religious or not except kind of the last part and they would say they would maybe pray for me and they would tell me to pray. That is about it though. I don't think they quite understand what it is. Uhm, I don't—we don't get taught about that, at all like within the Christian circles. So, they kind of do their best to link it to what they believe in.*

Aurora acknowledges that the difference is not only in the explanation of the hallucination, but in the steps that need to be taken to protect herself from it happening again.

*Aurora: I guess the WHAT I SHOULD DO NEXT is a lot different coming from them or coming from someone who thinks it is a brain thing. Because for them it is like you need to get the sin out of your life and you need to pray and you need to do this, and then for people looking at it with a more secular brain view they would be like don't drink caffeine before going to sleep, don't stress yourself out, make sure you go to bed at the same time every night type of thing.*

Though Aurora chooses to believe that her hallucinations occur for organic reasons of the brain, many Experiencers, including Aurora, are open to the possibility that the presence of evil can serve as an explanation as well.

Luke seems slightly unsure if his demons were hallucinations or real when he talks about seeing demons at the bus depot. *"And then when I got to the bus depot I started seeing demons, and... not... well maybe they were real demons, or my hallucination. But they were in the wall too. And they looked like people."* Similarly, Joseph is unsure if he has hallucinations or if he can hear his subconscious speaking to him *"I think when I hear voices in my head it kind of ... (laughs) it's my subconscious? You know? Like, well I don't know if it is either my subconscious, or ... if it is a hallucination. That is hard for me to distinguish."*

Likewise, Gunnar mentions seeing a dark entity during an LSD trip, something he describes as *"a sharp spikey three-dimensional shadow that was radiating malicious intent. Waiting to ambush me when I went to use the washroom."* However, he, too, acknowledged that what he saw was perhaps an entity, rather than a hallucination.

### ***Sense-Making Extract 8: Gunnar***

*Gunnar: So, I thought, well this thing is real. One, that also means that other supernatural things are real, so that is actually really cool. But also, it means that I have this chance to practice compassion towards a being that is obviously in a great deal of pain because beings that radiate malevolence aren't in a good spot. So, they might be in need of some help. So, this is a great opportunity for me to go and help a tortured soul. So, I went chasing after it and of course it wasn't there when I got there (chuckles) and I was like "Aww shucks." (snaps fingers)*

Finally, Cleo is uncertain if the demons she has been seeing are a byproduct of madness, or glimpses into the very real presence of Satan in the world.

### ***Sense-Making Extract 9: Cleo***

*Cleo: So, when I came out of it I really felt like, "Wow there is so much more to this." But I kind of felt really unsure because this had rocked my world and turned my world upside down that I was like, "Am I actually seeing the things that I'm seeing or am I just going COMPLETELY CRAZY?" (brief laugh) Like, that thought had entered my mind, right? But so, I'm like—the more I TALK to the sisters at the church and the more I said things to them the more I realize, no I'm not going crazy. And the more I listened to their talks and stuff I'm like, no, I'm not.*

At times, multiple viewpoints, of what the hallucination can be, are present in the same conversation, with individuals involved in the sharing holding different understandings about the hallucination. This situation can occur, for example, in clinical conversations when a client is hallucinating and does not see it as part of a mental illness. Below, Drea, a mystic who speaks of being trained in protecting herself from dark beings, exchanges understandings of these entities with a man near her work. As one of my participants, whose hallucinations permeate multiple aspects of her life (self, work, friendships), she takes a stance of receptive openness to most individuals who approach her. She works near a community center for the homeless and speaks about how many individuals share their hallucination experience with her. But, she still must keep a distance to ensure she is protecting herself, not from the individuals, but from the negative spirits that she, at times, can sense around them.

### ***Sense-Making Extract 10: Drea***

*Drea: I work with a lady who has a lot of individuals from a community clinic come in and talk to her. Because they have visions and they have voices. And a lot of different experiences. And they just want to be heard. And to feel like it is normal or they can be excited to talk about it. Because generally they are. That is probably the most exciting part of their life is that mental stuff that happens [Mnhmm]. And sometimes it is clairvoyance, sometimes it is spirits, sometimes it is delusions. But either way it is really real to them. It is their experience. And tons of people have talked to me about it. Sometimes I'm not as open to talking to these people because I can feel that there is negative energy surrounding*

*them. Or entities, or things like that. And I am very sensitive, so I don't necessarily want that. In case something decides to, say, latch onto me. In a sense. Not that I cannot do other things to protect myself. I have been trained to do that. But sometimes I just don't feel that I want to. And some days I feel more vulnerable than others. But on a good day when I am feeling comfortable and more grounded and protected I am more willing to have those conversations. And I am very interested in picking their brains and trying to find out how they view things. And how they would answer my questions.*

*Adam: What type of stuff do you ask?*

*Drea: Well, there was a man that I was talking to once. And I think he does a lot of meth. And what he was saying is—he kept referring to this woman. She was like a deity, but I think really what it was is that an evil entity disguised itself as a woman to take advantage of him because he was so susceptible. So, what I asked him was, “What are your thoughts on powerful women? And what are your thoughts on real life goddesses?” And he said, “They really intimidate me. They really scare me.” And I kind of asked him why. And he said, “Well because they are really powerful.” And I said, “Yes they are.” And so that is kind of where I got the idea that this spirit that maybe was communicating with him or taking him over to make him think or do things a certain way was not necessarily a woman's spirit but coming off in the shape of a woman because it would overpower him in the way his mental state was at. As opposed to like a male dominant voice.*

*Adam: Did you go into that with him?*

*Drea: A little bit. I was kind of standing outside smoking a cigarette and he was also outside and I had kind of seen him there before so I asked him a question and then he was very excited to just talk about it a little bit and so... But he did keep thinking and reflecting and you could tell he was kind of having multiple viewpoints coming in. So, he wasn't really sure which one he wanted to listen to. So, that was interesting.*

In Drea's extract, both she and the individuals she speaks with have different understandings of the hallucinations they experience. Drea sees these as possible entities or negative energies that have attached themselves to the men, who are in a state of vulnerability due to drug-use. On the other hand, the man she speaks with perceives the woman as a female deity. What is remarkable about this conversation is that both Drea and the man to whom she is speaking are open and curious with one another about their understanding of the hallucination. Here, the experience of sense-making is marked with curiosity about how another person might interpret the experience. Drea's description that she engages in conversations of this type only when she is feeling well-protected is also notable as it indicates awareness of the danger or discomfort that can present to a listener when speaking about hallucinations, particularly of the demonic sub-type. A colleague (T. Walton, personal communication, May 15 2019) used the term “infection” for this possibility of the demonic entity or other negative energy spreading from one individual to another. This is further worked with in the Ontological Cross-Bleed Facet. Drea's response is also notable for her level of understanding regarding how real and meaningful the hallucinations seem to many of the men with whom she speaks. The degree to which Drea's understanding is partially due to her own lived-experience with voices is uncertain, but it is



possible that individuals who have themselves experienced hallucinations will have a better understanding of the degree to which hallucinations can appear as real for others.

It can be the case as well that a single individual holds multiple understandings regarding their hallucination. With Drea and the man to whom she speaks, each holds and shares their varied understandings regarding the hallucination; whereas Joseph voices his uncertainty regarding what his hallucinated voices are: *“They could have been anything. They could have been spirits. (Pause) But ... I guess they were spirits. I guess what I am trying to come... honestly, I guess that the gods are trying to tell me don’t sleep with this woman, right? This is a bad woman.”*

As can be seen, uncertainty extends beyond the basic questioning of the hallucination’s existence into why it has occurred, and some individuals simultaneously talk about hallucinations as though they are hallucinations and as though they are actual supernatural entities existing in the world. In addition, some individuals describe being uncertain if their hallucinations are due to drug-intoxication, drug-withdrawal, a mental illness, or some combination of all three. For example, Marcel explains that he speaks with his counsellors about the hallucinations, in part to determine whether they were happening due to intoxication, withdrawal, or his dysthymia diagnosis.

### ***Sense-Making Extract 11: Marcel***

*Marcel: Well, I am never going to know—I mean there is—I know what causes the hallucinations. But I don’t know which of the causes is the more prominent cause or which of the causes is the less prominent cause. Right? So, if you say there is four causes for something. Okay they all probably in some amount add up to the hallucinations but which ones are more prominent and which ones are less prominent? So, I will probably never know.”*

Nicole also mentions that it is difficult to know exactly why she has the hallucinations. *“The fact is I don’t know if it is because of the mental illness or the drugs or because I got institutionalized along the way.”*

For Marcel and Nicole, the sense of uncertainty regarding the hallucination does not involve only the sense of the veracity of the hallucination as it is occurring. For example, recall the beginning of the section on the Sense-Making Facet when Marcel walks into another room in his home to see if he has left YouTube on because he hears sounds (Sense Extract #1) and Nicole recruits housemates to check if there are insects on her bed (Sense Extract #6). What we see now is that this experience of uncertainty extends beyond the question of whether the hallucination (the sounds or the insects) are real, and into why the hallucinations are occurring. Due to this uncertainty, Listeners can be recruited in conversation during social sharing to help Experiencers make sense of the hallucinations. However, some Experiencers appear to continue with a sense of uncertainty regarding why the hallucination has occurred. Some of my participants seem to have settled on there being multiple possibilities for the hallucination’s occurrence, and this explanation appears to be a workable one for them.

The idea that others can be recruited into the activity of sense-making generalizes beyond experiences directly involving checking to see if the hallucination is real or engaging in a conversation with others regarding the reason behind the hallucination. As an example of a subtype of Sense-Making Facet that does not fit into either of these categories, Aurora has her friend take her position on the bed in her room while Aurora explains how she saw the woman in the yellow dress. Aurora physically acts out the movement of the hallucination from the mirror's angle so that her friend can see what she saw while paralyzed.

### ***Sense-Making Extract 12: Aurora***

*Adam: (laughing) Whose idea was it to have her like lay down on the bed?*

*Aurora: Mine (laughing)*

*Adam: Do you remember how you posed all that for her?*

*Aurora: Well, we were just sitting on my bed and then I was telling her about it and then I realized we are sitting in the exact same spot that it happened. So I was like, "Okay, put your head right here and then look in the mirror." And so she could see the corner, so then I basically acted out my hallucination and I started walking towards her really slowly from that corner so that I could... kind of like show her what the hallucination was like. So, she wasn't scared when it was happening, it was just me walking towards her. She could see me coming in the mirror, but I think it made it real to her what exactly I was seeing, like how the physics of it worked with the mirror and then the corner of my room.*

*Adam: When you were walking towards her, did you try to really act it out?*

*Aurora: No. (laughing) I wasn't like (pause) silent and like (laughing) imitating. I was explaining this is how she was walking, and it was really scary, and she was going slow. I was saying this like as I walking — it was just me. (laughing) Yeah.*

In this extract, Aurora uses her friend's ability to hold the position on the bed in which Aurora was sleeping when she had the hallucination, while Aurora takes the position of the woman-in-the-yellow-dress. Aurora claims that acting the hallucination out "makes it real" to Aurora's friend, because she is able to see how the physics works with the mirror and the corner of Aurora's room. Later in this extract, Aurora mentions that her friend stated she became scared, indicating that others can become frightened when hearing about hallucination experiences.

### **5.3.5 Listener Sense-Making**

Experiencers spoke about needing to check if the hallucination was real, needing to make sense of why it was happening, and searching for the meaning behind the hallucination. Listeners, on the other hand, spoke of experiences of shock and sense-making around the hallucinated experiences. Though the set of Listener responses related to shock, sense-making and is similar to the lived-experience of listening mentioned in the Care Facet, the accent is placed on sense-making rather than showing interest for the other. While Listener actions of sense-making tended to involve getting descriptions of the hallucination, reasoning out why the

hallucination occurred, or figuring out if care was needed, the lived-experience of sense-making for Listeners eludes precise determination. Katie, for example, queries her husband's hallucinations to get more information.

***Sense-Making Extract 13: Katie***

*Adam: So, for you... like the bear and the woman you talked about being kind of like "what?" (Katie laughs briefly.) So, what do you actually follow up as far as what you say when he told you about those two instances?*

*Katie: Well—because he was just like, "Oh, I saw a bear charge at the car," or, "Oh, I saw a woman between the cars today." So, then I'm kind of (brief laugh) asking for more details on it. So, I ask, you know, like "What do you mean?" (laughing) "Can you describe it to me, some?" Just asking for more details on the hallucination and what was happening and what happened afterwards just to get more context, I guess. Because they are really complex, and... strange. Because visual hallucinations as far as I know are an anomaly in themselves. Like usually auditory hallucinations are more common. So, to have really complex visual hallucinations is just like, "What?" (laughs) So yeah—we definitely—I definitely ask him about context in more detail than say I would for a shadow or a bug.*

Although Esther believed her friend when she spoke of the ghost soldier in her home, she speaks about how she tried to make sense of the occurrence, and the multiple questions the encounter brought up for her.

***Sense-Making Extract 14: Esther***

*Esther: I think the other questions for me of course were... okay. Okay, so if this is an actual phenomenon, an actual experience, then why do some people have this kind of experience and other people don't? So why does Sarah have a first-hand story about a ghost and she is the only person that I have encountered to date that does? So, there is that question. There was the question of I wonder if it has anything to do with the length of time the civilization has existed in a particular location? So, is there any connection there? Because people in maritime Canada would be more open I think. So, you wouldn't be looked at as though you had two heads (Adam laughs) if you were talking about a ghost story or an experience with ghosts in the Maritimes the same as you would in the province of Saskatchewan... And at the time I was struggling with trying to reconcile —especially you know I'm putting quotes around this, but you've got a "university educated" woman who is "sharp." It wasn't even an arts degree, you know a fine arts degree or anything like that. She did a Bachelor of Arts. So, there was just so much inconsistency... for me.*

As Esther is beginning to illustrate, revealing the hallucination can leave Listeners caught off-guard and temporarily confused as they try to make sense of the situation. This experience is something Zack, whose grandmother was having religious hallucinations while in a nursing home, describes as a "disturbance."

***Sense-Making Extract 15: Zack***

*Zack: I think the reason it sticks out in my mind is that it was (long pause), uh, (pause) I don't know how you would really describe it. It is like when you are really young, and you find out that one of your friends has tried their first beer and you are twelve years old. "Oh my goodness." And I think that was the first time that I was met with that. It was not... not a taboo, but a ... disturbance.*

*Adam: Yeah. Can you say more about that? Why was it disturbing for you and how did you experience that disturbance?*

*Zack: ...There's an unspoken understanding that everyone is looking at the same thing. You know, like my blue is your blue, and my hospital is your hospital, and the thing you see outside the window is the thing that I see outside the window. And all of a sudden it was like, NO, you are seeing something very, very different.*

*Adam: What would be going through your head when you were actually in her presence?*

*Zack: Probably just... shock. Like I don't know what I would have... I was in high-school. (laughs) I'm ashamed to say that I don't think I had any sophisticated thoughts in my skull.*

*Adam: (relating) Yeah. (both chuckle)*

*Zack: So, I probably just felt discomfort and tried to get rid of the discomfort. I don't know what I would really—I don't know that I really reflected on it until years later.*

*Adam: Can you describe the discomfort?*

*Zack: uhm—what would be similar? (long pause) Huh. (thinking). I don't know... I'm trying to think of another situation where one would have similar discomfort. I find it difficult to explain feelings. Uhm, maybe like when you are a child and you have done something that your parents disapprove of and there is that like, "Oh no, I've messed up." But you don't ... it seems trivial, it's just like—or it seems trivial looking back on it but at the time you are—I don't know, there is some sort of burden upon you and you wish you could just be somewhere else where that pressure is gone.*

Zack describes a disturbance, a burden, a shock, in response to hearing about his grandmother's hallucination. His assumptions of the world - that everyone is looking at the same thing, that his blue is her blue - are brought into question, as he realizes that his grandmother sees something very different than what he perceives. Zack describes this discomfort as being like when you are a child and you have done something that your parents disapprove of. For me, this is an embodied sense that something is *wrong*, *off*, and *irreversible*. As Zack indicates, this feeling can be strong, and can be difficult to work through.

Importantly, Zack reported that he did not reflect on this experience until years later, at which point he began to regret his response to his grandmother's hallucinations. Yet, his response is not surprising. Contextual factors influencing Zack's response include his young age,

his relationship with his grandmother, the context of her hallucinations occurring in a progressive illness, and the religious and frightening content of the hallucinations themselves. Yet, this disturbance or shock can occur in other relationships and hallucination contexts as well. Esther describes something similar as an aspect of her lived-experience when her friend is telling her about the ghost that lives in her house.

### ***Sense-Making Extract 16: Esther***

*Esther: I think the reason that I remember fairly well is because of the shock of it. Because I wasn't expecting anything like that. And for that reason, it impressed me. It was totally out of the norm. The only imagining that I was doing was taking her words as they were told and then constructing, okay so this is where the ghost sits and so I would imagine that being sitting there on the edge of the bed. But was I doing other fanciful thinking? No. Because inside my head I was still scrambling. Trying to piece things together and make sense.*

Esther describes a similar internal response as Zack, though her external response was different. Whereas Zack left his grandmother's room to sit in the waiting area, Esther stays with her friend and asks questions about the ghost that lives in her house. But Esther's description of a "shock," that "it was totally out of the norm," and that inside her head she was still "scrambling" is similar to Zack's description of a disturbance, as though he was a child who had done something wrong and was about to be caught.

### **5.3.6 Conclusion to Sense-Making**

The Sense-Making Facet captures the degree to which hallucinations confuse and disorient both Experiencers and Listeners as they struggle to figure out what is going on with the hallucination. Experiencers must make sense of the hallucination itself - Is the hallucination real? Why is the hallucination happening? What does the hallucination mean? To accomplish this sense-making, Experiencers indicated they often recruit trusted others to assist in these answers, as well as to provide support for any distress caused by the hallucination experience. Experiencers primarily described sense-making as done through quick check-ins, an action of checking that indicates a quick connection of shared world-building between Listeners and Experiencers as they together make sense of what is occurring.

My sense is that this checking behavior is quite primordial for humans, and that it is one way we are able to create a shared sense of perceptual reality with social others. It is difficult to describe the experiential nature of checking, as aspects of the checking experience could primarily lie under conscious awareness. Regardless, for my Experiencer participants, checking does not result in a certainty. Rather, the result of checking entailed turning partially away from one's own perception of the world, for instance in the belief that there are insects on their body or in their bed. This turning away is not complete, and Sense-Making is therefore marked with a lingering uncertainty, in which the answers to whether a hallucination is real, why it is happening, and what it means, remain open to many possibilities rather than a single definitive answer.

For Listeners, Sense-Making often involves the experiential process that occurs once they hear about the hallucination and need to make sense of what is occurring, as well as the realization that individuals in the world might have different perceptions of the same thing. Listener sense-making is partially an experience of confusion and shock but can also involve dually managing this internal confused response with an external expression of care for the other person. I further explore this notion in the next section, Dual-Processing.

## **5.4 Facet Three: Dual-Processing**

### **5.4.1 Introduction to Dual-Processing**

The Dual-Processing Facet examines the duality of external expressions and internal thoughts and experiences that can occur for Listener participants when hearing about and responding to hallucinations. This duality can be considered a “front of house” and “back of house” structure, similar to what is considered in restaurants, retail spaces or theaters where what happens in the kitchen or office (back of house) is primarily unseen by customers who see only the guest areas (front of house). Within this duality, what is said and what is thought are not always the same. In addition, this Facet explores the degree to which experiences and processes of sense-making and care are simultaneous. The Dual-Processing Facet can help build empathy for Listeners by contouring and complexifying the lived-experience of the Listener’s perspective, acknowledging that Listeners must sometimes work through internal experiences of shock and confusion while still providing external support for the individual who is sharing the hallucination. Some Experiencers also described an awareness that their observed reaction of Listeners was not the full story, and it appears that some Listeners might not be able to entirely mask their internal reaction from an Experiencer during the sharing.

### **5.4.2 Listener Dual-Processing**

During her interview, Ally described the internal dialogue she engaged in while reassuring her grandmother in the hospital during a hallucination in which her grandmother believed that they were being held captive in a Nazi lab. Ally spoke about masking an inner process of questioning during the interaction. Note, there is a secondary duality in which Ally feels both close to, and quite removed from, her grandmother during the episode.

#### ***Dual-Processing Extract 1: Ally***

*Adam: Did you feel distanced from her throughout the hospital stay? Or did you feel quite close to her?*

*Ally: Part of it — you can — both.*

*Adam: Both?*

*Ally: Really close in that this was a particular experience that I was sharing with her. A very intimate experience that I was sharing with her. But at the same time... because of my personality, uhm, there was part of me that stood back and went, “Oh, this is*

*really interesting? How is she responding this way?” And almost making mental notes as well.*

*Adam: Can you say more about that?*

*Ally: The standing back?*

*Adam: The standing back and thinking, yeah. That is something everyone has mentioned.*

*Ally: It is just you become very clinical, right? But you are still there. You are still there, and you are still present with the person. But there is that other person that is stepping away from you and looking at it from over there. Almost like a second person looking at it is going, “Well this is very interesting. When she does this her heart rate goes up. When she does this her heart rate goes down. This is a very interesting delusion that she is having. Where is this coming from? How does this tie into the thing with my cousin and the comment that my Aunt made about our family having Jewish heritage?” ... Right?*

*Adam: How did you manage that dual... process? Like the questioning in the back, and the support and reassurance in the front, with her? Was that difficult to manage, or easy to manage, or just...*

*Ally: It just was.*

Later, Ally elaborates on the benefit of a dual-process.

*Ally: That dual-process also allowed me to control my emotions at that point. Because you can detach a little bit. It allows you to step outside of the situation and think, “Okay, what is best? How do I respond to this?” Instead of focusing on, “I am freaking out. This is disturbing to me.” What it does is it removes me from the conversation, right?”*

A couple of points are noteworthy in this extract. The first is that, despite Ally’s internal pulling away from her grandmother’s hallucinatory experience, she was able to maintain intimate contact with her grandmother, able to balance “becoming very clinical” with “still being present with the person.” In this dual stance, which I remark during the interview as “questioning in the back and support and reassurance in the front,” Ally is able to control her emotions and detach a bit instead of freaking out. Ally is reciprocating care for her grandmother while she is in the hospital. Ally is returning her grandmother’s kindness from when Ally was a child and her grandmother would look out for her. Ally’s decision in this moment to stay with her grandmother appears to be an easy one, but the experience was not marked with ease. Ally states that she engaged in the dual-processing, in part, because it took the focus off of “I am freaking out. This is disturbing me.” In some ways, it is Ally’s connection with her grandmother, in combination with this internal retreat into a curious stance of sense-making, that provides the resourcefulness called for by the moment. However, Ally is not *only* present with her grandmother. A detachment occurs, in addition to staying in the room and providing sincerity, support and warmth to her grandmother, she also becomes “like a second person” that is “stepping away” and “looking at it from over there.”

This detachment is possibly an internal exit similar to Zack's pull described in previous sections (Care Extract #22, Sense Extract #16) to physically remove himself from his grandmother's presence when she talks of her hallucinations while in the hospital. Ally's movement into sense-making, and her masking of the back-of-house reaction from the front-of-house response, is brought on, in part, by a sense of shock, what Katie describes below as a "taken abackedness" (Sense Extract #14). Many Listener participants mention something similar when they are initially told of the hallucination.

Listeners also spoke of being caught off-guard by the hallucinations, prompting this front of house/back of house duality. They describe a conflicting reaction of shock and confusion, along with a simultaneous pull toward curiosity about the hallucination. Katie tells how her husband has recently seen more complex hallucinations while driving, including a woman appearing in the street and a bear charging his car. I asked Katie what was happening for her when he shared these new hallucinations.

### ***Dual-Processing Extract 2: Katie***

*Katie: ... THOSE have definitely made me a little bit more like... 'Okay'...*

*Adam: Can you describe that, "Okay...?"*

*Katie: Like ... there is an initial moment of, "What the fuck? Are you okay?" Especially because of the more complex nature of these two hallucinations I'm kind of just like—it throws me off-guard. And I think it is the fact that it has also changed. Because the shadows and the bugs have been a constant theme, though they have decreased lately. But these were SO MUCH DIFFERENT. So that was a little (quietly) off-putting. I would say. Just it made me stop and think. I am just like, "Whoa, actual figures and like a narrative." So, I just feel uneasy I guess. When he first told me about the woman and the bear. The bear was really weird because you could tell he was distraught about it. So, I think also his distress over that also makes me feel a little distressed. And I think maybe it was the fact that he was driving both times that really freaked him out.*

Here, Katie's overall experience includes distress ("What the fuck?"), care for her husband ("are you okay?"), and sense-making ("It just made me stop and think"). She experiences being slightly taken aback and simultaneously curious, as she tries to make sense of the situation. Katie uses multiple terms to capture this taken abackedness - "what the fuck?," "it throws me off-guard," "was a little (quietly) off-putting," "it just made me stop and think," "whoa actual figures and like a narrative," "uneasy," and "a little distressed." Importantly, it appears that this internal reaction is not always masked, as Katie does communicate this curiosity when her husband initially tells her about the bugs and shadow figures he will often see out of the corner of his eye. Elsewhere in the interview, Katie states that her husband's bug hallucinations are less concerning for her because he is not distressed by them.



### ***Dual-Processing Extract 3: Katie***

*Katie: (laughing) I KNOW that it didn't freak me out. You know? I can just say that, I was just like, "Hmm, okay tell me more." So, it wouldn't have spooked me or scared me or anything like that. I would have been puzzled I guess. Probably would have been my reaction. But it has just been integrated into our lives.*

*Adam: Can you describe that being puzzled, possibly?*

*Katie: So it would be—if I am puzzled by something that—I would definitely... So I find it interesting obviously because of my curious nature. A little because it is out of the usual everyday so there is kind of like a... taken abackness? But not like, ... distressed. Just kind of like a pause. And then my brain starts working and being like, "Well what does that mean?" Basically.*

*Adam: Yeah. Yeah! And what are you saying while your brain is doing that?*

*Katie: Probably exactly like, "What do you mean?" or, "Tell me more, I am curious." Or, "What is that?"*

Katie's description here of "a pause. And then my brain starts working and being like, 'well what does that mean?'" is remarkably similar to what Ally describes as the "second person" that steps outside of her to ask questions about what is happening with her grandmother.

In the Care and Sense-Making Facet sections, shock was introduced as a potential component of the Listener's experience. In the Dual-Processing Facet, some Listeners can be seen managing this shock as a part of their front of house/back of house duality. Chris, for example, describes his internal dialogue when encountering a research participant during a research study. Near the end of a screening interview, the potential participant states he sees large, hospital-sized giants walking around Saskatoon. The participant reports that the giants arrived on earth because humanity is sinful and that the giants will not depart until humanity repents. Chris describes the caller as stating these things matter-of-factly, without any awareness that these statements could be considered extraordinary. Chris formulates questions that will not be offensive while, inside his mind, he is reeling.

### ***Dual-Process Extract 4: Chris***

*Chris: Because there is so much going on in my head; They are not eligible. Does this person need help? How did it get this bad? Where is this conversation going? I'm really interested in what he has to say next. How long will this conversation last? How am I going to end this? All while trying to listen to what he is saying at the same time. And being interested, and also forming an appropriate response... You don't want to offend them. You also don't want to go, "What the hell?!" You just have to go, "Okay, and what does this mean?" or "Can you tell me more about that," or, "Is there anything else that is going on as well?"*

Here, Chris speaks to the work that can be involved in such moments. Internally, his mind is asking all the questions in the first part of the extract while also trying to listen to what the participant is saying *and* forming an appropriate response. Though not explicit, Chris is also taking a stance of care and responsibility for this participant. This care is manifested in his decision not to say “what the hell!” but instead to continue listening, continue forming questions, continue worrying about whether the person is okay, and to simultaneously be asking questions framed without judgement. Chris was prepared for this encounter due to previously having worked clinically with individuals who experience hallucinations. That he speaks to the effort involved in managing this encounter, despite his previous training, illustrates how challenging encounters of this type might be for individuals without prior clinical experience.

Given Chris’s significant prior exposure to hallucinations, it was the extreme unlikelihood of the caller’s hallucinations that shocks Chris. Note the dual presence of care and sense-making in his experience as well:

*Chris: Because my mind goes logically like how could you possibly believe this or see these things? And then the other half—my good human side of the brain goes, “This person is not well.” Which then bleeds into other thoughts of “How do things get this bad?” Those are the biggest things—this is unbelievable, this person is unwell, how does it get that bad? That is kind of the three thoughts. But the first thing I’m doing is reacting. Serious shock...of...this is nuts. Which is uncompassionate of me, but I think visceral enough that it is, okay. This wasn’t a stock hallucination. This was well beyond that.*

Chris also describes the pull towards care for the caller, and the navigation that must occur as he manages his professional role as a research assessor, the shock of his human response to a hallucination that is so unbelievable, and his understanding that this person might need help. Chris ultimately stated, “*I felt bad because there was nothing I could offer him.*” When I ask him what he likely did immediately after the phone call, he says that he probably sat back in his office chair – yet another illustration that there is often a sense of needing to pull back from these experiences, either physically or mentally.

It appears that Listeners tend to respond to the shock and disturbance of hallucinations with multiple processes of action and internal experience. One possible outcome consists of leaving the situation. Another is to voice curiosity. One participant, Nolan, described fully surrendering into an experience of pure listening and focused sensitivity (Care Extract #19) Thus, dual-process is not an aspect for all participants, but seems to be an element of most Listener experiences when they maintain external interest in the hallucination while internally working out what is going on.

#### **5.4.3 Experiencers observing Dual-Processing**

Dual-process can involve a “hiddenness,” in that the Listener’s external words and actions might differ from his or her internal process. That part of the dual-processing occurs internally does not mean, however, that some Experiencers are not aware of this duality. Drea and Cleo both acknowledge that there might be more going on than what is stated with individuals to whom they reveal their hallucinations. In her interview, Drea mentions learning to

mask aspects of her identity as a mystic when she is beginning to date someone new. I ask her why that is.

***Dual-Processing Extract 5: Drea***

*Drea: I've made people feel a little confused and uncomfortable. But to my face they would never be like, "I don't think so. That is weird." They are just like... (high kind-of-fake voice) "Ohhh, okay well I am sorry that I don't really understand THAT." Not everyone has been very respectful about it, if I do want to talk about it or bring it up. So that kind of hurts a little bit because if anything I would want my significant other to be very receptive of the things that I do.*

Cleo can see aspects of this inner response in her husband as well.

***Dual-Processing Extract 6: Cleo***

*Adam: Did you tell anybody about your experience of God putting his hands on your back?*

*Cleo: Yes. I did. I've told—I actually just had a speech at the church the other day. I have been talking to a lot of church people about it. I've told my husband, but my husband is not really there yet. So, he kind of looks at me like I'm a little crazy (brief laugh) but he is my husband, so he listens.*

In Cleo and Drea's extracts, we see that, at least at times, Listeners are not successful in keeping their internal shock or confusion out of observation for the Experiencer, or that, at times, Listeners do not attempt to mask their disapproval or confusion. In the first extracts of this section, Katie says she would probably say "tell me more" to her husband. Similarly, Chris reports that he asked the potential research participant, "can you tell me more about that." Chris and Katie have different responses than what Drea reports receiving from some of the men she is on dates with who say, in a higher fake type of voice, "Ohhh, okay well I am sorry I don't really understand THAT." In Cleo's extract, her husband listens to her, but she can see in his face he might think she is a "little crazy."

Cleo is also able to speak from the Listener's standpoint concerning an experience of dual-process. In the extract below, she describes how she would respond to a friend in Florida who reported some of the same experiences Cleo is now having, such as seeing demons or people with lizard eyes. When Cleo's friend first told her about these experiences, Cleo did not believe her, but now she sees them differently since she has started to see similar things.

***Dual-Process Extract 7: Cleo***

*Cleo: I was talking to a friend of mine who is down in Florida and she has had so many visions and things like that and at first I'm thinking, "God this girl is crazy dude," but now I am like, "No she is not. Not at all!"*

*Adam: Like she used to tell you about similar things?*

*Cleo: She used to tell me about similar things and I was kind of like, “Really?” And then some things she would tell me, and I would just think, “That sounds crazy.” I wouldn’t say that to her. But I would listen to it.*

*Adam: What would you actually say to her?*

*Cleo: Uhm, I would just kind of like, “Okay,” and then I would listen to what she was saying and then later I would — and I was listening to it, but I was like, “Is she really? Is she seeing things? Is she...” I didn’t really know— exactly—what it was. And then I would go and tell my husband and he was like, “Okay, she sounds a little crazy.” And I was like, “Okay, it must be that.” Some of the stuff she sees I’m like “Whoa this is wild.” And I just try to listen. And part of me is thinking, that is really wild. Really wild. You know? But I’m just ... I just try and be open because I want her to feel like she can always talk to me.*

In this extract, Cleo speaks to a difference between what she thinks internally, “God, this is crazy,” “really?,” “that sounds crazy” and what she states, “Okay.” Here, Cleo takes the experiential stance of listening explored in the Care Facet. Even though part of her is thinking, “whoa this is wild. Really wild,” she tries to be open and listen. Cleo wants this friend always to feel like she can talk to her, so she does not challenge what her friend has seen, or intentionally let on that she is having doubts or has been thrown off-guard. After Cleo has experienced her own hallucinations following her baptism, she transitions from thinking “God this girl is crazy” to “no she is not, not at all.”

Finally, it is important to note that Experiencers can account for dual-process as well. Drea explains her own interior silence when she encounters people who are skeptical about her experiences.

### ***Dual-Processing Extract 8: Drea***

*Drea: So, something that would probably make me feel good—I never—I never really take offense. Because if somebody doesn’t understand, they just don’t understand.*

*Adam: Yeah*

*Drea: But if they say, “I don’t want to understand.” Then I am like, “You are limiting yourself but I respect that.” I won’t say, “You are limiting yourself,” to them. But I will be like, “I respect that that is where you are at.” But something that I would—if somebody was interested in understanding more but they didn’t really know what to say I would probably be receptive to them saying something like, “I can’t personally contribute anything to this conversation, but I am interested in listening and learning about your experience.”*

Here, we see that Drea also keeps silent an aspect of what she is thinking. Instead of saying, “you are limiting yourself, but I respect that,” she verbalizes “I respect that that is where you are at.” A primary difference between Experiencer and Listener dual-processing is that many Listeners report working through an unexpected confusion once the hallucination is shared, while Experiencers, as we saw in the Care Facet, tend to assume that the person they are sharing

with will be dismissive of what they are reporting. Drea's statement at the end of extract 8 above gives language to two ways Listeners can perhaps respond when they are unsure what to do - either by stating that they can not contribute to the conversation because they have not experienced hallucinations, or perhaps even that they are caught off-guard but still care about the person and want to hear more.

#### **5.4.5 Conclusion to Dual-Processing**

Through descriptions of Listener experiences responding to hallucinations during instances of social sharing, we are provided an understanding of the challenge brought to some Listeners during these exchanges. Most Listeners report a sense of shock or confusion when hearing about the experiences, and indicate that it is their established sense of care and closeness for the individual experiencing the hallucination that enables them to work through this confusion, maintain contact with the social moment, and provide care and support for the person they are speaking with while simultaneously trying to make sense of what is occurring and masking aspects of their internal process. However, Experiencer descriptions indicate that Listeners do not always successfully mask their inner experience and that Experiencers might have a sense of the difficulty that can be involved in hearing about and responding to hallucinated phenomena. Yet, it appears that, at least in some cases, the masking of the inner response is not always necessary, and that honesty regarding the reaction, such as with Drea's phrasing of *"I can't personally contribute anything to this conversation, but I am interested in listening and learning about your experience,"* perhaps illustrates a middle-path by which Listeners can be open about their inner experience and also verbalize and express support for the Experiencer during the moment of sharing. Even so, there will always be situations and relationships where a masking of the candid response, rather than a re-shaping of the candid response, will be more appropriate.

Awareness of this Facet should bring a heightened sensitivity to the listening half of social sharing. In particular, awareness of the potential struggle in hearing about these experiences might help Listeners make sense of their experiences in the moment of sharing - a pull to step away either externally or internally, the added stress of managing their internal confusion while trying to provide external care, and possibly some degree of forgiveness when the process of listening either does not go as planned, or is viewed with regret later in life.

### **5.5 Facet Four: Ontological Cross-Bleed**

#### **5.5.1 Introduction to Ontological Cross-Bleed**

Ontological Cross-Bleed Facet acknowledges the transition of a hallucination to something that exists beyond the momentary perceptual consciousness of an Experiencer. Through a process of living and telling, Experiencers can transfer awareness of their hallucinations to Listeners and the wider social community. This transition can occur through a direct channel and results in specific hallucinations existing as objects of consciousness for individuals for whom they were not direct sensations. In addition to explicit telling, some Experiencers describe ways in which their hallucinations bring about positive change. When Experiencers live their lives differently because of a hallucination, they indirectly share their

hallucination experience with those they encounter. This Facet challenges our perception of hallucinations as something that occur only for the individual perceiver, and adds to our overall awareness of the ways in which hallucinations can be communally shared and play important roles in our personal and social lives.

### **5.5.2 Direct Cross-Bleed: Hallucinations becoming present for Listeners**

I intentionally chose the term “ontological” for the Cross-Bleed Facet to draw attention to the way in which hallucinations gain a social or intersubjective existence outside of the singular perceptual subjectivity in which they first occur. Ontology is, “a branch of metaphysics concerned with the nature and relations of being, as well as a particular theory about the nature of being or the kinds of things that have existence” (Merriam-Webster.com). Ontology is a philosophical domain that deals largely with the properties of the world-as-world, of “what is.” With this in mind, the Ontological Cross-Bleed Facet acknowledges the ways in which hallucinations can move beyond the subjective consciousness of the original perceiver, “cross-bleeding” into other subjective domains and becoming part of the world for others.

To begin, some Experiencers intentionally share information about their hallucination with others. Through this verbal exchange, the hallucination becomes experientially available for the other person. This cross-availability happens in many contexts, many different relationships, and for many reasons. For Listeners, once a hallucination has been described, it becomes present for them as an object of consciousness. The Listener not only gains awareness of the hallucination as an aspect of the Experiencer’s interior world, but the hallucination can also become a part of the wider intersubjective relational world that both Experiencers and Listeners inhabit.

Katie’s account provides one of the clearest delineations of ontological cross-bleed among those I interviewed. Her husband’s bear hallucination becomes real to her as an object of consciousness in vivid and striking ways. Katie describes how her husband’s bear hallucination becomes something she can visually see in her imagination, and further, something she is aware of when driving past the intersection where he saw the bear charge the car.

#### ***Cross-Bleed Extract 1: Katie***

*Katie: In my head it is a brown bear. But it is not a brown bear. So, thinking about what happened I just kind of see this thing materialize. But it would be like a bear that is brown but if you really increase the sharpness on it so that it is not quite reality, right?*

*Adam: Yeah. Uh-huh.*

*Katie: So, an increase in contrast or sharpness. And then it ferociously comes up from the side. And I know exactly where it is. And I can see it—it is this intersection. There is this intersection right around where he saw it. And there are these ditches with sloughs and stuff and I can just see this swamp bear basically coming out of the slough and then running at the car all ferocious and then it just disappears. That is how I see it. I don’t know how he saw it. Just based on it charging the car and disappearing.*

*Adam: Yeah. But you have—like it is a part of you?*

*Katie: Yeah! It is a character in my head. And same with the ghost woman. She is a character in my head too. Uhm... yeah. And the bugs are characters in my head (laughing).*

*Adam: Well, do you become aware of like—like if there is a specific place that he sees something or that he startled at, do you pay attention more to that place?*

*Katie: Oh yeah! I definitely look. I am definitely cognizant. So... yeah they exist as like beings in our... world (laughs).*

Once a Listener is told of a hallucination, it is possible for that hallucination to not merely step into awareness and then vanish never to be thought of again. Hallucinations carry the potential to impact the world, the Experiencer, and Listeners who hear about them. Through this process, the hallucinations come to have an existence beyond the moment of perception. Through the exchange of social sharing, hallucinations can enter the lived-understanding of the world and gain the attentional focus of others. For Katie, the bear exists not only as a hallucination in her husband's mind, but it becomes something she can "see" in her mind's eye at that particular intersection.

Similar to Katie's descriptive awareness of her husband's hallucinations, Euk is able to recount her best friend's hallucinations at length, and with great sensitivity. What this seems to illustrate is that Listeners can develop a complex and nuanced understanding of how the hallucinations are experienced for the other person. In this way, the hallucinations become an "object of consciousness" for Listeners, despite the person never having undergone the hallucination directly. This awareness of the hallucination can occur both as an object of association with the Experiencer (an understanding of what might be happening in another's internal world), as Euk describes below, or as an object in the world, as Katie described above. This extract marks the very beginning of Euk's interview. Note the descriptive detail she provides about her friend's hallucinated experiences, and the focused sensitivity required to understand variations in these hallucinations depending on the tone of his day. Euk's stance of focused-sensitivity was previously examined in the Care section (Care Extract #18)

### ***Cross-Bleed Extract 2: Euk***

*Adam: Can you tell me about a time that someone spoke of an experience of a hallucination with you?*

*Euk: Yes. So, several times. My best-friend has schizoaffective disorder. So, schizophrenia and bipolar, so he does experience multiple sensation hallucinations. So, he experiences auditory hallucinations, physical hallucinations, visual hallucinations and taste as well. I think everything except for smell. So, auditory hallucinations are usually on kind-of-normal or good days and those are kind of like whispers, uhm in his head. And then on bad days when he is really stressed they increase to a woman screaming for help. For visual, again on good days they are kind of like shadows, just seeing something out of the corner of his eye, and they can progress to seeing like a shadowy figure kind of crossing his path and maybe darting behind something. He does sometimes see the creature that is stalking*

*him. Which ties into his paranoid delusion. That he has a creature stalking him. So, he says that sometimes he sees that creature. And for feeling he says sometimes his fingers feel wet, like they have been dipped in cold water and they stay wet. He can't touch white jelly beans. He is not sure if that can qualify as a hallucination but he says the feeling of it is unnatural. And sometimes in his dreams upon first waking he can taste what white paint tastes like. But he says it only happens upon waking.*

*Adam: Okay, how did you come to know about all of these?*

*Euk: Just from knowing him.*

The specificity and detail with which Euk is able to describe her friend's hallucination is remarkable. She is familiar with the creature that stalks him as well as that he cannot touch white jelly beans and sometimes wakes up with the taste of white paint in his mouth. She also is able to describe, in detail, the variations in his voice-hearing experience and how the voices change according to his mood or the valence of his day. She understands not only that he sees shadows, but that there is a progression of the shadows from shadows moving out of the corner of his eye to shadows becoming the creature that is stalking him. Euk not only understands that her friend hallucinates, or that he sees and hears things, but she provides detailed explanations of how his hallucinations present and the variations in these presentations. Euk goes on to describe how she has gained this knowledge over time, in part due to their close friendship and in part through their joint presentations for the Partnership Program. The specificity of her description shows that, though she might have never directly sensed these internal events, she has developed an appreciation of her friend's inner world as it relates to these experiences. In this way, the hallucinations, even as they remain in the perceptual realm for the Experiencer, become a sense she, as Listener, has about that other person.

This exchange of detail regarding hallucinations, as illustrated in Euk's extract, can play a role in healing rituals as well. As a mystic healer, Drea will sometimes share visions she experiences during Reiki sessions with clients. However, she is careful to ask them if they would like to hear what she saw, and she understands some will be more receptive than others. The following extract illustrates a more complicated version of ontological cross-bleed than the examples provided above because Drea's hallucinations can be seen as originating in the internal consciousness of her client. Note that she says it can be difficult to sense what is hers and what is her client's during some sessions.

### ***Cross-Bleed Extract 3: Drea***

*Drea: So, when I got involved with my Reiki practice and I started working on people I would pick up on different things. SO, a lot of—I get different—I guess hallucinations would come in then. And I did ask consent from one of my clients to share a story that I experienced with her and then some things that she said after that. I generally just have my hands on the head and I send energy that way. And when things really start to flow, and I start to get more into a meditative state, I see images or feel things and then I put them into images. And the first thing that I saw was a horse come up to me. And I could see the frost on the grass. And the horse blew its nose, its breath, into my hands. And it felt like it was*



*kind of accepting me and was happy that I was there. And then soon after that kind of just “who” (sound effect, soft wind blowing snow sound) and dissipated. And after that as I continued to work on her I saw the face of her grandmother, which I just assumed because I had never met her grandmother. And so, I saw the face of the grandmother in almost like a cloud. And it was almost like she was thanking me for taking care of her granddaughter. I also feel a lot of emotions coming in. And it is hard to recognize what is mine and what is theirs. If you think too much it gets all jumbled up and feels the same. But that is one of the experiences that I had during Reiki. Also, I hear voices sometimes when I am in kind of a meditative state.*

*Adam: Do you mention that to clients while it is happening, or do you keep that to yourself?*

*Drea: No, I stay completely quiet during the whole Reiki session. Because I don’t want to interrupt anything. I want to receive all that I receive. Sometimes I forget certain things that come up. Other times I will be excited to tell them after. If they are open to receiving it. It really depends on who the person is. Generally, if the person is open and attuned to that stuff already they are already aware that something happened during session.*

*Adam: Can you give an example of that?*

*Drea: Oh. So, at the end of our session with the woman who had the horse and the grandmother I said, “Do you want to hear about the things that I experienced and saw?” And I knew that she was open to it because we had talked about spirits before. Not everyone wants to know that you saw their dead grandmother while you were working on them.*

Drea goes on to talk about how she has a conversation with this client regarding the horse accepting her and the positive feelings that came from the grandmother. She describes the horse in vivid terms—it is a black stallion, young and full of energy. It exists as a full object for her in the encounter. She speaks of other clients as well for whom she has seen things, sometimes colours leaving a body during the release of emotional trauma, other times darker things, evil things.

Importantly, it is not only through telling that hallucinations can transfer over into awareness for Listeners. For example, Luke told how his mother first realized he might have heard voices when she witnessed him speaking to himself during a car ride. Likewise, as Ally sat in her father’s hospital room, she described sometimes looking over her shoulder if her father appeared to see somebody enter the room. Listeners reflexively direct their attentional focus to something that is seen and responded to by the Experiencer.

Through this process, hallucinations not only become objects of consciousness for Listeners, but can become a part of the shared social world that both Listeners and Experiencers inhabit. The social cross-bleed of hallucinations seems to be particularly the case when hallucinations are long-standing and there is a close relationship between Listener and Experiencer. An example will help illustrate. Olivia describes how her son had an imaginary friend when he was younger who was part of a larger imaginary family. Eventually, Olivia

became distressed by the constant presence of the family and asked her son to request that the family move away.

***Cross-Bleed Extract 4: Olivia***

*Olivia: My son had an imaginary friend. He had an entire family. And they followed us. If we went somewhere they were driving behind us and stuff like that. And it got to a point where I was just like, "Son, it is time for them to move. They need to move." Because he talked about them a lot ... Having my early childhood education background it didn't bother me or anything but they just hung around too much. At one point I said it was time for them to move. It was a whole family and they were just... it became a bit too much.*

*Adam: Can you say more about that? Because that is an instance where somebody else was having something that you could potentially qualify as a hallucination that they shared with YOU. So, can you maybe just talk about how you first...*

*Olivia: It is hard to remember. I tried to be very open, and supportive and listen and communicate and all of those different types of things. I'm sure with him it would have been—I don't think I would have set a place at the table or anything. But if he was talking about them I wouldn't have shut him down. Because I would have probably seen it as his way to express some other things that were going on for him. Possibly through these—through this family. It was a time when their dad and I were going through a rough.... So, he must have been over four. I don't even remember what he would tell me about or anything. It was just the one time that they were driving behind us that I was like, I just said to him (laughing), "I think it's time for them to move."*

*Adam: Did they move?*

*Olivia: Yea. I don't remember anything else after that. I think he sort of you know...*

*Adam: —took care of it?*

*Olivia: Yeah. (brief laugh) Or he just didn't talk about them anymore. I think he was comfortable enough talking about them. We lived in an apartment and you know, I probably said it was getting a bit crowded (both laugh briefly).*

*Adam: Does he—do you guys talk about that within the family anymore?*

*Olivia: We talk about it a little. We just sort of laugh. I have a good relationship with my kids. They know I take mushrooms. They—I think my kids think I'm a little bit odd but... that is alright.*

Note that her awareness for the family is keen enough that if Olivia had decided to set places for the family at the dinner table, she could have. Once the Listener has been told about a hallucination, awareness of it can stay with them for long time. Olivia is able to recall this family that followed them, even decades later. Chris often remembers the potential research participant's hallucinations of giants, who were the size of Saskatoon's largest medical building,

walking around the city. He states, “*It pops into my head a couple of times a year, obviously it is something I will never forget.*” And, “*it is like a flashbulb memory in some ways. It is so unique that it is going to stick with you for a while.*”

Many Experiencers reported being changed by their hallucinations, often in life-altering ways. Esther, whose experience occurred during her every-day life and without the use of substances, describes an encounter with her “inner child” that profoundly changed her. She was in her forties at the time, decades after she met Sarah and became acquainted with her friend’s ghost story. She shares the following:

***Cross-Bleed Extract 5: Esther***

*Esther: Okay. So, I will tell you this one. It was just a mundane day. I was in my kitchen and I bent down. I had one hand on the table and I bent down because there was a piece of paper that had fallen off the table. I bent down to pick it up. And as I was straightening up the hallucination, if you wish to call it that, I saw—and I shouldn’t say “if you wish to,” let’s just say it was a hallucination that I saw. It was my inner child.*

*Adam: Oh wow.*

*Esther: And it was not just a hallucination. It was an experience with my inner child. Never before had I had that kind of experience. And I have not repeated that particular experience since. The way that I viewed it is that it was like my inner child made themselves known to me at that point in time. And once that is done, you don’t need to do it a second time. It is a very powerful, very impactful experience. The physical appearance was a little larger than a toddler but like a smaller person with a head of just beautiful golden curls and not a yellowy golden but a really... muted just beautiful head of amazing curls (both laugh). Blond, just like the archetype.*

*Adam: Was that the kind of hair you had when you were younger?*

*Esther: Not nearly as curly as this. I did have curly hair but not like this. When I talk of the experience it is more of a—there is an instantaneous knowing that that is what it is. Recognition. I KNOW. Like what I did is I started laughing. And I said (joking higher pitched voice), “Why you little devil you! It’s been you that’s been doing that all this time. You that’s been pushing me there.” And again, it is just so real that you know it. And the amount of love that I felt for that being was beyond anything. And it did have the effect of changing my life. Or let me put it this way—it was a very significant contribution to my life. The living of my life. I lived my life differently because of that experience. Because thereafter what I knew is that an inner child is a real thing. So, all you can say is that it manifests in some way. And there is no way to explain how that happens. But the fact is that it is real. And it was as real—the inner child was more real than that table was in the room. So, it is very powerful gift to be walking forward in your life knowing that there is a part of you that is just fighting like hell to make things good for you and maybe simultaneously protecting that inner child as well.*

Esther related that she shares her encounter with her inner child with others when they are in need of support and she perceives that they would be receptive to the lesson the story holds. In this way, the change in her world is directly shared with others, perhaps having an impact on them as well.

### ***Cross-Bleed Extract 6: Esther***

*Esther: You are selective in who it is you tell that to and like I said I use it as a tool to help someone who I perceive is suffering. You want to give them something to help. And I don't like drugs (both laugh). This was a better option. Absolutely there are times when I feel I am going out on a limb with my credibility. And my credibility is important to me. I'm a practical person. I am highly rational. For some people who know me I think that these things would be inconsistent in the same way as my experience with Sarah [who had the ghost in her home] was. The people that I tend to tell it to would be friends who are needing some support and they need to find that support and know that it is there, and it is inside them.*

What Esther describes above is two types of sharing. The first is an intentional sharing, in which she shares this story of her inner child with someone whom she believes is suffering. The second is a more general sharing in which she “lives her life differently” due to the encounter. The first type of cross-bleeding, in which Esther shares some specifics of the encounter with her own inner-child, has the potential to achieve two things in the Listener hearing about her encounter. First, it allows the possibility of Esther's own inner child to become an object of consciousness for that individual. Second, and perhaps more importantly, her description of her encounter with her inner-child creates a possibility that the Listener might be able to envision their own inner-child. In this way, by telling others about her encounter, Esther's description has the possibility of connecting the individuals she tells with their own inner-child – a connection which, for Esther, was of immense meaning.

These two types of cross-bleeding (direct and inadvertent) demonstrate the two types of cross-bleeding that participants described - a direct cross-bleed in which the hallucination itself becomes an object of consciousness for the individual hearing about it, and an indirect cross-bleed where the hallucination experience *changes* the Experiencer in some ways, leading them to live their life differently in a way that is recognized by others. In this inadvertent cross-bleed subtype, the hallucination itself does not become an object of consciousness for the experiencer, but rather the hallucination is known indirectly through observations of the change in the Experiencer. The following section explores this second type of inadvertent, or indirect, cross-bleeding.

### **5.5.3 Indirect Cross-Bleed: Life-changing**

Many participated provided remarkable accounts of the ways in which hallucination experiences altered their lives, profoundly shifting their view of self, God, or others. Some participants even spoke to the ways in which their hallucinations prevented suicide, saving their lives. Largely, these hallucination experiences created a more understanding stance for my participants, and might have changed them in ways that indirectly have an impact on how they

interact with others and their world. Simon speaks about how his mushroom experience, and the hallucinations specifically, increased his sensitivity to the fact that others might experience the world differently.

***Cross-Bleed Extract 7: Simon***

*Simon: I found that before I tried mushrooms my mind was closed off. I don't know, I feel like I was very narrow – very narrow-minded. I didn't really, I guess appreciate the finer things in life. As a result of having taken the mushrooms I found that I appreciate the smaller things more in life. I guess. Just going out for a walk and seeing (thoughtful pause) nature do its thing. It is beautiful to me now. As opposed to I never realized that before. It just kind of allowed me to view the world with an open mind. Without any judgments. I guess without my ego interfering in my life. And some of that stayed with me as I came down from the mushrooms... It changes your perception of things. It just changes the experience. Just doing mundane things, it gives it new life.*

Joseph describes his hallucination experience as changing him in similar ways. Part of this change comes from a hallucination experience in which he was hiding in bushes, concealed from a man he believed wanted to harm him. In the same experience, he also describes how his hallucination of seeing two people having sex on the lake came to take on meaning for him regarding a woman in his life.

***Cross-Bleed Extract 8: Joseph***

*Joseph: And something about that trip... something about talking about that trip made me feel like I could get on with my day. Like I could focus more. I was more alert. I could be more gentle. It taught myself I could be more gentle. Because the fact that someone was going to murder me because I was sleeping there and the guy that was going to harm me... He taught me — thinking of violence, all that people can do to each other. He taught me that you should be gentle, to have a gentle soul.*

*Adam: What's the meaning to you now for it?*

*Joseph: Well (pause) I don't know... just to stay calm. Don't over—don't blow things out of proportion. Uhm (pause) you know just stay cool. You don't have to worry about everything. Everything is taken care of. Everybody has a destiny, right? And uh, sleeping with a girl isn't—like sleeping with a girl shouldn't be your ULTIMATE destiny. There is far more greater things out there.*

*Adam: And all that came from the hallucination that you saw?*

*Joseph: Yeah.*

In the above examples, participants reveal the ways their hallucinations changed them. Simon indicates a more relaxed attitude and an ability to see the world differently, and Joseph reports living life with a gentler soul. Many of these individuals say they have become more relaxed about the world. As these participants live their life differently, they inadvertently and

indirectly share this hallucination experience with those they encounter. Perhaps the best example of inadvertent sharing within the data is Gunnar's decision to start wearing brighter colours after a mushroom-induced hallucination experience. He is looking at the stars with his future husband at the time.

***Cross-Bleed Extract 9: Gunnar***

*Gunnar: Post that event it did lead to some really incredible experiences. Even without the use of hallucinogens. But that night was pretty life changing. It — before that night, for my whole life I was like a goth kid. I was like spooky. I'm wearing all black now, but I usually don't. But yeah, spooky, into horror movies, always wearing black, black hair. After that night I was done with my entire goth life. I bought bright colours and pastels and—*

*Adam: And that traces back to that night?*

*Gunnar: Oh, yes. I went from being a goth kid to being like, uhm, a Care Bear Cheerleader. It impacted my life in that way as well. And I think that it also affected my work relationships in an interesting way in that I started to dress differently at work and people noticed and they asked. Well, they didn't really ask but they would say—they would complement—they would be like, "Oh, that is really nice. You are wearing colour. You should do that more often." And I kept getting that positive feedback so, —and I liked it (laughing) of course. And you know I did things like I stopped being so concerned with my outlandish presentation of myself at work. Where I was perfectly fine coming to work wearing a bright floral print shirt. Or bringing little fake flowers to put on my desk. I don't think anybody WILL ask me about these things but if they do I'm not afraid to say, "I just like flowers." I don't have to go through the whole spiel of, "Hey, I did mushrooms one night in the summer and it changed my life."*

*Adam: That is interesting because you are kind of sharing the experience but they don't know about the experience. But you are still sharing that new vision of you... or whatever. They just don't know where it is coming from.*

*Gunnar: Yeah, and that is important to me to have the expression and to... I don't know, just kind of HINT at it with other people. It is a way of SHARING this experience publicly without getting too muddled in the details. Just being all like, "Hey, I feel like a beautiful person and I am going to express that. You don't really need to know why."*

The hallucination-related change Gunnar describes in this extract is remarkable. Gunnar transitions from being a "goth kid" who is a "little spooky" and into horror movies and the colour black to someone for whom it is important to share the beauty of the world with others, someone who wears bright colours, and is a "Care Bear Cheerleader." Yet, he states that he desires to share this experience of transformation with others through his lived-expressions rather than through a direct telling of what he saw while he was hallucinating. In this way, he is able to share his profound shift in view without revealing his mushroom use or getting into the "muddled details" of his hallucination experience. However, through their observation of Gunnar's transformation, his co-workers are indirectly aware of Gunnar's hallucination

experience. As explored in the next section, this indirect awareness is true as well for other participants whose voices encouraged them to live when they were considering suicide.

### **5.5.4 Indirect Cross-Bleed: Voices Stopping Suicide**

Two of my Experiencer participants, Allistaire and Drea, provide an account of their voices saving their lives by stopping suicide attempts. In both cases, merely through *living*, these participants are inadvertently sharing their hallucination experience with others.

Gunnar's husband Allistaire, a pantheist, describes an occurrence where he was feeling suicidal and a voice told him to live. We spend some time in the interview exploring how his life, his every breath, in some ways is a sharing of that moment with others. He talks about how he took the four elements outside to do a ritual in the moonlight. During the ritual, he hears the voice of Freya, a goddess.

#### ***Cross-Bleed Extract 10: Allistaire***

*Allistaire: And that was the only time I've ever felt I communicated with the gods... and that is weird (uneasiness enters his voice) because uh... it was... uh, so I asked, "Okay what is the one thing that I've got to do? Like what is the one thing you need from me? Because have you heard of this Christ guy? He's got ALL these rules. He's got all this shit he wants his followers to do. What do you want me to do?" And then she turned—and then the one—and I HEARD it. That is why it is a hallucination. And I heard, "live." (pause) And, that is why I started living my life as a work of art. That was the one thing I'm supposed to do is LIVE. BEING ALIVE IS ENOUGH. And it didn't feel like my voice. I didn't say it to myself. And I'm one that has struggled with suicidal thoughts before. Basically, if you become an older goth you've gotten over your suicidal tendencies because those that don't—well, there is a filter (tongue in cheek). That is horrifying joke but... that was my filter moment. When I heard "live" and from that moment forward I've never been tempted to kill myself. Not once. Never been tempted to self-harm at all because that is all you are supposed to do is live. Being alive is enough. Existing is enough. And that profoundly changed me. But I HEARD it. Sorry I've never told you that. (indicating Gunnar)*

*Gunnar: No. That's cool.*

*Allistaire: I've never told anyone that. (Brief laugh, says "sorry," sniffles crying)*

*Adam: How is it to share that right now?*

*Allistaire: (voice slightly shaky) Uhm... intimate... but that is okay because you are a scientist, so you are basically a priest... yeah it's the same basic function.*

While the clinical literature tends to focus on the role of command hallucinations in instructing suicide, Allistaire had a quite different experience with his "voice" or "God." The way he sees it, that voice might have saved his life. Drea also provides an account of voices

encouraging her to live. She indicates her experience with the voices was a pivotal moment in her life.

### ***Cross-Bleed Extract 11: Drea***

*Drea: At that point I drank a LOT... uhm, seventeen and eighteen. And I got in my first real relationship where I was really in love, but I didn't feel worthy because I was self-destructing. And I was suicidal at the time. But anytime I went to go and act on it something would get in the way (snaps fingers, briefest of laughs). Or messages would come in and they would tell me not to. One time I was sitting in my car and I was very, very serious about it. And so, I was thinking about how I could go about it with hurting as few other people as possible. And one of the voices said, "Well that is awfully fucking selfish." And it was kind of demeaning me a bit. And I was like, "Okay." And then another voice said, "Well, if this is rock bottom then now what?"*

*Adam: Mm.*

*Drea: And that was a very nurturing voice. It was almost like, "Shut up lady, let me tell her." (both laughing a bit) And that was a really nurturing voice. And I was like, "I don't know. I don't know what now. But I guess it doesn't GET any worse than feeling like this." So, I kind of almost like mentally killed myself and then thought, "What now?" And I thought, you know, starting right now you can do whatever you want, and you can be whoever you want. That is when I started getting better.*

*Adam: At that moment? Like those two voices? That interaction in your car?*

*Drea: Mmhmm.*

In this extract, Drea links her decision to no longer consider suicide to the voices she hears while she sits in her car. After this point, she indicates that she turns her life around, begins to see herself as more worthy and takes a less self-destructive stance towards herself. In a way, she is born anew after this experience, as she asks herself "what now?" and proceeds to the rest of her life. For Drea, the voices saved her life and improved her life. She states that after this interaction in her car, she started to get better. In Drea's interactions with others after this moment, she is indirectly sharing this moment by presenting the new version of herself she gained during this exchange in her car.

### **5.5.4 Conclusion to Ontological Cross-Bleed**

The Ontological Cross-Bleeding Facet illustrates the transmission of the hallucination as an object of consciousness from Experiencer to Listeners during the social sharing. Experientially, this transmission is marked as a coming into awareness for the Listener of the specific descriptions of the hallucination, as well as an understanding regarding the ways in which this hallucination presents perceptually for the Experiencer. Through this process, hallucinations are able to take on a social life of their own, as they are no longer limited solely to the perceiving consciousness of the original Experiencer.



A second type of ontological cross-bleeding involves the significant changes that some Experiencers report in their sense of self, others, or world after encountering hallucinations. These significant changes were not confined to hallucinations only occurring in certain contexts, and were reported by individuals with drug-assisted, religious, non-need for treatment, and psychosis-related hallucinatory experiences. In this indirect cross-bleeding subtype, changes brought on by the hallucination in the individual are witnessed and experienced by others. In this way, though the Experiencer might never directly share their hallucinatory experiences, they indirectly share this experience when they share their changed self.

## **Chapter Six: Discussion**

*In talking with one another the person who is silent can, 'let something be understood,' that is, he can develop an understanding more authentically than the person who never runs out of words. Speaking a lot about something does not in the least guarantee that understanding is furthered. On the contrary, talking at great length about something covers things over and gives a false impression of clarity to what is understood, that is, the unintelligibility of the trivial.*

Heidegger, 2004, p. 165

### **6.1 Introduction to Discussion**

In this dissertation, I addressed the primary research question of, “what is the lived-experience of the social sharing of hallucinations from Experiencer and Listener standpoints?” In addition to this research question, I kept three primary goals for the program of research and the document in mind: (a) ensuring that the results of the analysis are directly accessible and applicable to the lay reader during the translational stage of the research; (b) building bridges of understanding between the Listener and Experiencer experience sets; and (c) examining hallucinations occurring in a wide variety of contexts so that results can speak beyond contextual factors.

To accomplish these aims, and answer my research question, I conducted interviews with a broad array of participants able to speak directly to the lived-experience of social sharing from Listener or Experiencer perspectives, with many participants being able to speak directly to both viewpoints. Through a hermeneutic process of analysis and writing, I focused the document on Facets that draw attention to central and widely applicable aspects of the lived-experience of the social sharing of hallucinations, through various permutations of context and relationship. In this final chapter, I review the Facets, address the clinical and research implications of the research, and propose recommendations to Listener and Experiencer readers who might benefit from this work.

### **6.2 Integration of the Four Facets**

As I have illustrated, variations of care and sense-making appear to be central experiences of the social sharing of hallucinations, for both Listener and Experiencer participants. In contrast to research indicating that individuals experiencing psychosis feel dismissed by family members and clinicians regarding their hallucinated experience (McCarthy-Jones, Marriott, Knowles, Rowse, & Thompson, 2013), for many Experiencer participants in my study the sharing experience was marked by *not* feeling dismissed and by a feeling of reassurance during the communication.

Counter to my expectations, no Experiencer participants mentioned deliberating beforehand regarding who they would speak to regarding the hallucination. Rather, most

Experiencer participants spoke of an innate understanding regarding who they could trust with their hallucination experience, with this trust being partially founded in either previous interactions of care or an understanding that the individual with whom they were sharing had had similar experiences (such as drug-use or mental illness). Experiencer participants described an added difficulty of knowing, to some degree, that Listeners could be distressed when hearing about the hallucinations or feel burdened by the need to “take care” of the Experiencer. Thus, Experiencers tended to share with individuals whom they knew could walk the middle-line of being able to handle the revelation of the hallucinatory experience, without becoming overburdened.

While the nuances of these experiences seem complex, the decision of whom and whom not to tell was typically reported as quite simple. Experiencers spoke of “trusting” the individuals they shared their hallucinations with, and many Listeners, to various degrees, spoke of being “honoured” by the fact that the individual felt comfortable sharing their hallucination with them. In this regard, my analysis shows that experiences of social sharing hallucinations are not only experiences of solitude and separation, but also experiences of connection and kinship.

Unexpectedly, many Listener participants also described how hallucinations became an accepted and non-bothersome part of their relationship and understanding of the person who originally experienced the hallucination, particularly for chronic hallucinations that were shared within the context of long-lasting relationships. Though Experiencer participants mentioned struggling to articulate in words aspects of their hallucinated experience, Listener participants generally developed an understanding of the hallucinations. This insight challenges our conception of hallucinations as something that exists *only for* the individual who perceives the hallucination and opens our awareness that the hallucinations enter social awareness and come to exist as objects of consciousness for those who are told about them. I used the term ‘ontological cross-bleed’ to indicate this quality. I utilize the term ontological to indicate that the hallucinations *comes into being* for the individual with whom the hallucination is shared. Whereas prior to the sharing, the hallucination exists within being only for the individual who directly perceived it, the sharing brings the hallucination into intersubjective “being”. Importantly, cross-bleeding can be framed as “infection” due to the disturbing nature of many hallucinations and the degree to which this disturbance can become present for a Listener once shared. When cross-bleeding is framed in this way, we can fully appreciate the challenge for Experiencers in deciding with whom to share disturbing hallucinations, and that decisions *not to share* such experiences can indicate a great deal of care for individuals who never hear about the hallucination. We begin to understand that, at times, the reluctance of individuals to share hallucinated experiences becomes less about worry of fear and stigma (though some participants did address these concerns) and more about concern for the Listener and an understanding that for various reasons what is shared could cause distress for the individual hearing about it.

Despite an initial reaction of confusion, many Listener participants experienced a state of listening to the Experiencer as well as a broadening of sensitivity and awareness beyond the content of the sharer’s words. Broadened aspects that Listeners were attentive to during the sharing often included the emotional state of the sharer, as well as the sharer’s over-all well-being, and other aspects of behavior or signs of distress. For Listener participants, this experience of listening and broadened sensitivity often occurred simultaneously with an

experience of shock or confusion. Thus, an important aspect of the Listener experience during the social sharing involved the dual-navigation of internal thoughts and external reactions as they responded to the hallucination.

While some Listeners maintained the shock and confusion internally while staying in contact with the Experiencer through an external expression of listening and sensitivity, other Listeners acted to remove themselves from the person reporting the hallucination. Zack's need to leave the nursing home room of his grandmother is the best example of this. In all, it appeared that the experiential state of Listeners required greater effort during interactions as they faced the challenge of simultaneously providing care, while making sense of the hallucination, *and also* managing differences between their external expressions and internal state.

In the end, what marks the communication of hallucinations is their maintained social absence. The Experiencer cannot point to the object directly in its material manifestation. The Experiencers can try to recreate the hallucination with descriptive detail, a gesture, or through reference to a shared image such as from a movie or television show, but the Experiencer cannot share the hallucination directly. In response, the Listener can say, "I think I understand what you are talking about," or, "I have seen that film"; but the Listener cannot say "I also see your hallucination." It is the absence of the possibility of this "I see it too" that creates the phenomenon of hallucinations. In the absence of a shared social material object, the Experiencer can, at best, rely upon description. In this regard, phenomenally speaking, hallucinations are objects defined as much by their elemental social absence as by their perceived actuality. Yet, my data have shown that, once shared, hallucinations take on a social component, as the hallucination becomes a potential object of consciousness for the Listener and enters the realm of discussable social reality.

Complicating the communication, many of my Experiencer participants understood their hallucinations not only perceptually, but emotionally and as a *certainty* rather than as pure sense perception. The result is that the Experiencer is left alone in their perception. And the Listener can, at best, work through the multitude of inner experiences to listen to the description of the hallucination and to broaden their sensitive awareness of the Experiencer. When appropriate (and sometimes when not appropriate), the Listener and Experiencer can join in laughter, and share in the acknowledgement that something is "goofy" or "off" regarding the hallucinatory experience.

What strikes me most about the experience of social sharing hallucinations is the various ways in which care stays invisible as Listener and Experiencer communicate to one another. A primarily example of this invisibility is the care of an Experiencer expressed by staying silent so that the Listener is saved from the "infection" or cross-bleed of a demon. Another example is the added layer of care present in Listener experiences of dual-processing when the decision is made (consciously or otherwise) to not only express listening and concern for the Experiencer as they share their hallucinated experience, but also to hide aspects of the reaction that are less socially desirable, such as saying "what the fuck?" Checking is itself a hidden care, as it illustrates the degree to which we world-build and participate in one another's lives. Through this lens of care, hallucinations are not made possible merely through the existence of our individual perceptual systems, but through the co-occurrence of our individual perceptual systems *and* our maintained social contact and connection with others. This sustained connection with others generates a general shared perceptual sense between us as human beings. This sense is so pervasive that it

becomes presumed, so obvious that we are caught off-guard when our assumption of the concrete mutuality of perception is violated.

### **6.3 Implications for Clinical Practice**

A central goal of this program of research was to generate data from a wide variety of hallucination experiences, including participants who have never sought treatment for their hallucinations and do not consider their hallucinations problematic. Due to this concerted effort on my part to maintain a research study that grouped hallucinations occurring in the context of mental illness with hallucinations occurring in other contexts, the recommendations below must be understood to come from a non-illness focused program of research. Further, some of these recommendations, such as the possible usefulness of separate explorations of the lived-experience of social sharing of hallucinations occurring in the context of serious mental illness are antithetical to my central goal of ensuring that such experiences are included with the other experiences I have examined with this research. Yet, throughout my interviews, I came to realize that chronic and severe persistent illness does create a significant uniqueness as its own lived-experience and that there are unique challenges to the friends and family members of individuals with chronically psychotic experiences.

My visitation of a local family group for individuals with first episode psychosis drove home important differences between serious mental illness and other contexts of hallucination experience. For example, individuals experiencing hallucinations within the context of a psychotic disorder may also be experiencing disorganization of thought and speech, social anhedonia, negative symptoms, and delusions. This mix of experiences creates a situation in which hallucinations may be one of the least problematic occurrences, and after meeting with the family group I was humbled with the realization that the results of my study would be ineffective in addressing the full range of experiences surrounding hallucinations occurring in the context of serious and persistent mental illness.

Though these differences must be acknowledged and will inform the structure and focus of our clinical research, I still wholeheartedly believe we must work to find points of connection and similarity between chronic psychosis and all other presentations, these connections can serve to reduce isolation and maintain the full humanity of individuals experience symptoms of psychosis. In the following section, I present a number of implications from the present research.

(1) *The findings of this research support the possibility that hallucinations need not be viewed as problematic, particularly in cases where the hallucinations are not disturbing and do not seriously impede functioning.* Indeed, two participants, (Allistaire and Drea) without prompting, vocalized that their audio hallucinations saved them from completing suicide. It is a critical mistake of psychology and psychiatry as helping professions to continue under-examining the diversity of presentations, impacts, and meanings that hallucinations can hold for individuals for whom they occur. Consistent with recent trends in hallucination research (Baumeister et al., 2017) indicating hallucinations are more common in the general public than previously thought and that many “non-need for care” individuals experience hallucinations without related problems, data generated in the process of my research supports that many members of the general public are able to sensitively integrate hallucinations into their lives,

including their shared social lives with close others. Further, Listener participants experienced *marked* worry, in addition to their confusion and shock, only when the Experiencer participants reported distress from the hallucination, or when distress or impairment was clearly present. This insight provides additional evidence to the clinical literature that, though it is important to stay aware of the potential for hallucinations to cause distress, hallucinations in and of themselves do not need to be viewed as problematic, particularly if they cause minimal interference in functioning and are not viewed as bothersome by the hallucinating individual (Intervoice, 2018).

We should also acknowledge that those who experience hallucinations might avoid sharing their hallucinations with others for a variety of reasons. While for some individuals these reasons will include worry that they will be stigmatized, judged, dismissed or misunderstood due to their experience, for other individuals a desire not to share the experience with certain others stems directly from a sense of *care* for this other individual and an understanding that the hallucination might cause distress for the person with whom they share. My research supports this understanding, as many Listener participants struggled initially to integrate the hallucinatory experience. However, despite this risk, the sharing of the hallucination often brought individuals closer together. More research in this area is necessary.

(2) My research indicates some degree of negative inner experience for Listeners when hearing about hallucinations. The descriptions provided by my Listener participants bring awareness to the potential reactions of shock and confusion that can occur for individuals who hear about hallucinations. These participants demonstrated a difficulty that *can* occur in responding to these experiences. Many individuals in this study spoke of a need to pull away from the hallucination experience, if not directly by removing themselves from the situation, then indirectly by engaging in a dual-processing that involved maintaining connection and care for the person sharing the hallucination while also retreating into themselves as they figure out what is going on and regain their footing. As we continue directing our clinical services to individuals struggling with serious mental illness and other diagnoses for whom experiences of hallucinations are common, *we must also continue to build pathways of sensitive understanding for those individuals with whom our clients share their hallucinated experiences.*

Simultaneous to research enhancing our understanding of the experience of *hearing* about hallucinated experiences, we should continue to integrate into our clinical models of treatment approaches that directly involve family members and other important social others in the system of care. Approaches such as the Network Therapy explored in chapter two of this document, provide valuable models for both the implementation and the utility of integrating family understandings into clinical care. Though these approaches are gaining ground, in part because of their promising effectiveness (Bergstrom et al., 2017; Bergstrom et al., 2018; Klapinski, 2015) and in part because of their consistency with inclusive values and human rights approaches (von Peter et al., 2019; Schutze, 2015) integrating the understanding of family and friends are not new. Silvano Arieti (1979) wrote decades before the current analysis about the added pressure on family members to juggle open-listening and broad-attentiveness to individuals with psychosis:

If the family member does not understand what the patient says, he must at least respond to his request for attention and to his desire to start a dialogue. To the extent that he is capable, the relative must influence and guide the patient, not by suppressing his activities but by increasing his knowledge and clarifying difficult situations. As we have

already mentioned, the cooperative family member gradually increased his awareness of the patient's sensitivity; he becomes more alert to what may affect the patient unfavorably. His "antennae" must be ready to capture what is disturbing; he must be on the alert, but not too solicitous or too eager, he must remain near enough to give when the need is there, but distant enough not to scare the patient when he is not yet capable of accepting warmth. (p. 147)

What I found is that many family members and friends naturally complete versions of Arieti's recommendations, but without having received the training to do so. Co-existent with this delicate balance, Listeners work through an inner process of disturbance. More research focused specifically on the Listener experience is necessary so that we can continue to support these individuals as they, in turn, support those for whom they care. Though this recommendation is primarily targeted at contexts of mental illness, hallucinations occurring in other contexts are also strikingly relevant. For example, many Listener and Experiencer participants spoke of the need to both give space and maintain contact for individuals who were hallucinating during drug intoxication. It is also important to note that, prior to the development of community mental hospitals, family members were primarily responsible for care and oversight of individuals experiencing serious mental illness (Gamwell, 1995). However, research, on the whole, has been under-attentive to the lived-experience of family members and friends with respect to needs and forms of care (Coffey & Hewitt, 2008). While it is important to place our research and clinical resources with the most vulnerable - in this case, most likely individuals experiencing hallucinations directly - it is also important to examine the impact of social and structural elements on this suffering and vulnerability. It is my belief that such an effort cannot be achieved without a more intentional drawing out of the experience of close others.

(3) It is important to note that, for those participants who experienced distressing hallucinations and who came into contact with clinical professionals, the reassurance provided by medical understandings was largely seen as positive. However, even participants reporting positive relationships with their providers acknowledged troubling aspects of these encounters. For example, many participants underreported their hallucinations to their psychiatrists. This stance stretched into Experiencers' social relationships with family members and case workers so that "trust" with close others in some ways became synonymous with the degree to which these individuals would "rat" them out to psychiatry, leading to unwanted medication changes. This issue is complex, as family members and case workers arguably have a responsibility to keep psychiatrists apprised of what has been happening.

In using some of our research measures to query hallucinations in serious mental illness (e.g., the PANSS), it is at times a recommended practice to ask clinical workers and family members involved with the client about their symptoms, and at times, to allow this information to override what clients are reporting (Opler, Yavorsky, & Daniel, 2017). Open Dialogue approaches provide a possible work-around for differences in client and family symptom reporting, in that service-users, family members, and relevant professionals discuss *together* what the hallucinations mean and how they should be understood. This practice draws the service-user into the circle of care, rather than leaving them outside, and creates a platform for holding their understanding of their experience simultaneous with, rather than opposed to,

medical understandings. *As possible, service-systems related to serious mental illness in North America should consider instating these programs and approaches, or research should be undertaken to explore the effectiveness of these approaches within the North American context, as well as expected challenges to implementation.*

### **6.3.1. Conclusion to clinical recommendations**

Though the majority of published research focuses on conversations of hallucinations occurring in clinical contexts (see Goicoechea, 2006 for an example), many of the participants in the present study primarily shared their experiences within the context of close personal relationships rather than with professionals. Though I did not focus on interview segments related to professional sharing, some of my participants who did share with professionals reported either negative experiences of their care, or felt the need to highlight that they were lucky in receiving high-quality care and being understood by their therapists. This finding illustrates there is still much work to be done within the clinical community in ensuring that these experiences are welcomed and approached in a way that acknowledges and works *with*, rather than against, the potential meaning of hallucinated experiences for those who have them.

## **6.4 Implications for research**

Below, I make recommendations for researching hallucination experiences, as well as propose avenues for continuing research on the social sharing of hallucinations. Most widely, I think it is important that we consider the degree to which as a profession, clinical psychologists approaching hallucinations from a medical perspective can be both dismissive and reassuring at the same time. It is interesting to me that some of my participants described being reassured by their clinical interactions precisely because they were being told what they were experiencing wasn't real. However, other participants experienced being told that what they were experiencing wasn't real as a dismissal. More research is necessary to explore how as clinical professionals working within the medical model, the same conversations could be taken as either dismissive or reassuring for different clients, or perhaps even the same clients at different times.

Prior to exploring further implications of this research, I must point to two important aspects of my own data generation that influenced the content of my interviews and the resulting analysis. First, there was likely a self-selection bias for individuals who had more positive experiences with hallucinations to participate in my study. This could partially explain the large presence of individuals who reported positive hallucination experiences, as well as positive experiences of sharing their hallucinations among my participant group. Second, phenomenological interview data is constructed from memory and in response to specific interview prompts. As such, much of what my participants report must be seen as situated within the interview, and beholden to the reconstructive tendencies of memory. Research methods involving observation or the ethical recording of naturally occurring conversations involving hallucinations would expand the current work to include data less prone to recreation. Below, I further explore implications of the present study for research on hallucinations and serious mental illness.

*(1) There is continued confusion in clinical psychology regarding how to define hallucinations, and the question of what is to be done with corollary experiences such as ghosts*



*and religious encounters.* I experienced significant difficulty in deciding what experiences to “allow” as hallucinatory into my data set. I ultimately decided to leave it up to my participants to define hallucinations, in part, because I wanted to collect a diversity of experiences. As a clinical discipline, we lack consensus regarding exactly how to think about encounters that could be classified as “supernatural,” “religious,” or “hallucinatory.” Most researchers seem to take an agnostic or impartial approach to this problem, with McCarthy Jones, a leading hallucination researcher, writing that he would be remiss to not address “the question as to whether it really is possible to hear voices from supernatural entities” (2012, p. 337). McCarthy-Jones came to the same conclusion as Moskowitz and Corstens (2007) that, for a given voice, we are unable to prove if it is divine or neuropsychological in origin. Moskowitz and Corstens wrote, “even if it is allowed that there might be genuine spiritual experiences, adequate means to distinguish such experiences from those better explained by neuropsychological mechanisms remain to be established and the two cannot be adequately distinguished at present” (p. 336). Ultimately, Jones (2012) wrote that “the question of God is unlikely ever to be settled in an fMRI scanner, and I suspect this is probably the way He would want it” (p. 337).

I agree with the authors mentioned above. Though difficult, it is necessary to continue refining to what degree experiences of the supernatural should be considered hallucinatory. It seems unlikely that a strict definition of hallucinations will ever be agreed upon by all researchers, particularly with several disciplines and professional standpoints holding stake in how hallucinations are approached. One possible next step in this direction would be a consideration of the various benefits and consequences of broadening or restricting our definitions, for instance, to include or exclude encounters with angels and demons. Collaboration with researchers working from within theological perspectives would further enrich this dialogue.

(2) *We should divide experiences of psychotic disorders according to other connected attributes of this presentation* (delusion, disorganization, intensity, chronicity). Future research studies could specifically focus on *differences* between the social sharing of hallucinations occurring in the context of schizophrenia and the social sharing of hallucinations occurring in other contexts so that we can better assist individuals with this diagnosis and their friends and family to navigate these experiences.

(3) Researchers conducting qualitative research that will involve interviews focused on social sharing should be aware of potential *ethical concerns regarding confidentiality*. *Such concerns arise when interviews involve accessing details of a delicate nature that are inherently about somebody who has not given consent to be interviewed.* My decision to give participants a chance to read over the interview transcripts placed those transcripts containing descriptions of possibly illicit activities outside of my direct control and increased the chances that someone mentioned in the transcript could be identified. For example, if a participant mentioned an ex-roommate, ex-romantic partner, or family member such as “father,” “mother,” or “grandmother,” then this other person would become identifiable for the person reading the transcript who knew that the participant was the interviewee. In reconsideration, I would have refrained from sending transcripts out to participants for transcript checking.

One way to address this problem is to generalize or change the relationship spoken of by the participant during the interview. However, there is a potential loss of meaning by changing

“grandmother” to “aunt” or generalizing “grandmother” to “family member.” When a central aspect of the research question involves exploring the specific impact of relationship context on the phenomenon, such shifts and generalizations can become problematic. An “ex-girlfriend” and an “ex-roommate” are relationships that hold important distinctions. Likewise, the specificity of “grandmother” holds greater phenomenological value than “family member.” In hindsight, it seems obvious that the identifying and implicating of persons not present for the interview would be a problem with releasing transcripts to participants. In future qualitative research of this nature, working out such ethical questions around transcript release will need to occur.

Relatedly, I should note that many of my Listener participants checked with the Experiencers about whom they would be speaking in the interview to get permission for the interview and that during the interview participants often acknowledged that they were speaking of others who did not consent to be interviewed, and ensured that I would be closely guarding and sensitively attending to information that concerned others. This activity is yet one other way an exchange of care was clearly present between the two groups of participants.

(4) Researchers engaged in the international consortium (Woods et al., 2014) on hallucinations have indicated that *further work is needed in order to grow our understanding of the way language, culture, and available repertoires of understanding impact hallucinations and the illness experiences that are associated with them*. As McCarthy-Jones (2012) wrote, “meaning is as important as medicine in recovery” (p. 340). My study confirmed that meaning is a valuable avenue of exploration, but perhaps makes the case for there being value in examining the diversity of understandings that are present *within* as well as *across* cultural positions. Many of my participants described hallucinations that were extremely significant – changing the way they see the world, the way they see others, the way they see themselves, or even decisions regarding whether they should take their own life. At the very least, my research should draw attention to the point that citizens of a mid-sized predominantly western city in the prairies of Canada are no less at the mercy of available understandings (religious, secular, spiritual, medical, supernatural) than any other group of people. It is likely that there should be a tremendous breadth of understandings and explanations in any community in which hallucinations are studied, particularly if disclosure of non-professional understandings is encouraged. For example, many of my participants drew from both religious/spiritual understandings and medical/secular understandings in describing or explaining their hallucinations.

The participants in my research also drew on discourses of hallucinations to increase their sense of control and decrease their distress. For example, they pulled on medicalized rather than religious understandings, when medical understandings provided a greater sense of control, or they pulled on religious understandings when the experience itself held immense spiritual value, or connected the individuals with a community of meaning, such as a church. This evidence that individuals choose among various available frameworks for understanding their hallucinations is consistent with McCarthy-Jones, Waegeli, & Watkins (2013) finding that there can be both pros and cons to medical or religious understandings, and that some individuals can fluidly move between them to maximize success.

Teo (2010) described epistemological violence as interpretations of data emerging from academic contexts that are presented as knowledge rather than interpretation. Hodgetts, Guimarães, and King (2018), in their call for papers for a special issue on rethinking epistemology in psychology for the journal *Theory and Psychology*, pointed out that “epistemological violence” can happen when psychology attempts to assimilate the psychologies of people who lie outside the scope of WEIRD psychology. WEIRD stands for Western, Educated, Industrialized, Rich and Democratic (Shultz, Bahrami-Rad, Beauchamp, & Henrich, 2018). Undoubtedly, my participants would fall into this category; however, I am reluctant to group my participants together in this way due to the great diversity in their hallucinatory experiences and in how they interpreted these experiences. There was not a single or *consistent* epistemological position for my participants. Indeed, many participants maintained the possibility of opposing but simultaneous understandings (that their perceptions were neurobiologically caused hallucinations *and also* real perceptions of spiritual beings). As such, I believe this epistemological violence can happen as well within WEIRD populations, particularly for experiences such as hallucinations that we perceive as anomalous or as falling outside of the mainstream. Recent movements such as the Hearing Voices Movement and Intervice are actively trying to remedy this problem. Adherents to these movements do so not by forcing psychological understandings of these experiences, but by opening up psychology itself to ensuring epistemological (and ethical) room for idiopathic understandings.

(5) *Considering serious mental illness.* I acknowledge that serious mental illness is under-represented in my data. Though some participants were able to talk from this perspective, my original intention of undertaking research of clinical usefulness for family members and friends of individuals experiencing hallucinations in the context of serious and persistent mental illness is not fully realizable, given my sample of participants.

There are at least three reasons for this outcome. The first reason is ethical: given the sensitive nature of the content of the interviews, it was not appropriate to interview individuals who had experienced extremely recent or current psychotic episodes or who were engaged in an inpatient program. Future researchers could partner more with inpatient teams, and, as is appropriate and ethical, invite service-user Experiencers who are on inpatient units and experiencing active and extreme psychosis to participate in research projects.

## 6.5 Implications for Experiencers and Listeners

Making firm recommendations or mandating what should be kept in mind when encountering conversations from either Listener or Experiencer perspectives is counter to the purpose and stance of this research. I have no desire to make recommendations for what should be said or what should be experienced, other than I hope that individuals are able to care for themselves while simultaneously caring for one another, as possible. I ask only for an awareness of the Facets and how they might have an impact on the lived-experience of the social sharing for every individual involved in these conversations. For example, for Listeners, to perhaps be aware of the shock or confusion as it occurs, or to understand the various presentations of dual-processing and the potential difficulty of working through them. For Experiencers, I hope there is some empathy for what could be happening for Listeners who are hearing about hallucination experiences and attempting to make sense of them, and a heightened awareness of the potential

for connection as they speak about their experience. For everyone, I hope that trust and honour are recognized when present in the exchanges, and that there is an enhanced realization that it is the connections between us as human beings, as friends and as family members, that make these conversations possible.

Cheryl Mattingly, an anthropologist, writes about how small moments, occurring in ordinary social routines, can lead to enormous consequences for our social and moral lives and how ethics are manifest in the little interactions that make up our day-to-day encounters (2013). I would argue that the social sharing of hallucinations is a spot where the small moments but enormous consequences of our day-to-day encounters are apparent. For the social sharing of hallucinations, possibilities of responding can, at times, be automatic, but other times responding requires considerations, decisions, and risks. The over-all message from my participants for other individuals who are thinking about sharing their hallucination experience appears to be that it is important to have *some* individuals with whom you can feel comfortable sharing your experiences. Individuals who are considering sharing their hallucinations with others should not assume that others will respond well, but also should not assume that others will respond poorly. The key is to be thoughtful and flexible about with whom to share and to understand that there might be surprises, for better or worse. It also may be helpful to understand that expressions of care might not be received as expressions of care - that care is in the eye of the beholder. With this in mind, it becomes clear that even the best intentions of support, can be viewed as uncaring.

In hearing and responding to hallucinatory experiences, Listeners, including clinicians and researchers, have their work cut out for them. Experiencer participants spoke about a fundamental transformation of perception and consciousness. Things are not only “hallucinated” but objects bleed into one another, multiple realities co-occur and must be made sense of, dimensions are opened and explored. Making the task even more challenging, these experiences not only violate positivistic assumptions about a single objective reality, but the very content of hallucinations can be otherworldly and frightening. It is not only assumptions regarding shared objective reality that are disturbed, but, at times, even our understanding of the person.

Though the majority of the present clinical research focuses on conversations of hallucinations occurring in clinical contexts, many of the participants of this study primarily shared their experiences within the context of close personal relationships rather than professionals. Ultimately, this study reveals that we make sense of hallucinations with one another and that elements of trust and honour are involved in decisions regarding with whom to share (or not to share) hallucinated experiences.

## **6.6 Final comments on the research**

My original intention was simple: to explore the lived-experiences of Experiencers and Listeners during the social sharing of hallucinations. I wanted to avoid pathologizing the hallucination experiences, invite individuals from multiple contexts and perspectives, and interrogate the accounts for meaningful aspects that could shed light on what it is like to inhabit these conversations from both perspectives. I wanted to build a “bridge of understanding” between these two poles and to cycle this information as directly as possible back to the lay reader, as well as into the clinical and research professional communities. My hope is that this research will be used in unforeseen ways, that it will become meaningful to a number of people

who encounter it, and that it improves our ability to *listen* to those involved in these conversations by drawing attention to some of the central aspects of these experiences as my participants recounted them. The Facets of Care, Sense-Making, Dual-Processing, and Ontological Cross-Bleed are a result of my own process of engagement, with these particular participants, localized to the particular geographical area in which the research took place, and located in the present historical moment. However, hallucinations themselves are geographically and historically universal and, though I make no attempts to generalize beyond this context and these accounts, I, of course, hope that what has been learned here can be applied to other areas.

Some of the Facets seem readily apparent and obvious. This obviousness is particularly the case with the Sense-Making and Care Facets, which together capture central and important components to the descriptions with which I was working. Such obviousness is not a bad thing, for one of the many gifts of phenomenological analysis involves this methodology's ability to draw attention to the obvious so that it can be seen anew. Lavery (2003), for instance, wrote that phenomenology allows us to return to and "re-examine these taken for granted experiences and perhaps uncover new and/or forgotten meanings" (p. 1). Dual-Processing and Ontological Cross-Bleed appear obvious in hind-sight, but without the process of the research and data immersion I'm not convinced I could have foreseen these Facet categories as being so central to the social sharing of hallucinations. This is particularly true of the inadvertent form of cross-bleed, in which life-changes of the individual who experienced the hallucination are apparent to social others.

Modern phenomenologists have posited (or acknowledged) that fundamentally, subjectivity is only made possible through contact with the Other (Buber, 1923; Levinas, 1961). As individual citizens, we are *divided*, but our self-awareness, our very consciousness and identities, are formed through our encounters with others. We are positioned in the world with others, and the world-as-world becomes such only because of this balance between separation and merger occurring between us as individuals. Genuine dialogue, genuine understanding, is made possible due to difference, as much as by similarity (Buber, 1923). Hallucinations seemingly draw attention to this truth, in that they remind us that we are our own perceiver, and that others are their own perceiver, yet we are connected in fundamental ways - semiotically through language, biologically through our joint existence in the elemental, and through our shared sensual involvement in materiality. Paradoxically, the Other's very separateness creates the possibility of the "Self" (Kunz, 1998). Clinical psychology, in its own way, understands and acknowledges the importance of our inescapable being-with-others, with Berscheid (1999) concluding that, "relationships with other humans are both the foundation and the theme of the human condition" (p. 261).

The current research draws attention to the truth of our connected separateness. I have no doubt that Facets of "care" and "sense-making" and "ontological cross-bleed" are general aspects of our intersubjective relation to one another and the material world, rather than unique to the phenomenon of the social sharing of hallucinations. These Facets are primordial necessities for the structure of human existence. It is not that hallucinations bring out these qualities in our relationships, but rather that our relationships with one another are grounded in these qualities, and the social sharing of hallucination highlights and brings them (temporarily) to the foreground.

## References

- Ali, S., Patel, M., Avenido, J., Bailey, R., Jabeen, S., & Riley, W. (2011). Hallucinations: Common features and causes. *Current Psychiatry*, 10(11), 22-29.
- Aleman, A. & Laroi, F. (2008). *Hallucinations: The science of idiosyncratic perception*. Washington D.C.: American Psychological Association.
- American Psychiatric Association (2013). *Diagnostic and statistic manual of mental disorders (5<sup>th</sup> ed.)*. Washington D.C.: American Psychiatric Association.
- Ames, N., Peng, C., Powers, J., Leidy, N., Miller-Davis, C., Rosenberg, A., Van Raden, M. & Wallen, G. (2013). Beyond intuition: Patient fever symptom experience. *Journal of Pain Symptoms Management*, 46(6), 807-816.
- Arieti, S. (1979). *Understanding and helping the schizophrenic: A guide for family and friends*. New York: Touchstone.
- Ashworth, P. (1997) The variety of qualitative research. Part two: Non-positivist approaches. *Nurse Education Today*, 17(3), 219-224.
- Babkoff, H., Sing, H., Thorne, D., Genser, S., & Hegge, F. (1989) Perceptual distortions and hallucinations reported during sleep deprivation. *Perceptual and Motor Skills*, 68(3), 787-798.
- Baker, S., & Edwards, R. (2012). How many qualitative interviews is enough? Discussion Paper. National Centre for Research Methods.
- Baumeister, D., Sedgwick, O., Howes., O., & Peters, E. (2017). Auditory verbal hallucinations and the continuum model of psychosis: A systematic review of the healthy voice-hearer literature. *Clinical Psychology Review*, 51, 125-141.
- Beaven, V., Read., J., & Cartwright, C. (2011) The prevalence of voice-hearers in the general population: A literature review. *Journal of Mental Health*, 20(3), 281-292.
- Berscheid, E. (1999). The greening of relationship science. *American Psychologist*, 54(4), 260-266.
- Bergstrom, T., Alakare, B., Aaltonen, J., Maki, P., Kongas-Saviaro, J. & Seikkula, J. (2017) The long-term use of psychiatric services within the Open Dialogue treatment system after first-episode psychosis. *Psychosis*, 9(4), 310-321.
- Bergstrom, T., Seikkula, J., Alakare, B., Maki, P., Kongas-Saviaro, P., Taskila, J., Tolvanen, A., & Aaltonen, J. (2018) The family-oriented open dialogue approach in the treatment of first-episode psychosis: Nineteen-year outcomes. *Psychiatry Research*, 270, 168-175.

- Berrios, G. (1982). Tactile hallucinations: conceptual and historical aspects. *Journal of Neurology, Neurosurgery, and Psychiatry*, 45, 285-293.
- Berrios, G., & Dening, T. (1996) Pseudohallucinations: A conceptual history. *Psychological Medicine*, 26, 753-763.
- Blom, J. (2010). *A Dictionary of hallucinations*. New York: Springer
- Blom, J. & Summer, I. (2012). General introduction. In *Hallucinations: Research and practice* (Blom, J. & Summer, I. eds). New York: Springer.
- Buber, M. (1937). *I and Though*. Translated by Ronald Gregor Smith. Continuum: London.
- Bucci, S., Birchwood, M., Twist, L., Tarrier, N., Emsley, R. & Haddock. (2013) Predicting compliance with command hallucinations: Anger, impulsivity and appraisals of voices' power and intent. *Schizophrenia Research*, 147(1), 163-169.
- Buus, N., Jacobsen, E., Bojesen, A., Bikic, A., Muller-Nielsen, K., Aagaard, J., & Erlangsen, A. (2019). The association between Open Dialogue to young Danes in acute psychiatric crisis and their use of health care and social services: A retrospective register-based cohort study. *International Journal of Nursing Studies*, 91, 119 - 127.
- Burr, V. (2003). *Social constructionism (2<sup>nd</sup> Ed)*. London: Routledge.
- Castelnovo, A., Vacallotti, S., Cambini, O., & D'Agostino, A. (2015) Post-bereavement hallucinatory experiences: A critical overview of population and clinical studies. *Journal of Affective Disorders*. 186, 266-274.
- Caqueo-Urizar, A., Rus-Calafell, M., Urzua, A., Escudero, J., & Gutiereez-Maldonado, J. (2015). The role of family therapy in the management of schizophrenia: challenges and solutions. *Neuropsychiatric Disease and Treatment*, 14(11), 145-151.
- Chaudhury, S. (2010). Hallucinations: Clinical aspects and management. *Industrial Psychiatry Journal*, 19(1), 5-12.
- Chernnomas, W., Clarke, D., & Chisholm, F., (2000) Perspectives of women living with schizophrenia. *Psychiatric Services*, 51, 1517-1521.
- Chronister, J., Choic, C., Kwan, K., Lawton, M., & Silver, K. (2015). The meaning of social support for persons with serious mental illness. *Rehabilitation Psychology*, 60(3), 232-245.
- Clark, C. (1997). *Misery and company: Sympathy in everyday life*. Chicago: University of Chicago Press.

- Coffee, M., & Hewitt, J. (2008). 'You don't talk about the voices': voice hearers and community mental health nurses talk about responding to voice hearing experiences. *Journal of Clinical Nursing*, 17(12), 591-1600.
- Cogan, N., Schwannauer, M., & harper, S. (2019). Recovery and self-identity development following a first episode of psychosis. *Journal of Public Mental Health, Ahead-of-print* (Ahead-of-print).
- Coleman, R. (2011) *Recovery: An alien concept*. Fife: P & P Press.
- Corrigan, P. & Watson, A. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice*, 9, 35-53.
- Corrigan, P., & Shah, B. (2017). Understanding and addressing the stigma experienced by people with first episode psychosis. NASMHPD Publications: Illinois Institute of Technology
- Corstens, D., Longden, E., McCarthy-Jones, S., Waddingham, R., & Thomas, N. (2014). Emerging perspectives from the hearing voices movement: implications for research and practice. *Schizophrenia Bulletin*, 40(S4), S285-S294.
- Cretchley, J., Gallois, C., Chenery, H., & Smith, A. (201). Conversations between carers and people with schizophrenia: A qualitative analysis using Leximancer. *Qualitative Health Research*, 20(12), 1611-1628.
- Crompton, L., Lahav, Y., & Solomon, Z. (2016). Auditory hallucinations and PTSD in ex-POWS. *Journal of Trauma & Dissociation*, 18(5), 663-678.
- Crotty, M. (1998). *The Foundations of Social Research: Meaning and Perspectives in the Research Process*. Crows Nest: Allen & Unwin.
- David, A. (2004). The cognitive neuropsychiatry of auditory verbal hallucinations: An overview. *Cognitive Neuropsychiatry*, 9, 107-124.
- Davidson, L. (2003). *Living outside mental illness: Qualitative studies of recovery in schizophrenia*. New York: New York University Press.
- Dillon, J. & Herrnstein, G. (2013). Hearing voices peer support groups: A powerful alternative for people in distress. *Psychosis*, 5(3), 286-295.
- Dissanaik, L., & Aguis, M. (2011). Hearing voices in the normal population. *Cutting Edge Psychiatry in Practice*, 1(3.3), 50-54.
- Elliot, R., Fischer, C., & Rennie, D. (1999) Evolving guidelines for the publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.



- Escher, S., & Romme, M. (2012) The Hearing Voices Movement. In *Hallucinations: Research and practice* (Blom, J. & Summer, I. eds). New York: Springer. (pp.385-393)
- Faccio, E., Romaioli, D., Dagani, J., & Cipolletta, S. (2012) Auditory hallucinations as a personal experience: Analysis of non-psychiatric voice hearers' narrations. *Journal of Psychiatric and Mental Health Nursing*, 20(9), 761-767.
- Fenekou, V., & Georgaca, E. (2010) Exploring the experience of hearing voices. A qualitative study. *Psychosis: Psychological, Social and Integrative Approaches*, 2(2), 134-143.
- Finlay, L. & Ballinger, C. (eds) (2006). *Qualitative research for allied health professionals: Challenging choices*. London: John Wiley & Sons.
- Finlay, L., & Evans, K. (2009). *Relational centered research for psychotherapists: Exploring meanings and purpose*. London: Wiley Blackwell.
- Finlay, L. (2009). Ambiguous encounters: A relational approach to phenomenological research. *Indo-pacific Journal of Phenomenology*, 9(1).
- Fischer, C., Laubscher, L., & Brooke, R. (eds.) (2016). *The qualitative vision for psychology. An invitation to a human science approach*. Pittsburgh: Duquesne University Press.
- Flanagan, E., Solomon, L., Johnson, A., Ridgway, P, Strauss, J., & Davidson, L. (2012). Considering DSM-5: the personal experience of schizophrenia in relation to the DSM-IV-TR criteria. *Psychiatry*, 75(4), 375-386.
- Flynn, W. (1962). Visual hallucinations in sensory deprivation. *The Psychiatric Quarterly*, 36(1-4), 55-65.
- Gadamer, H. (1975). *Truth and method. Second Revised Edition*. Trans: Weinsheimer, J., & Marshall, D. London: Continuum.
- Gamwell, L., & Tomes, N. (1995). *Madness in America: Cultural and medical perceptions of mental illness before 1914*. Cornell Studies in the History of Psychiatry, Ithica: Cornell University Press.
- Georgaca, E. (2000). Reality and discourse: A critical analysis of the category of 'delusions'. *British Journal of Medical Psychology*, 73, 227-242.
- Giorgi, A. (2008). *Psychology as a human science: A phenomenologically based approach*. New York: Harper & Row.
- Goicoechea, J. (2006) Diagnostic discourse in patient-staff interactions: A conversation analysis clarified by patient interviews. In Fischer, C. (Ed.) *Qualitative Research Methods for Psychologists: Introduction Through Empirical Studies*, Amsterdam: Elsevier.

- Guts, K., Halling, S., Pierce, A., Romatz, E., & Schulz, J. (2016). *Aloneness is not the last word: A dialogal phenomenological study of deep connection*. In Fischer, C., Laubscher, L., & Brooke, R. (eds.) (2016). *The qualitative vision for psychology. An invitation to a human science approach*. Pittsburgh: Duquesne University Press.
- Halling, S. (2008) *Intimacy, transcendence, and psychology: Closeness and openness in everyday life*. New York: Palgrave.
- Hansen, H., Stige, S., Davidson, L., Moltu, C., & Vaseth, M. (2018). How do people experience early intervention services for psychosis? A meta-synthesis. *Qualitative Health Research*, 28(2), 259-272.
- Harly, E., Boardmen, J. & Craig, T. (2012). Friendship in people with schizophrenia: a survey. *Social Psychiatry and Psychiatric Epidemiology*, 47, 1291-1299.
- Harper, D. (1999). *Deconstructing paranoia: An analysis of the discourses associated with the concept of paranoid delusion*. (Doctoral Dissertation). Retrieved from: <http://www.criticalmethods.org/thesis0.htm>
- Harper, D. (2004) Delusions and discourse: Moving beyond the constraints of the rationalist paradigm. *Philosophy, Psychiatry, & Psychology*, 11, 55-64.
- Heidegger, M. (2004). *Being and Time*. Stambauch, J. (trans). Albany: State University of New York Press.
- Hendryx, M., Green, C., & Perrin, N. (2009). Social support, activities, and recovery from serious mental illness: STARS study findings. *The Journal of Behavioral Health Services & Research*, 36(3), 320-329.
- Hill, K., Varese, F., Jackson, M., & Linden, D. (2012) The relationship between metacognitive beliefs, auditory hallucinations and hallucination-related distress in clinical and non-clinical voice hearers. *British Journal of Clinical Psychology*, 51(4), 434-447.
- Hepworth, C., Ashcroft, K., & Kingdon, D., (2013) Auditory hallucinations: A comparison of beliefs about voices in individuals with schizophrenia and borderline personality disorder. *Clinical Psychology and Psychotherapy*, 20, 239-245.
- Heriot-Maitland, C., McCarthy-Jones, S., Longden, E., & Gilbert, P. (2019). Compassion focused approaches to working with distressing voices. *Frontiers in Psychology*, 1(10), 1664-1078.
- Hill, D., & Linden, E. (2013). Hallucinatory experiences in non-clinical populations. In *Hallucinations: Research and Practice* (Blom, J. & Summer, I. eds). New York: Springer.

- Hill, K., Varese, F., Jackson, M., & Linden, D. (2012). The relationship between metacognitive beliefs, auditory hallucinations, and hallucination-related distress in clinical and non-clinical voice hearers. *British Journal of Clinical Psychology*, 51(4), 434-447.
- Hodgetts, D., Guimarães, D., & King, P. (2018). Call for a special issue of theory & psychology. Accessed at:  
<https://indigenousspsych.org/News/Towards%20Rethinking%20the%20Primacy%20of%20Epistemology%20in%20Psychology.pdf>
- Hufner, K., Brugger, H., Kuster, E., Dunsser, F., Stawinoga, A., Turner, R., Tomazin, I., Sperner-Unterweger, B. (2018) Isolated psychosis during exposure to very high and extreme altitude – characterization of a new medical entity. *Psychological Medicine*, 48(11), 1872-1879.
- Husserl, E. (2001). *Logical investigations*. Dummett, M. (trans). New York: Routledge.
- Intervoice: The International Hearing Voices Network (2018). Accessed at:  
<http://www.intervoiceonline.org/>
- James, W. (1902). *The Varieties of Religious Experience: A Study in Human Nature*. New York: Barnes and Noble Books.
- Jefferson, G. (2004). Glossary of transcript symbols with an introduction. In G.H. Lerner (Ed). *Conversation Analysis: Studies from the First Generation*. (pp:13-31). Amsterdam: John Benjamins.
- Johns, L., Kompus, K., Connell, M., Humpston, C., Lincoln, T., Longden, E., Preti, A., Alderson-Day, B., Badcock, J., Cella, M., Fernyhough, C., McCarthy-Jones, S., Peters, E., Raballo, A., Scott, J., Siddi, S., Sommer, I., & Laroi, F. (2014) Auditory verbal hallucinations in persons with and without a need for care. *Schizophrenia Bulletin*, 40(suppl4), S255-S264.
- Jones, S., Fernyhough, C. & Laroi, F. (2010). A phenomenological survey of auditory verbal hallucinations in the hypnagogic and hypnopompic states. *Phenomenology and the Cognitive Sciences*, 9, 213-224
- Jones, S., Guy, A., & Omrod, J. (2003). A Q-methodological study of hearing voices: A preliminary exploration of voice hearers' understanding of their experiences. *Psychology and Psychotherapy: Theory, Research and Practice*, 76, 182-209
- Jones, N., & Luhrmann, T. (2015) Beyond the sensory: Findings from an in-depth analysis of the phenomenology of “auditory hallucinations” in schizophrenia. *Psychosis: Psychological, Social and Integrative Approaches*, 8(3), 191-202.
- Jones, N. & Shattell, M. (2013). Engaging with voices: Rethinking the clinical treatment of psychosis. *Issues in Mental Health Nursing*, 34, 562-563.

- Kalhovde, A., Elstad, I., & Talseth, A. (2014). "Sometimes I walk and walk, hoping to get some peace." Dealing with hearing voices and sounds nobody else hears. *Qualitative studies on Health and Well-Being*, 9, 23-69.
- Kay, S., Fiszbein, A., & Opler, L. (1987) The Positive and Negative Syndrome Scale for Schizophrenia. *Schizophrenia Bulletin*, 13(2), 261-276.
- Kłapciński, M., & Rymaszewska, J. (2015). Open Dialogue approach – about the phenomenon of Scandinavian Psychiatry. *Psychiatria Polska*, 49(6), 1179-1190.
- Koyanagi, A., Stickley, A., & Haro, J. (2016). Subclinical psychosis and pain in an English national sample: The role of common mental disorders. *Schizophrenia Research*, 175(1-3), 209-215.
- Kvale, S., & Brinkmann, S. (2009). *InterViews: Learning the Craft of Qualitative Research. Second Edition*. Los Angeles: Sage.
- Kråkvik, B., Laroi, F., Kalhovde, M., Hugdahl, K., Kompus, K., Salvesen, Ø., Stiles, T., & Vedul-Kjelsås, E. (2015). Prevalence of auditory verbal hallucinations in a general population: A group comparison study. *Scandinavian Journal of Psychology*, 56(5), 508-515.
- Kunz, G. (1998). *The Paradox of Power and Weakness: Levinas and an Alternative Paradigm for Psychology*. State University of New York Press: Albany.
- Langridge, D., (2007). *Phenomenological Psychology: Theory, Research and Method*. London: Pearson.
- Laroi, F. (2006) The phenomenological diversity of hallucinations: Some theoretical and clinical implications. *Psychologica Belgica*, 46(1/2), 163-183.
- Laroi, F., & van der Linden, M. (2005). Normal subjects' reports of hallucinatory experiences. *Canadian Journal of Behavioral Science*, 37, 33-43.
- Laroi, F., Luhrmann, T., Bell, V., Christian Jr., V., Despande, S., Fernyhough, C., Jenkins, J., & Woods, A. (2014). Culture and hallucinations: Overview and future directions. *Schizophrenia Bulletin*, 40(4), S213-S220.
- Laroi, F., Sommer, I., Blom, J., Fernyhough, C., ffytche, D., Hugdahl, K., Johns, L., McCarthy-Jones, S., Preti, A., Raballo, A., Slotema, C., Stephane, M., & Waters, F. (2012). The characteristic features of auditory verbal hallucinations in clinical and nonclinical groups: State-of-the-art Overview and Future Directions. *Schizophrenia Bulletin*, 38(4), 724-733
- Laverty, S., (2003) Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative*

- Methods*, 2(3). Article 3. Retrieved June 2017 from [http://www.ualberta.ca/~iiqm/backissues/2\\_3final/html/laverty.html](http://www.ualberta.ca/~iiqm/backissues/2_3final/html/laverty.html)
- Levinas, E. (1969). *Totality and Infinity: An Essay on Exteriority*. Trans. Alphonso Lingis, Pittsburgh, PA: Duquesne University Press.
- Lewis, R. (2007) A 10-year-old boy evacuated from the Mississippi Gulf Coast after Hurricane Katrina presents with agitation, hallucinations, and fever. *Journal of Emergency Nursing*, 33(1), 42-22.
- Lidbom, P., Boe, T., Kristoffersen, K., Ulland, D., & Seikkula, J. (2015). How participants' inner dialogues contribute to significant and meaningful moments in network therapy with adolescents. *Contemporary Family Therapy*, 37(2), 122-129.
- Longden, E., Corstens, D., Escher, S., & Romme, M. (2012) Voice hearing in a biographical context: A model for formulating the relationship between voices and life history. *Psychosis: Psychological, Social, and Integrative Approaches*, 4(3), 224-234.
- Longden, E., Read, J., & Dillon, J. (2018). Assessing the impact and effectiveness of hearing voices network self-help groups. *Community Mental Health*, 54(2), 184-188.
- MacDonald, E., Sauer, K., Howie, L., & Albiston, D. (2005). What happens to social relationships in early psychosis? A phenomenological study of young people's experiences. *Journal of Mental Health*, 13, 467-479.
- Marconi, A., Di Forti, M., Lewis, C., Murray, R., & Vassos, E. (2016). Meta-analysis of the association between the level of cannabis use and risk of psychosis. *Schizophrenia Bulletin*, 42(5), 1262-1269.
- Mattingly, C. (2013). Moral selves and moral scenes: Narrative experiments in everyday life. *Ethnos*, 78(3), 301-327.
- McCarthy-Jones, S. (2012). *Hearing Voices: The Histories, Causes and Meanings of Auditory Hallucinations*. New York: Cambridge University Press.
- McCarthy-Jones, S., & Longden, E., (2015) Auditory verbal hallucinations in schizophrenia and post-traumatic stress disorder: common phenomenology, common cause, common interventions? *Frontiers in Psychology*, 6, 1071
- McCarthy-Jones, S., Thomas, N., Strauss, C., Dodgson, G., Jones, N., Woods, A., Brewin, C., Hayward, M., Stephane, M., Barton J., Kingdon, D., & Sommer, I. (2014). Better than mermaids and stray dogs? Subtyping auditory verbal hallucinations and its implications for research and practice. *Schizophrenia Bulletin*, 40(S4), S275-S284.

- McCarthy-Jones, S., Trauer, T., Mackinnon, A., Sims, E., Thomas, S. & Copolov, D. (2014) A new phenomenological survey of auditory hallucinations: Evidence for subtypes and implications for theory and practice. *Schizophrenia Bulletin*, 40(1), 225-235.
- McCarthy-Jones, S., Marriott, M., Knowles, R., Rowse, G., & Thompson, A. (2013) What is psychosis: A meta-synthesis of inductive qualitative studies exploring the experience of psychosis, *Psychosis*, 5(1) 1-16.
- McCarthy-Jones, S., Waegeli, A., & Watkins, J. (2013) Spirituality and hearing voices: considering the relation. *Psychosis*, 5(3), 247-258
- McNeil, D., Eisner, J., & Binder, R. (2000) The relationship between command hallucinations and violence. *Psychiatric Services*, 51(10), 1288-1292.
- McKetin, R. (2018). Methamphetamine psychosis: Insights from the past. *Addiction*. 113(8), 1522-1527.
- Metzner, R. (2017) Entheogenesis: Toward an expanded worldview of our time. *Merriam-Webster.com*. Retrieved May 8, 2011, from <https://www.merriam-webster.com/dictionary/hacker>
- Moskowitz, A., & Corstens, D. (2007). Auditory hallucinations: Psychotic symptom or dissociative experience? *Journal of Psychological Trauma*, 6(2-3), 35-63.
- Murray-Swank, A., & Dixon, L. (2004) Family psychoeducation as an evidence-based practice. *CNS Spectrums*, 9(12), 905-912.
- Nadkarni, S., Arnedo, V., & Devinsky, O (2007) Psychosis in epilepsy patients. *Epilepsia*, 48(S9), 17-19.
- Nygaard, M., Sonne, C., & Carlson, J. (2017). Secondary psychotic features in refugees diagnosed with post-traumatic stress disorder: a retrospective cohort study. *BMC Psychiatry*, 17(1), 5.
- Opler, M., Yavorsky, C., & Daniel, D., (2017). Positive and Negative Syndrome Scale (PANSS) Training: Challenges, solutions, and future directions. *Innovations in Clinical Neuroscience*, 14(11-12), 77-81.
- Otto, T. personal communication May 15, 2019
- Pallesen, S., Olsen, O., Eide, E., Nortvedt, B., Gronli, J., Laroi, F., Nordmo, M., & Glomlien, F. (2018). Sleep deprivation and hallucinations: A qualitative study of military personnel. *Military Psychology*, 30(5), 430-436.
- Parker, I., Georgaca, E., Harper, D., McLaughlin, T., & Stowell-Smith, M. (1995). *Deconstructing psychopathology*. London: Sage Publications

- Patocka, J. (1998). *Body, community, language and world*. Trans: Kohak, E. Chicago: Open Court.
- von Peter, S., Aderhold, V., Cubellic, L., Bergstrom, T., Stastny, P., Seikkula, J., & Puras, D. (2019). Open Dialogue as a human rights aligned approach. *Frontiers in Psychiatry*, 10(387), 1-6.
- Pienkos, E. (2014). Using phenomenology to understand hallucinatory experiences (commentary on Shapiro, Bussing & Nguyen, "Pseudohallucinations in an adolescent: Considerations for diagnosis and treatment in the case of "Kate"). *Pragmatic Case Studies in Psychotherapy*, 10, 260-270.
- Pienkos, E., Giersch, A., Hansen, M., Humptson, C., McCarthy-Jones, S., Mishara, A., Nelson, B., Park, S., Raballo, A., Sharma, R., Thomas, N., & Rosen, C. (2019). Hallucinations beyond voices: A conceptual review of the phenomenology of altered perception in psychosis. *Schizophrenia Bulletin*, 45(suppl1), S67-S77.
- Pinchbeck, D. (2003). *Breaking open the head*. New York City: Broadway Books.
- Pollan, M. (2019) *How to change your mind: What the new science of psychedelics teaches us about consciousness, dying, addiction, depression, and transcendence*. New York: Penguin Press.
- Pugh, M., Waller, G., & Esposito, M. (2018) Childhood trauma, dissociation, and the internal eating disorder 'voice'. *Child Abuse & Neglect*. 86, 197-205.
- Rhodes, J. & Jakes, S. (2009). *Narrative CBT for Psychosis*. London: Routledge.
- Romme, M., & Escher, S. (1993). *Accepting voices*. MIND.
- Russell, G., & Bohan, J. (1999). Hearing voices: The uses of research and the politics of change. *Psychology of Women Quarterly*, 23(2), 403-418.
- Sacks, O. (2012). *Hallucinations*. Picador: London
- SAMHSA (2012) - recovery principles pamphlet
- Schütze, W. (2015). Open dialogue as a contribution to a healthy society: Possibilities and limitations. *Postępy Psychiatrii I Neurologii*, 24, 86-90.
- Sebersen, K., Norberg, A., Talseth, A. (2014) Being in a process of transition to psychosis, as narrated by adults with psychotic illnesses acutely admitted to hospital. *Journal of Psychiatric and Mental Health Nursing*, 21, 896-905.
- Siegel, R. (1977). Hallucinations. *Scientific American*, 237(4), 132-140.

- Siegel, R. (1984). Hostage hallucinations: Visual imagery induced by isolation and life-threatening stress. *The Journal of Nervous and Mental Disease*, 172(5), 264-271.
- Seikkula, J., Alakare, B., & Aaltonen, J. (2001). Open Dialogue in psychosis I: An introduction and case illustration. *Journal of Constructivist Psychology*, 14(4), 247-265.
- Seikkula, J., Arnkil, T., & Eriksson, E. (2003) Postmodern society and social networks: Open and anticipation dialogues in network meetings. *Family Process*, 42(2), 185-203.
- Shahid, Patel, Avenido, Bailey, Jabeen & Riley (2011). Hallucinations: Common features and causes, awareness of manifestations, nonpsychiatric etiologies can help pinpoint a diagnosis. *Current Psychiatry*, 10(11), 22-29.
- Shimodera, S., Inoue, S., Tanaka, S., & Mino, Y. (1998). Critical comments made to schizophrenia patients by their families in Japan. *Comprehensive Psychiatry*, 39(2), 85-90.
- Shultz, J., Bahrami-Rad, D., Beauchamp, J., & Henrich, J. (2018). The origins of WEIRD psychology. *SSRN*. Available at SSRN: <https://ssrn.com/abstract=3201031>.
- Siddi, S., Ochoa, S., Laroi, F., Cella, M., Raballo, A., Saldivia, S., Quijada, Y., Laloyaux, J., Rocha, N., Lincoln, T., Schlier, B., Ntouros, E., Bozikas, V., Gaewda, L., Machoda, S., Nardi, A., Rodante, D., Deshpande, S., Haro, J., & Preti, A. (2019). A cross-national investigation of hallucination-like experiences in 10 countries: The E-CLECTIC study. *Schizophrenia Bulletin*, 45(S1), S43-S55.
- Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretive phenomenological analysis: Theory, method and research*. London: SAGE Publications Inc.
- Soosay, I., Silove, D., Bateman-Steel, C., Steel, Z., Bebbington, P., Jones, P., Chey, T., Ivancic, L., & Marnana, C. (2012). Trauma exposure, PTSD and psychotic-like symptoms in post-conflict Timor Leste: an epidemiological survey. *BMC Psychiatry*, 12(229).
- Soundy, A., Stubbs, B., Roskell, C., Williams, S., Fox, A., & Vancampfort, D. (2015). Identifying the facilitators and processes which influence recovery in individuals with schizophrenia: A systematic review and thematic analysis. *Journal of Mental Health*, 24(2), 103-110.
- Strickland, B., Gall, S. (2016). *Gale Encyclopedia of Psychology*, 3<sup>rd</sup> Ed. Farmington Hills: Gale.
- Stuber, J, Rocha, A., Christian, A., & Link, B. (2014). Conceptions of mental illness: Attitudes of mental health professionals and the general public. *Psychiatric Services*, 65(4), 490-497.



- Suri, R. (2010). Making sense of voices: An exploration of meaningfulness in auditory hallucinations in schizophrenia. *Journal of Humanistic Psychology*, 51(2), 152-171.
- Telles-Correia, D., Moeira, A., & Gonçalves, J. (2015) Hallucinations and related concepts – their conceptual background. *Frontiers in Psychology*, 6(991).
- Thomas, N., Farhall, J., & Shawyer, F. (2013). Beliefs about voices and schemas about self and others in psychosis. *Behavioral and Cognitive Psychotherapy*, 43(2), 209-223.
- Thomas, S., Rossell, S. & Waters, F. (2016) The changing face of hallucination research: The International Consortium on Hallucination Research (ICHR) 2015 Meeting Report. *Schizophrenia Bulletin*, 42(4), 891-895.
- U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration (2009) Evidence Based Practices: Knowledge Informing Transformation. Family Psychoeducation: The Evidence. Center for Mental Health Services. Accessed: <https://store.samhsa.gov/system/files/theevidence-fp.pdf>
- Underwood, R., Kumari, V., & Peters, E. (2016) Appraisals of psychotic experiences: an experimental investigation of symptomatic, remitted and non-need-for-care individuals. *Psychological Medicine*, 46, 1249-1263.
- van der Zwaard, R., & Polak, M. (2001). Pseudohallucinations: a pseudoconcept? A review of the validity of the concept related to associate symptomatology. *Comprehensive Psychiatry*, 42, 42-50.
- van manen, M. (1990). *Researching lives experience: Human science for an action sensitive pedagogy*. Ann Arbor: The Althouse Press.
- van Manen, M. (2011) Phenomenology online: A resource for phenomenological inquiry. Accessed at: <https://www.phenomenologyonline.com/inquiry/methods-procedures/reflective-methods/thematic-reflection/>
- van Manen, M. (2014) *Phenomenology of Practice*. Taylor & Francis: New York
- Varese, F., Morrison, A., Beck, R., Heffernan, S., Law, H., & Bentall, R. (2016). Experiential avoidance and appraisals of voices as predictors of voice-related distress. *British Journal of Clinical Psychology*, 55(3), 320-321.
- Vilhauer, R., & Sharma, H. (2018). Unsolicited reports of voice hearing in the general population: a study using a novel method. *Psychosis*, 10(3), 163-174.
- von Peter, S., Aderhold, V., Cubellis, L., Bergstrom, T., Stastny, P., Seikkula, J., & Puras, D. (2019). Open Dialogue as a human rights-aligned approach. *Frontiers in Psychiatry*, 10, 387.

Walton, T., personal communication, May 15 2019

Wang, J., Lloyd-Evans, B., Giacco, D., Forsyth, R., Nebo, C., Mann, F., & Johnson, S. (2017). Social isolation in mental health: A conceptual and methodological review. *Social Psychiatry and Psychiatric Epidemiology*, 52(12), 1451-1461.

Waters, F., Chiu, V., Atkinson, A., & Blom, J. (2018). Severe sleep deprivation causes hallucinations and a gradual progression toward psychosis with increasing time awake. *Frontiers in Psychiatry*, 9, 303.

Waters, F., & Fernyhough, C. (2017) Hallucinations: A systematic review of points of similarity and difference across diagnostic classes. *Schizophrenia Bulletin*, 43(1), 32-43.

Waters, F. & Fernyhough, C. (2017). Hallucinations: A systematic review of points of similarity and difference across diagnostic classes. *Schizophrenia Bulletin*, 43(7), 32-43.

Wertz, F., Charmaz, K., McMullen, L., Josselson, R., Anderson, R., & McSpadden, E. (2011). *Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry*. New York: Guilford Press.

Willig, C. (2013). *Introducing qualitative research in psychology (Third Edition)*. New York: Open University Press.

Windell, D., Norman, D., Lal, D., & Malla, A. (2015). Subjective experiences of illness recovery in individuals treated for first-episode psychosis. *Social Psychiatry and Psychiatric Epidemiology*, 50(7), 1069-1077.

Woods, A., Jones, N., Alderson-Day, B., Callard, F., & Fernyhough, C. (2015). Experiences of hearing voices: analysis of a novel phenomenological survey. *Lancet Psychiatry*, 2(4), 323-331.

Woods, A., Jones, N., Bernini, M., Callard, F., Alderson-Day, B., Badcock, J., Bell, V., Cook, C., Csorda, T., Humpston, C. Krueger, J., Laroi, F., McCarthy-Jones, S., Moseley, P., Powell, H., Raballo, A., Smailes, D., & Fernyhough, C. (2014). Interdisciplinary approaches to phenomenology of auditory verbal hallucinations. *Schizophrenia Bulletin*, 40(S4), S246-S254.

Yaden, B., Khoa, D., Nguyen, L., Kern, M., Belster, A., Eichstaedt, J., Smith, M., Winter, N., Hood, R., & Newberg, A. (2016). Of roots and fruits: A comparison of psychedelic and nonpsychedelic mystical experiences. *Journal of Humanistic Psychology*, 57(4), 338-353.

Zahle, J. (2018). Values and data collection in social research. *Philosophy of Science*, 85(1), 144-163.

Ziskind, E., & Augsberg, T. (1962). Hallucination in sensory deprivation: method or madness? *Science*, 137(3534), 992.

## **Appendices**

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## Appendix A

Poster Advert: Experiencers

**Have you ever experienced a hallucination?  
Have you spoken to another person about the  
hallucination?**

**We are interested in your input on the  
experience of speaking about hallucinations.**

**We are interested in any of the sensory modalities  
(visual, auditory, etc.) and the variety of contexts  
(spiritually centred, mental health related, etc.) in  
which hallucinations can occur.**

\*We are particularly interested in conversations about hallucinations that have occurred outside of professional contexts and in hallucinations that are not drug induced.

Research has shown that hallucinations can be understood and experienced in many different ways. We are interested in what the experience of speaking to another person about a hallucination is like, as well as some of the challenges or benefits of these conversations.

**Duration:** A single 1–1.5 hour interview with the possibility for a brief follow up interview.

**Methods:** The interviews will take place in a private room on the University of Saskatchewan campus.

**Compensation:** We will provide you with compensation for your time

This research project was approved on ethical grounds by the University of Saskatchewan Research Ethics Board.

**To learn more, please contact:**

Adam Pierce at: adam.pierce@usask.ca or (306) 966-6687

## Appendix B

Poster advert: Listeners

# **Has someone else ever spoken to you about their hallucination?**

**We are interested in speaking to you about your experience during this conversation.**

**We are interested in any of the sensory modalities (visual, auditory, etc.) or contexts (drug induced, spiritually centred, mental health related, etc.) in which hallucinations can occur.**

\*We are particularly interested in conversations about hallucinations that have occurred outside of professional contexts.

Research has shown that hallucinations can be understood and experienced in many different ways. We are interested in what the experience of speaking to another person about a hallucination is like, as well as some of the challenges or benefits of these conversations.

**Duration:** A single 1 – 1.5 hour interview with the possibility for a brief follow up interview.

**Methods:** The interviews will take place in a private rented room on the University of Saskatchewan campus or within the community.

**Compensation:** We will provide you with compensation for your time

This research project was approved on ethical grounds by the University of Saskatchewan Research Ethics Board.

## Appendix C

### Contact E-mail for Professionals

Thank you for your potential interest in passing along information about the study “The Social Sharing of Hallucinations.” I am conducting this project through the Department of Psychology at the University of Saskatchewan. I am working on my PhD in Clinical Psychology and am completing this research as part of my dissertation. I also hold a Masters in Existential-Phenomenological Clinical Psychology from Seattle University, where I graduated in 2010. Between my two educational experiences I worked for years in community mental health, and my research stems directly from conversations I had with clients and their families during service delivery.

The purpose of this project is to explore the experience of individuals who have been involved in conversations about hallucinations. I am speaking to individuals who have experienced a hallucination and spoken with another person about the hallucination as well as with individuals who have spoken to someone else about the other person’s hallucination. Participant groups are not matched, so we do not need to speak to both an experiencer and a listener about the same conversation. Though some of these conversations will occur in a clinical context (for instance with a psychologist, psychiatrist, or general physician) I am particularly interested in conversations that occur outside of professional contexts, such as conversations between friends, family members, neighbors, strangers, colleagues, and so on.

My hope for this study is that it will be of help to individuals who engage in these conversations from both sides of the interpersonal exchange. This help could come in at least three forms: (1) non-prescriptive recommendations for what to do and what to say during these interactions; (2) a developed empathic understanding of what the experience is like for individuals engaged in these dialogues, and (3) a capturing of this experience in such a way that eventual readers of an analysis might feel less alone in their (possible) struggle to navigate these interactions. As much as possible I hope to cycle information from the analysis back into the local community through creating informational brochures and passing along the information from my analysis along to non-profit organizations and local community mental health organizations that work with individuals likely to experience hallucinations.

If you know of someone who you believe might be interested in participating in this study, please pass along the included advertisement and encourage the person to contact me about the study. I request that you do not pass along names or contact information of individuals that you believe might be interested. Inclusion criteria for the study is that individuals must be over the age of 18, fluent in English, and not currently experiencing an acute psychotic episode.

If you have further questions feel free to contact Adam Pierce by e-mail at [adam.pierce@usask.ca](mailto:adam.pierce@usask.ca). or telephone at (306) 966-4102. You may also contact my faculty supervisor, Dr. Linda McMullen, by phone at (306) 966-6666 or e-mail [linda.mcmullen@usask.ca](mailto:linda.mcmullen@usask.ca). The study was approved by the University of Saskatchewan’s Behavioural Ethics Board on July 5, 2017.

Once again, I would like to thank you greatly for your interest in the current study!

## Appendix D

### Initial Contact for Experiencers

\*I will give a slightly altered version as appropriate (i.e., based on participants' unique e-mail interactions) and for phone correspondence.

#### **Experiencers**

Dear \_\_\_\_\_,

Thank you for your interest in the research project titled, "The Social Sharing of Hallucinations." I am conducting this research through the Department of Psychology at the University of Saskatchewan under the supervision of Dr. Linda McMullen. In this research project, we are interested in speaking with individuals who have experienced a hallucination and have spoken with someone else about the hallucination. If you have experienced a hallucination in the past, of any variety, and for any reason, we invite you to take part in this research project. We are asking participants to participate in an interview that will last approximately 1 to 1.5 hours. This interview will focus on your experience of speaking with another person about the hallucination. For instance, we might talk about what that experience was like for you, how the other person responded, and if the conversation had any impact on how you understood the hallucination. The modality (visual, audio, olfactory, etc.) and context (drug induced, related to psychosis, sleep related, spiritual, etc.) of the hallucination does not matter; we are inviting participants from all contexts and perceptual modalities in which hallucinations occur. If you are above the age of 18, speak fluent English, and are not currently experiencing an acute state of psychosis, we invite you to take part in this study. If you are interested in participating, or if you would like further information, please reply to this e-mail to set up a time to talk or call me at (306) 966-4102. The next step will be to collect some brief information from you regarding eligibility as well as to tell you more about the study and answer any questions that you have.

Sincerely,

Adam R. Pierce, MA  
Clinical Psychology Graduate Student  
University of Saskatchewan

## Appendix E

### Initial Contact for Listeners

\*I will give a slightly altered version as appropriate (i.e., based on participants' unique e-mail interactions) and for phone correspondence.

#### **Listener contact,**

Dear \_\_\_\_\_,

Thank you for your interest in the research project titled, "The Social Sharing of Hallucinations." I am conducting this research through the Department of Psychology at the University of Saskatchewan under the supervision of Dr. Linda McMullen. In this research project, we are interested in speaking with individuals who have spoken with someone else about the other person's hallucination(s). We are asking participants to participate in an interview that will last approximately 1 to 1.5 hours. The interview will focus on your experience of having had another person tell you about his or her hallucinatory experience. Some topics that we might cover include what the conversation was like for you, how you made sense of the other person's hallucinatory experience, and what, if any, impact the conversation had. We are interested in conversations that occur around hallucinations of all varieties. As such, the modality (visual, audio, olfactory, etc.) and context (drug induced, sleep deprivation, spiritual, psychosis related, etc.) of the hallucination does not matter. If you have had a conversation with another individual who has experienced hallucinations about their hallucinations, are over the age of 18, and speak fluent English, we invite you take part in this research project. If you are interested in participating, or if you would like further information, please reply to this e-mail to set up a time to talk or call me at (306) 966-4102. The next step will be to collect some brief information from you regarding eligibility as well to tell you a bit more about the study and answer any questions that you have.

Sincerely,  
Adam R. Pierce, M.A.  
Clinical Psychology Graduate Student  
University of Saskatchewan



## Appendix F

### Demographic Questionnaire: Experiencers

**Note: Each participant will complete this form with me over the phone before I set an interview date with him or her. Most of the information on this form relates to eligibility.**

*\*Only individuals who have experienced hallucinations are eligible to participate in this study at this time.*

Have you experienced hallucinations:	Yes	No
Did you speak with another person about your hallucinations:	Yes	No
Are you willing to speak with me about what this conversation was like for you:	Yes	No
Is English a primary language for you?	Yes	No
Are you currently experiencing an acute psychotic episode?	Yes	No
Are you currently hospitalized in an in-patient setting?	Yes	No

Age:

Gender:

Participant Identification Number:

Date:

## Appendix G

### Demographic Questionnaire – Listeners

**Note: Each participant will complete this form with me over the phone before I set an interview date with him or her. The information on this form relates to eligibility.**

*\*Only individuals who have spoken with another individual about that other individual's hallucinations are eligible for this study.*

Have you spoken with another individual about his or her hallucination(s):	Yes	No
Would you be willing to speak with me about what this conversation was like for you:	Yes	No
Is English a primary language for you?	Yes	No

Age:

Gender:

Name:

Date:

## Appendix H

### Consent Form



# *Participant Consent Form*

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**Project Title:** (1) The Social Sharing of Hallucinations

**Researcher(s):** Adam Pierce, Graduate Student, Department of Psychology, University of Saskatchewan, e-mail: [adam.pierce@usask.ca](mailto:adam.pierce@usask.ca), (306) 966 - 4102

**Supervisor:** Dr. Linda McMullen, Department of Psychology, University of Saskatchewan, (306) 966-6666, e-mail: [linda.mcmullen@usask.ca](mailto:linda.mcmullen@usask.ca)

**Purpose(s) and Objective(s) of the Research:** Little research has been done on what the experience of speaking with another person about hallucinations is like. This paucity of research exists despite the fact that many of the most meaningful conversations around hallucinations occur outside of professional contexts, often with friends, family members, colleagues, neighbors, or other individuals in the community. This research project is designed to generate knowledge on what it is like to be involved in conversations about hallucinations, for both the experiencer and for individuals who have had other persons share their experiences of hallucinations with them. I will analyze each of these sets of experiences for commonalities and differences, as well as develop material that can be passed on to other individuals who might have these conversations in the future. I will also examine aspects of the language used to talk about these conversations.

**Procedures:** We invite you to participate in a single 1-1.5 hour long, individual interview (possibly with a follow-up interview) on the topic of speaking with another person about a hallucination. At each interview, I, the interviewer, will ask you to describe an experience of sharing in a conversation about a hallucination. I will also ask general questions such as how this conversation went for you and what your response was to the conversation. With your consent, I will audio record each interview. I, the student researcher (Adam Pierce), will also transcribe the interviews, after which I will ask you to review the transcripts for the purposes of accuracy, and sign transcript release forms for each interview. If you have any questions at any time regarding the current study, including, but not limited to the purpose, procedures, or your participation, do not hesitate to ask me (the interviewer) or my faculty supervisor using the contact information I have provided.

**Funded by:** Faculty Supervisor's Research Funds, and a Graduate Teaching Fellowship

**Potential Risks:** Though I do not intend to provoke negative emotions through the interview questions, the overall topic could be considered sensitive or emotionally laden. For your well-being, **I ask that you do not participate if you are currently experiencing an acute psychosis.** If at any point a question or discussion makes you feel uncomfortable, you can choose to not answer that question without any penalty. You may also discontinue participation at any time without explanation or penalty. After you have completed participation or have withdrawn from the study, I will give you a sheet that provides a more in-depth explanation of the research topic.

**Potential Benefits:**

- You may receive no personal benefits from participation in this study.
- The current research will fill a gap in knowledge surrounding how conversations around hallucinations are experienced outside of professional contexts.

**Compensation:** For your time, we will provide you with \$50.00 compensation for the interview. I, the interviewer, will provide you with this compensation at the research site at the end of each interview. Should you decide to withdraw from participation at any time, you will still be compensated the full \$50.00.

**Confidentiality:**

- We will use a pseudonym (a name, that is not your actual name, which we will use to refer to you in the data) when transcribing the data to conceal your identity. I, the interviewer, will provide you with the opportunity to choose your pseudonym at the end of the first interview. Please keep in mind that this name will be used to refer to your communications. As such, please ensure that your pseudonym choice is one you are comfortable with being used to refer to you and it does not risk identifying you.
- During transcription we will remove identifying information (i.e., names). Though we will use the data for a research paper, presentations, and/or publications, at no point will you be identified. Only the researcher and the supervisor of the current project will have access to the consent forms, and original data.
- Please be aware that there are **limitations to confidentiality**. For example, if a participant communicates something that brings into question the safety and/or well-being of a child (i.e., child abuse), I, the interviewer, will be legally required to share this information with a third party (i.e., law enforcement or protective services). Further, should a participant indicate that he or she is a danger to him or herself (i.e., suicidality) or to others, I, the interviewer, will be required to breach confidentiality through contacting relevant law enforcement or crisis services.

- **Storage of Data:**

- I, the interviewer, will store your data on an audio recording device(s) temporarily, which I will keep in my possession. Shortly after each interview, I will transfer the audio file(s) to my password protected computer and my faculty supervisor may also save the files to her password protected computers. I will then permanently delete the audio files from the audio recording device(s).
- I, the interviewer, will make transcripts from the saved audio files using a word processing program. We (the student researcher and faculty supervisor) will save these transcripts on our password protected computers. Should we (the student researcher or faculty supervisor) make printed copies of the transcripts, we will

keep them in our possession when we are using them. When we are not using the transcripts we printed, we will store them in a locked cabinet on the University of Saskatchewan campus or in a locked cabinet at the student researcher's home. Once the printed transcripts are no longer needed, we will shred them.

- We will store your consent form in a locked cabinet in the office of the faculty supervisor, separate from the transcripts of the interviews.
- We will keep data for a minimum of five years following the student researcher's completion of his doctoral degree.
- We will back-up and archive audio-recordings and transcripts on a secure server owned and managed by the University of Saskatchewan – the Paws cabinet server.
- At the end of 5 years following the completion of Adam Pierce's dissertation, all data will be permanently destroyed. Paper-based data will be shredded and electronic data will be irrevocably deleted.

**Right to Withdraw:**

- Participation is voluntary, and you are free to withdraw from the interviews at any time. Withdrawal will not result in any form of penalty. Further, you can choose not to answer questions that you are not comfortable answering.
- Should you wish to withdraw, your data will be removed from data collection and destroyed completely.
- Your right to withdraw data from the study will apply until June 2018, after which we might have already pooled your data and your data may no longer be separable from the data set. After this date, it is also possible that some form of research dissemination will have already occurred and it may not be possible to withdraw your data.

**Follow up:**

- To obtain results from the study, please feel free to contact either the student researcher or his faculty supervisor using the contact information we provided above.

**Questions or Concerns:**

- Contact the researcher using the information at the top of page 1;
- This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office [ethics.office@usask.ca](mailto:ethics.office@usask.ca) (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

**Consent:**

Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records

**I would like to review the transcripts of my interviews. Yes\_\_\_ No\_\_\_**

If you would prefer to be contacted for the purpose of transcript release through a means other than how we are currently in contact with you, or you anticipate a change in your contact information, please inform the interviewer, so he can make this note. Once a transcript is sent to you by the researcher, you will have two weeks to review the transcript and provide any revisions. If you indicate that you would like to review the transcripts, but after the two-week period have not responded to the initial request for transcript review or reminder requests, this will be taken as an indication that you do not wish to make any changes, and the transcript(s) will be used in the form sent to you. Though your transcripts will be labeled as either reviewed and altered, reviewed but unaltered, or not reviewed, your specific changes will not be highlighted throughout the transcripts.

**I grant permission to be audio taped:**

**Yes: \_\_\_\_ No: \_\_\_\_**

**I would like to be sent the final results of the research:**

**Yes: \_\_\_\_ No: \_\_\_\_**

\_\_\_\_ **Please E-mail at:** \_\_\_\_\_

\_\_\_\_ **Please mail a physical copy to:** \_\_\_\_\_

**Continued or On-going Consent:**

- This consent form pertains to your participation in the primary interviews. If after the first interview you continue to participate through partaking in a follow up interview, we will understand this participation as your consent to continue participating. Before the follow up interview, the interviewer will provide a brief verbal review of the consent process.

\_\_\_\_\_  
*Name of Participant*                      \_\_\_\_\_  
*Signature*                                      \_\_\_\_\_  
*Date*

\_\_\_\_\_  
*Researcher's Signature*                      \_\_\_\_\_  
*Date*

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***

## Appendix I

### Interview Debriefing Form

Thank you for taking part in this research project entitled, “The Social Sharing of Hallucinations.” I am conducting this project through the Department of Psychology at the University of Saskatchewan. The purpose of this project is to explore the experience of individuals who have been involved in conversations about hallucinations. For this project, we are speaking to individuals who have experienced a hallucination and spoken with another person about the hallucination *and* individuals who have spoken to someone else about the other person’s hallucination. Though some of these conversations will occur in a clinical context (for instance with a psychologist, psychiatrist, or general physician) we are particularly interested in conversations that occur outside of professional contexts, such as conversations between friends, family members, neighbors, strangers, colleagues, and so on.

A recent worldwide movement, The Hearing Voices movement, acknowledges that individuals and communities will have their own understanding of what hallucinations are, and what hallucinations mean, and that this will not always overlap with the medicalized understanding of hallucinations. By speaking with individuals outside of medical and professional contexts, my hope is to get some sense of what the experience of speaking with another person about a hallucination is like for non-professionals. The hope of the current research project is to collect accounts from individuals who have been involved in these conversations and to analyze these accounts for commonalities, as well information about what may have been helpful, harmful, or difficult about these conversations.

My hope for this study is that it will be of help to individuals who engage in these conversations from both sides of the interpersonal exchange. This help could come in at least three forms: (1) non-prescriptive recommendations for what to do and what to say during these interactions; (2) a developed empathic understanding of what the experience is like for individuals engaged in these dialogues, and (3) a capturing of this experience in such a way that eventual readers of an analysis might feel less alone in their (possible) struggle to navigate these interactions.

If you have further questions feel free to contact me, Adam Pierce, by e-mail at [adam.pierce@usask.ca](mailto:adam.pierce@usask.ca), or phone at (306) 966-6687 You may also contact my faculty supervisor, Dr. Linda McMullen, by phone at (306) 966-6666 or e-mail [linda.mcmullen@usask.ca](mailto:linda.mcmullen@usask.ca). You can also use this contact information to obtain a copy of the study results. The study was approved by the University of Saskatchewan’s Behavioural Ethics Board on July 05, 2017. Any questions concerning your rights as a participant can be addressed to the Office of Research Services at (306) 966-2975 & [ethics.office@usask.ca](mailto:ethics.office@usask.ca) or from out of town, call toll free (888) 966-2975

Once again, I would like to thank you greatly for your participation in the current study! If you are experiencing distress, I encourage you to consult some of the mental health resources I provided at the end of the consent form. If you would like another copy of the resources, please contact me, Adam Pierce, using the above contact information.

For more information on the Hearing Voices Movement, please check out the following online resource: <http://www.intervoiceonline.org/>

Thank you!

Adam Pierce, M.A.  
Clinical Psychology Graduate Student  
University of Saskatchewan  
(306) 966-6687



## Appendix J

### Transcript release initiation email

Dear \_\_\_\_\_,

On \_\_\_\_\_ you participated in an interview for the research project “The social sharing of hallucinations.” You indicated that you would like to review the transcript from your interview, and therefore I have attached a password protected copy of the transcript. The password is the pseudonym you chose. Feel free to contact me with any questions or concerns you have related to accessing the document.

Any changes you make to this document will be made to the final transcript of your interview. The purpose of you reviewing this document is to ensure that you are informed of the content of the interview, and fully consent to the use of this interview in the current research project. If you would like to retract your interview from the data, you can do so without any penalty. Please note that after November 2017, it is possible that we will have already integrated your data with the data of other participants or used it in publications, and therefore retraction after this date might not be possible.

Please keep in mind that individuals are sometimes surprised to see such things as pauses, false starts, and other such occurrences in transcripts of these interview, but these are quite common and in no way detract from the quality of the interview. If you have any questions or concerns about this, please do not hesitate to contact me.

I ask that you return your revisions within two weeks of \_\_\_\_ (insert date sent to participant) \_\_\_\_\_. If you would like an extension, please contact me. If you do not respond before the two-week period is up, I will assume you have read the transcript and do not wish to make any changes.

Thank you again for your generous participation in this project.

Sincerely,

Adam Pierce

[Adam.pierce@usask.ca](mailto:Adam.pierce@usask.ca)

(306) 966-6687

## Appendix K

### Transcript release form



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I, \_\_\_\_\_, have reviewed the complete transcript of my personal interview in this study, and have been provided with the opportunity to add, alter, and delete information from the transcript as appropriate. I acknowledge that the transcript accurately reflects what I said in my personal interview with Adam Pierce. I hereby authorize the release of this transcript to Adam Pierce to be used in the manner described in the Consent Form. I have received a copy of this Data/Transcript Release Form for my own records.

\*Though we will indicate each transcript as either reviewed and altered, reviewed but unaltered, or not reviewed, any specific changes will be embedded within the transcript, and we will not highlight them.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Signature of researcher

## Appendix L

### Snowball Recruitment Handout

Thank you for your potential interest in passing along information about the study “The Social Sharing of Hallucinations.” I am conducting this project through the Department of Psychology at the University of Saskatchewan. I am working on my PhD in Clinical Psychology and am completing this research as part of my dissertation. I also hold a Masters in Existential-Phenomenological Clinical Psychology from Seattle University, where I graduated in 2010. Between my two educational experiences I worked for years in community mental health, and the current research grows directly out of conversations I had with clients and their families during service delivery.

The purpose of this project is to explore the experience of individuals who have been involved in conversations about hallucinations. I am speaking to individuals who have experienced a hallucination and spoken with another person about the hallucination and individuals who have spoken to someone else about the other person’s hallucination. Participant groups are not matched, so we do not need to speak to both an experiencer and a listener about the same conversation. Though some of these conversations will occur in a clinical context (for instance with a psychologist, psychiatrist, or general physician) I am particularly interested in conversations that occur outside of professional contexts, such as conversations between friends, family members, neighbors, strangers, colleagues, and so on.

My hope for this study is that it will be of help to individuals who engage in these conversations from both sides of the interpersonal exchange. This help could come in at least three forms: (1) non-prescriptive recommendations for what to do and what to say during these interactions; (2) a developed empathic understanding of what the experience is like for individuals engaged in these dialogues, and (3) a capturing of this experience in such a way that eventual readers of an analysis might feel less alone in their (possible) struggle to navigate these interactions. As much as possible I hope to cycle information from the analysis back into the local community through creating informational brochures and passing along the information from my analysis along to non-profit organizations and local community mental health organizations that work with individuals likely to experience hallucinations.

If you know of someone who you believe might be interested in participating in this study, please pass along the included advertisement and encourage the person to contact me about the study. I request that you do not pass along names or contact information of individuals that you believe might be interested. Inclusion criteria for the study is that individual’s must be over the age of 18, fluent in English, and not currently experiencing an acute psychotic episode.

If you have further questions feel free to contact Adam Pierce by e-mail at [adam.pierce@usask.ca](mailto:adam.pierce@usask.ca), or telephone at (306) 966-4102. You may also contact my faculty supervisor, Dr. Linda McMullen, by phone at (306) 966-6666 or e-mail [linda.mcmullen@usask.ca](mailto:linda.mcmullen@usask.ca). The study was approved by the University of Saskatchewan’s Behavioural Ethics Board on July 5, 2017.

Once again, I would like to thank you greatly for your interest in the current study!

## **Appendix M**

### **Interview Guide – Experiencers**

Can you please tell me about a time when you experienced a hallucination?

Who have you told about this experience?

How did this person respond?

Can you tell me a bit about that conversation? (who was around, where were you, how long, etc.)

What was this like for you?

What do you think was going on for the person you told?

What influenced your decision to tell them?

Did your understanding of the hallucination change after you spoke with the other person?

Looking back now would you have done anything differently?

Looking back now do you wish that the person you told had done anything differently?

Have you spoken with them about it since?

Do you think it is difficult for others who have not experienced hallucinations to hear about hallucinations?

Other than yourself, if anyone, who would you say knows your hallucination the most or best?

How do you think those who know about it would describe your hallucination, or how you experience it?

Was there anyone you have wanted to talk to about the hallucination that you have not talked to?

Anything you think would be helpful for others to know about what the experience of telling someone else about a hallucination is like?

## **Appendix N**

### **Interview Guide – Listeners**

Can you tell me about a time that someone spoke of an experience of a hallucination with you?

How did you respond?

What was this experience like for you?

What were you thinking while this was happening?

Is there anything in your response that you wish you had done differently?

How did the person experiencing the hallucination respond to the conversation?

Did anything change between you and this other person because of the conversation?

Where does your understanding of hallucinations come from?

What would you want someone who was going to talk to someone else their hallucination to know about your experience hearing about another person's hallucination?

Is there anything else that you think it would be important to know about your experience or anything that I haven't asked that you think is important?

## Appendix O

### Transcription Key

[indicates overlapping speech]; much of this has been removed for clarity  
--indicates interruption if used at the end of a speech segment or false start in the middle of a speech segment  
(indicates preverbal information such as laughter, sighs, long pauses, body movement)  
{ Indicates information that will be removed or masked }; most of this has already been changed  
... indicates a trail off or slowly and thoughtfully turning into a new phrase mid-speech  
*Italics* indicates stress on the word

## Appendix P

UNIVERSITY OF  
**SASKATCHEWAN**

Behavioural Research Ethics Board  
**Certificate of Approval**

PRINCIPAL INVESTIGATOR DEPARTMENT Linda McMullen Psychology

BEH#

INSTITUTION(S) WHERE RESEARCH WILL BE CONDUCTED

University of Saskatchewan

STUDENT RESEARCHER(S)

Adam Pierce

FUNDER(S)

UNIVERSITY OF SASKATCHEWAN

TITLE

The Social Sharing of Hallucinations

ORIGINAL REVIEW DATE

07-Jun-2017

APPROVAL ON

05-Jul-2017

APPROVAL OF:

Application for Behavioural Research Ethics Review

Appendix A: Poster Advertisement, Experiencers

Appendix B: Poster Advertisement, Listeners

Appendix C: Contact Email for Professionals

Appendix D: Initial Contact for Experiencers

Appendix E: Initial Contact for Listeners

Appendix F: Demographic Questionnaire:

Experiencers

Appendix G: Demographic Questionnaire: Listeners

Appendix H: Consent Form

Appendix I: Interview Guide — Experiencers

Appendix J: Interview Guide — Listeners

Appendix K: Debriefing Form

Appendix L: Transcript Release Initiation Email

Appendix M: Transcript Release Form

Appendix N: Emergency Protocol

EXPIRY DATE

04-Jul-2018

Full Board Meeting

Date of Full Board Meeting:

Delegated Review

CERTIFICATION: The University of Saskatchewan Behavioural Research Ethics Board (Beh-REB) is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2 2014). The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

Please send all correspondence to:

Research Services and Ethics Office  
University of Saskatchewan