

**“I'm not telling an illness story. I'm telling a story
of opportunity”: Making sense of
voice hearing experiences**

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STATEMENT OF AUTHENTICATION

I, Stephanie Ilona Clements, hereby declare that this submission is my own work and that it contains no material previously published or written by another person, except where acknowledged in the text. Nor does it contain any material that has been accepted for the award of another degree.

In addition, ethical approval from the Northern Sydney Local Health District Human Research Ethics Committee was granted for the student presented in this thesis. Participants involved in the study gave their informed consent.

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THESIS ABSTRACT

Background/aim: Traditional approaches to voice hearing discourage the exploration of this experience. Current evidence suggests that understanding voice hearing experiences (VHE) facilitates recovery; yet, little is known about how voice hearers make sense of this phenomenon. This study aimed to explore how adults with lived experiences of voice hearing understand their VHE.

Method: A phenomenological approach guided the study design. In-depth, semi-structured interviews were conducted with five participants who attended the Hearing Voices Recovery Support Group in Sydney, Australia. Participants completed the Self-Identified Stages of Recovery questionnaire and the Revised Beliefs About Voices Questionnaire. Thematic analysis was employed to uncover the ‘essence’ of this phenomenon.

Findings: Understanding the voice hearing experience was characterized by an overarching theme of ‘tension and recalibration’. This overarching theme permeated each of five sub-themes: beliefs about voices; navigating the relationship with my voices; learning to live with my voices; rediscovering myself with my voices; and, influences to understanding my voices.

Conclusion: This study highlights how voice hearer’s understanding of VHE evolves over time, and throughout phases of recovery. Clinical implications include early intervention to support individuals to: explore their VHE to derive personal meaning; navigate their relationships with voices to promote mutually beneficial relationships; and, regain a positive sense of self.

SECTION 1: LITERATURE REVIEW

1. Introduction

1.1 Introduction to topic

Voice hearing, clinically referred to as ‘auditory hallucinations’, are defined as perceptions experienced in the absence of external sensory stimuli (Gregory, 1987; Honig et al., 1998). Hearing voices often has pervasive effects on the lives of those who hear them, known as ‘voice hearers.’ Currently, multiple perspectives exist regarding explanations for voice hearing. Traditional psychiatric approaches view voice hearing as a sign of mental illness. As such, the dominant treatment aims to eliminate voice hearing through medications. However, contemporary schools of thought informed by the Hearing Voices Movement perceive voice hearing experiences (VHE) as being understandable in the context of life events (Corstens, Longden, McCarthy-Jones, Waddingham & Thomas, 2014). A small but significant body of literature has begun to explore how voice hearers make sense of their VHE, and how this influences coping and recovery (Beavan, 2011; Fenekou & Georgaca, 2010; Holt & Tickle, 2015; Knudson & Coyle, 2002). The existing literature exploring the essence of understanding VHE is currently limited.

1.2 Aim and structure of literature review

This review aims to summarise and critique the existing literature surrounding voice hearers’ understanding of their VHE. This includes understanding the concept and experience of voice hearing; theoretical explanations for voice hearing; traditional and contemporary schools of thought around VHE and their therapeutic approaches; and, the ways voice hearers understand their VHE.

1.3 Database search method

A rigorous database search was undertaken to ensure all relevant literature was identified for contribution to this review. Multiple databases were searched: including CINAHL, PsycINFO, Medline, Scopus and Web of Science. Google Scholar was also used. Search terms included 'hearing voice*', 'auditory hallucination*', 'schizo*', 'psycho*', 'make', 'sense', 'sense-making', 'mean*', 'understand*', 'explor*', 'life experience*', 'lived*', 'experien*' and 'personal experience*'. No temporal restraints were used. Studies were limited to those published in English. Abstracts of retrieved articles were screened for relevance and reference lists of accepted articles were hand-searched to identify additional publications.

1.4 Conceptual framework guiding the study

The Model of Human Occupation (MoHO; Kielhofner, 2002) was used to guide this study. Volition is at the core of the person (Figure 1), encompassing an individual's values and beliefs. The MoHO emphasises the importance of the individual's desires in terms of goals and life direction (Kielhofner, 2008).

Individuals with VHE are often affected by self- and societal stigma, leading to a re-evaluation of their identity. Having a sense of hope, a core component of recovery, is correlated with a strong sense of self (Andresen, Caputi & Oades, 2010). Receiving a diagnosis of lifelong mental illness, or being associated with one, can compromise an individual's identity. The MoHO depicts the individuals as engaging in a feedback loop within their context (Figure 1), demonstrating how negative environmental experiences such as stigma, or a lack of helpful responses to voice hearing, directly influence volition, habituation and performance capacity. Through negative reinforcement, individuals can experience isolation, hopelessness or depression, reducing their motivation and impeding their opportunities to engage in meaningful activities. Habitual routines may be disrupted, potentially leading to role loss. Individuals experiencing debilitating symptoms may view themselves as being even less capable of performing previously valued roles. Further, individuals' environments may not afford opportunities to people who experience voice hearing. Being relegated to the 'sick role'

involves a substantial cost to personal identity, as individuals may cease to be recognised in their productive and relational roles (Kielhofner, 2008).

To overcome these challenges, voice hearers demonstrate a remarkable level of resilience. Perhaps those who accept and understand their VHE are more likely to reclaim a positive sense of self. Having social networks that embrace understanding VHE, and that allow acceptance of these experiences, support social and emotional well-being (Hammell & Iwama, 2012). Therefore, supporting voice hearers to understand their experiences holistically may empower them to regain a positive identity whilst searching for sustainable coping strategies. These values closely align with those embodied by the Hearing Voices approach, a contemporary school of thought that normalises VHE. This approach encourages voice hearers to take ownership of their experiences and seek holistic coping strategies (Corstens et al., 2014).

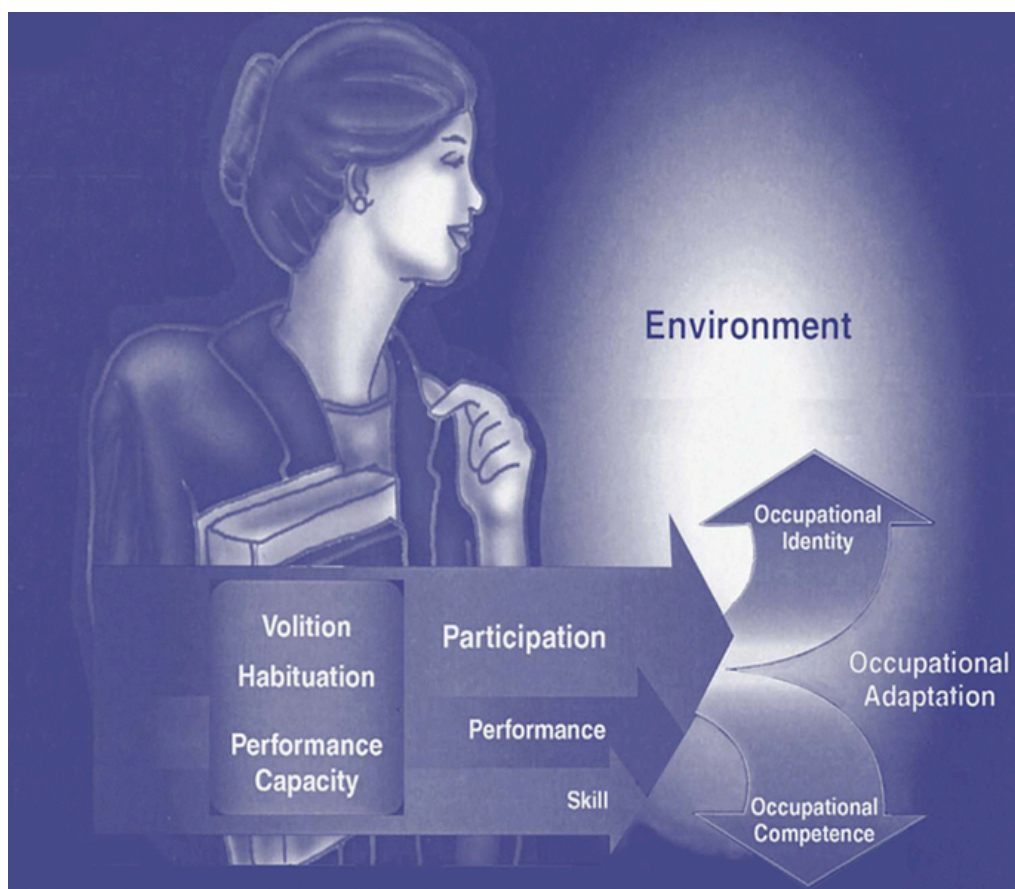


Figure 1: Model of Human Occupation (Kielhofner, 2002).

2. Hearing voices

2.1 Voice hearing: Conceptualisation and prevalence

Voice hearing is commonly experienced by a range of individuals, including those with psychotic disorders, depression, drug withdrawal or intoxication, or during high stress or sleep deprivation (Lakeman, 2001). Perceptions of voice hearing, and their inherent value, are strongly dependent on cultural contexts (Beavan, 2007). For example, voice hearing is considered a means of ancestral communication for some Maori people of New Zealand (Beavan, 2007). Conversely, the Westernised view of voice hearing is as a prime symptom of psychiatric disorders.

‘Voice hearing’ describes any extra ordinary perceptual experience that is perceived as separate from oneself (Beavan, 2007). According to a review of 17 epidemiological studies across nine countries, voice hearing is experienced by roughly 5-15% of the adult population (Beavan, Read & Cartwright, 2011). Individuals with distressing experiences of voice hearing are likely to come into contact with mental health services. Within psychiatry, ‘auditory hallucinations’ are defined as perceptions experienced in the absence of external sensory stimuli (Gregory, 1987; Honig et al., 1998). This implies that such experiences are delusional. According to the DSM-V criteria, delusions and hallucinations are considered core symptoms of psychiatric disorders (American Psychiatric Association, 2013), including:

- Schizophrenia (approximately 50%) (Haddock & Slade, 1996; Honig et al., 1998);
- Affective psychosis (approximately 25%) (Haddock & Slade, 1996; Honig et al., 1998); and
- Dissociative disorders (approximately 80%) (Honig et al., 1998).

Estimates from the 2010 Survey of People Living with Psychotic Illness found that 0.5% of Australians aged 18-64 have been diagnosed with a psychotic illness and are in contact with mental health services (Morgan et al., 2011). Individuals experiencing

‘auditory hallucinations’ experience a greater burden of disease, including higher rates of poor physical health and comorbidities (Morgan et al., 2011). Voice hearing can therefore have pervasive effects across multiple life domains.

2.2 The experience of voice hearing

Voice hearers describe VHE as complex, often confusing and idiosyncratic to each individual. For some people, voices are perceived as providing commentary, companionship, support, guidance or protection (Beavan, 2007). For others, voices may be derogatory, threatening or commanding. Self-harm may result from individuals following the voice’s commands, or as an attempt to gain relief from distressing voices (Kalhovde, Elstad & Talseth, 2014). Numerous studies have correlated negative voices with overwhelm and a loss of control or meaning to life (Honig et al., 1998; Knudson & Coyle, 2002). Derogatory voice content is strongly correlated with depressive symptoms (Soppit & Birchwood, 1997).

Voice hearing often leads to a re-evaluation of self-identity. Qualitative studies have demonstrated that voice hearers who perceived themselves as ‘different,’ avoided disclosing their VHE to others (Kalhovde et al., 2014). Instead, individuals described preferring to inform family and friends that they are depressed or drug addicted (Kalhovde et al., 2014).

Individuals may experience ongoing limitations to their engagement in meaningful activities due to voices being disruptive or intrusive (Kalhovde et al., 2014). Romme and Escher (1989) found that 275 out of 450 individuals (61%), reported experiencing demanding voices that severely impaired their contact with other people. Forty-three percent of participants noted that the voices took over their thoughts (Romme & Escher, 1989). Internal confusion may significantly impair one’s productivity, potentially leading to loss of work, social and leisure activities. Unemployment can lead to financial insecurity, which may impact housing, such as forcing the individual to relocate to an area of lower socio-demographic status (McCarthy-Jones, 2012). Since voice hearing can cause pervasive effects on the hearer’s life, it is crucial that treatment options effectively support individuals to cope with their VHE. Multiple theoretical

explanations have informed how the mental health system approaches the care of people with VHEs.

3. Theoretical explanations and approaches to voice hearing

Various schools of thought hypothesise the etiology or origins of voice hearing and therefore, how VHE are understood. These include illness, spirituality, maladaptive coping and personal relevance perspectives.

3.1 Illness perspective

The dominant theory for explaining voice hearing is the conventional illness perspective within psychiatry. This perspective views voice hearing as symptom called a ‘delusion,’ as it is considered an *excess* or *distortion* of an individual’s normal functioning (Clarke, 1998). Voice hearing is believed to be a result of structural and/or functional abnormalities of the brain (Davidson & Strauss, 1995); however, to date, the pathophysiology of voice hearing remains unidentified (de Leede-Smith & Barkus, 2013). Biological perspectives assert that the distress associated with voice hearing is caused by the form, frequency and intrusiveness of voices (Leudar & Thomas, 2000), with little onus on the content of voice hearing as impacting distress (Read & Argyle, 1999).

The psychiatric approach to voice hearing focuses on ‘symptom’ reduction, primarily through the prescription of antipsychotic medications (Leudar, Thomas, McNally & Glinksy, 1997). Evidence for the use of medications in eliminating or suppressing the occurrence of voice hearing indicates that they are ineffective for the majority of voice hearers. A study involving patients with schizophrenia found that the highest reported reason for discontinuing medication, was that voices were either insufficiently improved, or made worse (Ascher-Svanum et al., 2010). These findings accounted for 28% of interviewed patients (n=429). The effectiveness of medication has been identified to be in reducing individuals’ emotionality towards voices (McCarthy-Jones & Longden, 2013; Suri, 2011). This approach has been criticised for suppressing the voices, rather than supporting individuals to learn to cope and effectively respond to

voices (Corstens, Escher & Romme, 2008; McCarthy-Jones & Longden, 2013; Romme, 2009). Additionally, negative side effects, such as weight gain and sedation, have been reported to outweigh the benefits of medication (Asher-Svanum et al., 2010; Kalthovde et al., 2014).

3.2 Spiritual perspectives

Spiritual perspectives of voice hearing explain the phenomenon as communication with spirits or beings (Boyd-Ritsher, Lucksted, Otilingam & Grajales, 2004). Voices have been attributed to higher aspects of self, supernatural entities, demonic wrath or shamanic potential (Murphy, 1976). Others describe the experience as ‘channeling,’ or becoming a voice for other beings (Roberts, 1989).

The nature of spirituality being idiosyncratic as well as abstract, poses a challenge to empirical research to explore the link between voice hearing and spirituality. As a result, very little literature exists beyond personal testimony. However, it is noteworthy here due to the number of voice hearers who have documented beliefs relating their VHE with spiritual meaning (Holt & Tickle, 2015; Murphy, 2000).

3.3 Maladaptive coping

Psychological traditions such as psychodynamic and cognitive behavioural approaches, that recognise the concept of ‘Self’, consider that every individual consists of ‘primary’ and ‘disowned’ selves that assist in adapting to the demands of daily interactions (Stone and Stone, 1989). This theory purports that vulnerable aspects of personalities are considered to become repressed by dominant selves. Voices are thought to represent the manifestation of an essential defense maneuver for the hearer, and are considered to be triggered by the individual dissociating from emotional content in response to overwhelming life events. For instance, studies indicate that childhood bullying leads to a two-fold increased risk for the presence of psychotic symptoms (Schreier et al., 2009). This perspective purports that defense mechanisms become part of an individual’s coping, often leading to unhelpful or unhealthy patterns of coping known as maladaptive coping (Chadwick, Birchwood & Trower, 1996).

Traditional practice in behavioural psychology involves distracting the hearer, or ignoring discussion surrounding the content or characteristics of voices, as this is seen to collude with the individual's delusional beliefs (Chadwick, Birchwood & Trower, 1996; Haddock & Slade, 1996; Leudar & Thomas, 2000). This approach contradicts qualitative evidence that emphasises the desires of voice hearers to be given opportunities to discuss their experiences (Coffey & Hewitt, 2008).

3.4 Personal relevance perspective: Experiences of trauma

Emerging evidence has challenged the deeply entrenched perception within psychiatry that voice hearing represents a 'meaningless pathological phenomenon' (Corstens, Longden & May, 2012). The association between trauma and hearing voices has been established in the literature (Read, van Os, Morrison & Ross, 2005; Romme & Escher, 2000; Romme & Morris, 2013). Three key findings support correlations between trauma and VHE. First, between 70-90% of voice hearers begin to hear voices following traumatic experiences such as loss of loved ones, serious illness or abuse (Corstens & Longden, 2013; Honig et al., 1998;). Romme and Escher (1989) found links to traumatising experiences in 70% of voice hearers accessing mental health services, and 50% of voice hearers who had not accessed mental health services. This suggests that VHE are an emotional response to real life challenges (Corstens et al., 2014). Second, triggers for voice hearing activation often relate to memories of earlier traumas (Honig et al., 1998; Romme et al., 2009). Finally, VHE often embody trauma experiences, or make reference to past traumas, through either their *characteristics*, for example, the hearer may identify the voice as belonging to a past perpetrator; or, *what they say* to the hearer, for example, hearing the voice of a lost loved one (Read, Fink, Rudegear, Felitti & Whitfield, 2008; Romme et al., 2009).

4. The Hearing Voices approach: An experiential perspective

It became clear that the concept of recovery from mental illness varied significantly between the mental health system and people with mental illness, known as consumers.

Traditionally, recovery has been defined by symptomatology, hospitalisation and level of functioning (Andresen, Oades & Caputi, 2003). Developed from consumer testimonies, ‘personal recovery’ refers to the process of attaining a productive and meaningful life as defined by the individual, even in the presence of ongoing symptoms (Anthony, 1993; Deegan, 1988). Deegan, a consumer advocate and psychologist, argued that consumers “are not passive recipients of rehabilitation services. Rather, they experience themselves as recovering a new sense of self and of purpose within and beyond the limits of the disability” (Deegan, 1988, p.11).

In the last two decades, grassroots advocates from Consumer/Survivor Movements have modelled recovery and advocated for a system-wide paradigm shift from a clinical fixation on symptom relief to embrace holistic concepts of recovery and well-being (May, 2007). National policy and frameworks, such as the Commonwealth’s (2013) National Mental Health Recovery Framework and the NSW Mental Health Commission’s (2014) Living Well strategic plan, detail directions with mental health services working toward a recovery orientation. Regaining hope, redefining identity, finding meaning in life and promoting responsibility with recovery are now considered key components of the recovery process (Andresen, 2007) and are considered part of the mental health system’s core business. Recovery principles recognise the importance of collaboration between clinician and consumer, and acknowledge that the consumers’ experiential knowledge is critical to treatment planning (Oades et al, 2005). One collaborative approach that acknowledges the consumers’ expertise in a meaningful and person-led way, is the approach informed by the Hearing Voices Movement.

4.1 The Hearing Voices Movement (HVM)

In the late 1980s, psychiatrist Marius Romme, researcher Sandra Escher, and a collective of voices hearers advocated for a drastic shift in the way voice hearing is understood and treated (Romme & Escher, 1989). Driving this paradigm shift were the needs of voice hearers to have their voices heard – both their own voice, and those of their voices (Corstens et al., 2014). Contrary to traditional psychiatry, Romme and Escher’s work values the testimonies of voice hearers. This originated through Romme’s discovery that if he accepted the reality of people’s voices, rather than viewing them as ‘hallucinations’, he was able to learn more about their origin and

meaning (Sapey & Bullimore, 2013). In doing so, Romme found he could support the development of more effective ways of coping. Reframing ‘auditory hallucinations’ as ‘voice hearing experiences’, considered within the person’s life context, allowed for an expansion in the way voices could be understood by voice hearers and health professionals (Corstens et al., 2014; Sapey & Bullimore, 2013).

Romme’s other key finding was that connecting voice hearers with each other significantly reduced social isolation (Romme & Escher, 1989). In 1987, networks were established outside the mental health system for voice hearers and professionals in the Netherlands (Romme & Escher, 1989). These expanded to the United Kingdom, and have since been established in many countries worldwide, becoming embedded in the international Hearing Voices Movement (Corstens et al., 2008). Research identifying the benefits of support groups has recently gained increasing attention. Benefits include: increased understanding of voice hearing through shared experiences; learning successful coping strategies to regain control over VHE; and, providing hope and empowerment for recovery (Dos Santos & Beavan, 2015; Oakland & Berry, 2015).

The philosophy of the HVM, and the support groups to arise from it, regard voice hearing as a real and meaningful experience (Corstens et al., 2008; Corstens et al., 2014; Romme & Escher, 2000). Romme has challenged traditional approaches to voice hearing by asserting that voices represent emotional problems within the hearer’s life, and has stated that “it doesn’t make sense to attempt to cure signals of problems” (Romme, 2009, p.9). The HVM approach differs from psychiatric approaches in two respects. First, voices may be perceived as beneficial and valued by the hearer; therefore, eliminating them may not be the goal of treatment. Supporting this assertion is the finding that most recovered voice hearers still hear voices (Harrow, Jobe & Faull, 2012; Romme & Morris, 2013). Second, voices may have a therapeutic importance, where the aim of therapy is better expressed as changing the relationship with one’s voices (Gagg, 2002). Furthermore, interpreting the VHE may be crucial to developing sustainable coping mechanisms that promote recovery (Romme & Escher, 2000).

4.1.1 Phases of recovery

In their seminal study involving 450 participants, Romme and Escher (1989) found that one-third of voice hearers coped with their voices and did not require clinical support. These findings suggested that it is not the experience of voice hearing that causes distress; rather, it is the way the hearer copes or responds to the voices. A significant proportion of voice hearers have been found to cope well with their voices, and have thus offered insights into effective ways of coping with distressing VHE (Romme & Escher, 1989).

Individuals who cope with their voices have been found to transition through three recovery phases (Romme & Escher, 1989;1993). First, the ‘startling phase’ described the onset of the initial, often overwhelming, VHE. Second, the ‘phase of organisation’ denoted the search for coping mechanisms and meaning to reach an acceptance of VHE. Third, the ‘stabilisation phase’ described the period where voice hearers developed sustainable coping strategies. Romme and Escher’s phase model of recovery has been reinforced by other first-person accounts of voice hearing (de Jager et al., 2015; Kalhovde et al., 2014; Romme & Morris, 2013). This form of coping, labelled the ‘turning toward/empowerment’ narrative (de Jager et al., 2015), highlights that accepting and understanding voices is crucial to achieving sustainable coping strategies. A second ‘turning away’ recovery typology has been found, which comprised voice hearers who expressed little desire to explore their experiences. Rather, effective medication was perceived to facilitate their recovery. There is some evidence to indicate that integrative approaches to voice hearing lead to better long-term psychological health (Staring, van der Gaag & Mulder, 2011). In fact, a lower capacity to make sense of psychotic symptoms had been associated with a poorer quality of life two years from baseline (Stainsby, Sapochnik, Bledin & Mason, 2010). This evidence came from a quantitative study assessing illness perceptions amongst 50 adults diagnosed with psychotic disorders. Qualitative evidence is required to understand *how* this understanding of VHE is obtained, as well as how it may influence long-term outcomes. First-person perspectives of this nature are currently underrepresented in the literature.

This review has explored the various explanations for voice hearing within traditional and contemporary schools of thought, as well as within the context of culture, spirituality, and life experience. These explanations will now be brought together to examine the current evidence surrounding how voice hearers understand their experiences.

5. Understanding voices

Various components of understanding VHE have emerged from qualitative literature. These include: explanations for voices; identity of the voices; power of the voices; function of the voices; relationships with voices; and, coping with voices.

5.1 Explanations for voices

Voice hearers have adopted a variety of explanatory frameworks to help understand their voices, including: stress; trauma; anxiety; depression; and, spirituality (Holt & Tickle, 2015). Although some voice hearers experience difficulty identifying an explanation for the development and maintenance of their voices, many individuals actively attempt to attribute meaning to their experiences (Baker, 1995; Holt & Tickle, 2015). Some voice hearers have described feeling unsupported in making sense of VHE. A lack of available information or open discussion about hearing voices may be possible explanations for this finding (Holt & Tickle, 2015). Voice hearers have described feeling obliged to accept the explanations of health care professionals, despite the fact these explanations did not resonate with their experiences (Holt & Tickle, 2015; Kalhovde et al., 2014). Further, participants reported feeling that their explanations were dismissed by health professionals. Many individuals have expressed dissatisfaction with mental health services' limited range of explanations for voices, many of which clearly emphasise a biomedical model (Coffey & Hewitt, 2008). Limited qualitative evidence exists to identify the range of explanatory frameworks used by voice hearers to understand their experiences (Fenekou & Georgaca, 2010; Holt & Tickle, 2015). Evidence exploring how voice hearers mediate opposing explanations between themselves and outside influences is lacking. Since such frameworks have been found to mediate coping and recovery (Fenekou & Georgaca, 2010; Knudson & Coyle, 2002), further investigations are warranted.

5.2 Identity of the voices

Identifying who one's voices represent has proven to be a useful way of understanding them (Holt & Tickle, 2014). Voice hearers report that making sense of their voice's identities, content, characteristics and origin helps to identify who/what voices represent (Escher, 2009). Voice identities reported in first-person accounts have varied from: representing people within the hearer's social world (Chin, Hayward & Drinnan, 2009; Jackson, Hayward & Cook, 2010; Mawson, Berry, Murray & Hayward, 2011); to spiritual forces (Jackson et al., 2010; Jones, Guy & Ormrod, 2003; Karlsson, 2008); and strangers (Beavan, 2011).

Individuals who have attempted to identify who/what the voices represent have been found to develop theories for understanding them (Holt & Tickle, 2015). Direct correlations have been reported between beliefs about voice identity and affective response (Birchwood & Chadwick, 1997). For instance, voices that are believed to be benevolent or malevolent evoke differing emotional responses. Similarly, understanding voices as representations of emotional problems has allowed individuals to develop contextualised coping strategies. For example, identifying voices as manifestations of unexpressed emotions has allowed individuals to release tension more appropriately (Knudson & Coyle, 2002). Revealing unresolved issues within voice content may allow for psychological intervention to be introduced to assist individuals to overcome painful life events (Read et al., 2008; Romme et al., 2009). Many voice hearers report difficulty identifying who/what their voices represent, however accepting and understanding voices are thought to support this process (Romme & Morris, 2013). Although such correlations have been found, emerging evidence from first-person perspectives is required to strengthen preliminary findings.

5.3 Power of the voices

Voice hearers commonly attribute power to their voices, which mediates their emotional response and coping ability. Power has been viewed along a continuum (Chin et al., 2009; Fenekou & Georgaca, 2010; Jones et al., 2003; Karlsson, 2008; Mawson et al., 2011). Some participants felt powerless and passive to their voices' influence, whilst others felt they were able to exert power over their voices (Jackson et al., 2011; Jones et al., 2003). Power dynamics between voice and hearer were closely linked to the participant's explanations for their voices. For example, participants adopting

pathological or spiritual frameworks were more likely to feel powerless (Jones et al., 2003).

Challenging voices is a commonly reported strategy for redistributing the power balance between voice and hearer. Two studies describe this interaction as a ‘battle for control’ (Chin et al., 2009; Mawson et al., 2011). Participants often mediated tension through testing their voices’ power, setting boundaries and using distraction techniques. Voice hearers often encounter challenges with this process of mediating the power dynamic with their voices. For example, although strategies involving boundary-setting may be useful, individuals who perceive their voices as dominating may be either reluctant or unsure of how to implement them. These studies have provided insights into how voice hearers attribute power to their voices, however few studies describe how voice hearers mediate this dynamic. Further research is warranted to strengthen existing literature explaining how beliefs about power influence emotionality and coping.

5.4 Function of the voices

Perceived functions of voices mediate the hearer’s emotional response toward their voices. Participants whose voices were perceived as playing an important function, such as giving companionship or guidance, did not find their voices disturbing. Some individuals have described voices as filling a painful emptiness in their lives (Kalhovde et al., 2014). Suri (2011) asserts that more research exploring the meaning of voice hearing is required to better understand their function in the hearer’s life. This emphasises the idea that exploring personal meaning within voice content can reduce distress and enhance recovery (Beavan, 2011; Beavan & Read, 2010; Fenekou & Georgaca, 2010). Qualitative approaches accessing key informants are crucial to this process; however, to date, few of these exist.

5.5 Relationships with voices

Consumer testimonies highlight a turning point in their recoveries as being influenced by a positive shift in their relationships with voices (Romme et al., 2009). Discovering alternative perspectives of understanding and interacting with voices was crucial to this

process. Treatment goals were not to eliminate the voices, but rather change the relationship so that it became helpful. A continuum of responses to the concept of a close relationship with voices has been reported, ranging from active rejection of the voices as part of the self, to acceptance of the relationship (Chin et al., 2009). Jackson et al. (2011) discovered that all participants had integrated the voices into their lives and valued their contribution.

Relationships with voices have been found to evolve over time (Beavan, 2011; Chin et al., 2009; Jackson et al., 2011). Beavan (2011) asserted that a developing relationship with voices entails a change to the hearer's role in relation to the voices. For example, some voice hearers may adopt a more active role and refer to voices for guidance. Positive relational changes concur with Romme and Escher's (1989) findings that voice hearers enter a stabilisation phase over time, which involves integrating the voices into one's life. Many individuals experiencing distressing voices are more likely to react with anger or aggression toward their voices (Fenekou & Georgaca, 2010). These findings suggest that some voice hearers may benefit from clinical support and guidance in order to counteract destructive communication patterns and change their relationships with voices. Few studies focus on positive relationships with voices (Jackson et al., 2011), hence further research in this area is warranted.

5.6 Coping with voices

The meaning voice hearers attribute to their VHE mediates their use of coping strategies (Knudson & Coyle, 2002; Romme & Escher, 1989). Knudson and Coyle (2002) assert that researchers have investigated coping strategies used by voice hearers in isolation from their perceived meaning. The authors challenge such investigations, and assert that coping strategies are often chosen based on the hearer's understanding of VHE. Two findings support this assertion. First, correlations exist between coping style and beliefs about voices. For example, a voice hearer who drew upon multiple explanatory frameworks to explain her voices used a variety of coping strategies, whereas a participant who offered one explanation mentioned a single coping strategy (Knudson & Coyle, 2002).

Second, coping strategies taught by health professionals that are incongruent with the hearer's beliefs are generally discontinued following instruction (Knudson & Coyle, 2002; Nelson, Thrasher & Barnes, 1991). For example, even though distraction techniques may reduce the intensity of VHE, an individual that believes their voices will punish any failure to attend to them, is unlikely to use such techniques (Knudson & Coyle, 2002). This study provided insight into two narratives, however further first-person accounts may strengthen its conclusions.

6. Proposed research and significance

This review has revealed significant implications of understanding VHE. First, voice hearer testimonies demonstrate that distressing voices are often mediated through acceptance and understanding (Beavan & Read, 2010; Fenekou & Georgaca, 2010; Knudson & Coyle, 2002). Second, understanding voices determines the use of coping strategies (Knudson & Coyle, 2002). Destructive communication patterns between voice and hearer may be resolved through understanding, to enhance coping and recovery. Third, through exploring experiences, voice hearers can uncover potentially hidden meanings that may be beneficial, or suggest significant clinical implications. Fourth, preliminary evidence indicates that recovery patterns involving understanding VHE lead to better long-term outcomes in terms of quality of life. These findings suggest a need for qualitative research to explore how voice hearers understand their VHE. Although research into each of these avenues has gained increasing attention, few studies (Fenekou & Georgaca, 2010; Holt & Tickle, 2015; Knudson & Coyle, 2002) have explored how voice hearers attain a holistic understanding of this phenomenon.

Studies adopting grounded theory designs have provided a preliminary theory base for voice hearer's understanding of their experiences (Fenekou & Georgaca, 2010; Holt & Tickle, 2015). However, participants included voice hearers being treated by a psychiatric hospital, and those with distressing VHE. Participants of the former study were exposed to medical discourse, which may have influenced their understanding. This appears likely given that most participants attributed their voices to mental illness (Fenekou & Georgaca, 2010). The perspectives of voice hearers who have been exposed to a therapeutic group setting adopting the HVM principles remains unexamined.

Therefore, a phenomenological approach will be used to draw upon consumer expertise, to inform and expand the current knowledge of how voice hearers understand their VHE. The question to be explored is:

How do adults with lived experiences of voice hearing, who have participated in a clinically based Hearing Voices Group, understand their VHE?

This study will contribute to the evidence base of first-person perspectives of understanding VHE holistically. Individuals will be sampled from within the Hearing Voices Recovery Support Group, a therapeutic group adopting the principles of the HVM, that encourages the exploration of VHE in a group context. The unique approach of accessing key informants of individuals exposed to the innovative perspectives of the HVM, may uncover significant implications for coping and recovery.

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SECTION 2: JOURNAL MANUSCRIPT

**“I’m not telling an illness story. I’m telling a story of opportunity”:
Making sense of voice hearing experiences**

Running head: Making sense of voice hearing experiences

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Target Journal: Psychiatric Rehabilitation Journal

(See Author Guidelines, Appendix H)

Abstract

Objectives: The current study aimed to explore how adults with lived experiences of voice hearing, who have attended a hearing voices support group, understand their VHE.

Methods: A phenomenological approach guided the study design. In-depth, semi-structured interviews were conducted with five participants who attended the Hearing Voices Recovery Support Group in Sydney, Australia. Participants completed the Self-Identified Stages of Recovery questionnaire and the Revised Beliefs About Voices Questionnaire. Thematic analysis was employed to uncover the ‘essence’ of this phenomenon.

Results: Understanding the voice hearing experience was characterized by an overarching theme of ‘tension and recalibration’. This overarching theme permeated each of five sub-themes: beliefs about voices; navigating the relationship with my voices; learning to live with my voices; rediscovering myself with my voices; and, influences to understanding my voices.

Conclusions and Implications for Practice: This study highlights how voice hearer’s understanding of VHE evolves over time, and throughout phases of recovery. Clinical implications include early intervention to support individuals to: explore their VHE to derive personal meaning; navigate their relationships with voices to promote mutually beneficial relationships; and, regain a positive sense of self.

Keywords: auditory hallucinations, psychosis, hearing voices movement, qualitative, understanding

Introduction

Hearing voices, referred to clinically as ‘auditory hallucinations’, can have pervasive effects across an individual’s life. Hearing voices may elicit profound emotional distress and a state of confused identity for individuals who hear them, known as ‘voice hearers’. Traditional approaches view voice hearing as a symptom of psychiatric disorders such as schizophrenia (American Psychiatric Association, 2013). First-line psychiatric approaches generally aim to mitigate distress by prescribing medications to eliminate or reduce voice hearing. Overall, evidence demonstrates that medication has low efficacy in eliminating voices (Asher-Svanum et al., 2010). Poor prognoses, and stigma associated with mental illness, can leave individuals feeling ‘different’, isolated, and with little hope for recovery (Romme & Escher, 1989). As such, voice hearers articulate therapeutic needs beyond medication management, and that validate their VHE (Clarke, 1998).

A significant proportion of voice hearers cope with their experiences well and have received no psychiatric diagnosis, indicating that responses to voices may cause distress rather than the experience itself (Romme & Escher, 1989). Accepting and understanding voices constituted a key difference between patient and non-patient voice hearers (Beavan, 2011; Honig et al., 1998; Romme & Escher, 1989). Through exploring and interacting with voices, individuals have learnt to negotiate boundaries to reduce powerlessness and distress. Such perspectives suggest a more collaborative role for health professionals that involves assisting voice hearers to accept and understand their VHE to develop sustainable coping and recovery.

The Hearing Voices Movement (HVM) arose from the work of Romme and Escher. It espouses the philosophy that voice hearing is a real experience that holds metaphorical meaning in relation to voice hearers' lives, emotions and histories (Corstens, Longden, McCarthy-Jones, Waddingham & Thomas, 2014; Romme & Escher, 2000). The HVM advocates for approaches that support exploration and sense-making in the context of life events, which may include trauma, grief and loss (McCarthy-Jones & Longden, 2013). Emerging evidence suggests that voice hearers who understand their experiences have improved quality of life outcomes, with significant reductions in distress and enhanced coping (Beavan, 2011; Knudson & Coyle, 2002; Stainsby, Sapochnik, Bledin & Mason, 2010).

A small but significant qualitative evidence base exists exploring what understanding voice hearers ascribe to their VHE. How voice hearers understand their VHE is comprised of a multitude of factors. The perceived origins of voices, and the identities and characteristics of the voices themselves contribute to the messages that voice hearers take from their voices, and how they respond (Fenekou & Georgaca, 2010; Holt & Tickle, 2015). How voice hearers are able to respond and relate to their voices is dependent on a. the power of voices (Jackson, Hayward & Cook, 2010; Jones, Guy & Ormrod, 2003), and b. voice hearers' ability to cope (Knudson & Coyle, 2002).

Understanding voices as embodiments of real-life people or events can enhance coping strategies that are targeted to specifically address distress related to the voice, and in doing so, supports sustainability of coping over time (Read, Fink, Rudegeair, Felitti & Whitfield, 2008; Romme, Escher, Dillon, Corstens & Morris, 2009). These preliminary studies enlisted the perspectives of voice hearers who were either receiving individual care in a public inpatient setting at acute times of distress (Fenekou & Georgaca, 2010), or in public community services (Holt & Tickle, 2015; Knudson & Coyle, 2002).

Perceptions and understanding of voice hearers who have been exposed to the HVM philosophy through clinical mental health services remain unexamined. Accessing key informants with exposure to emancipating perspectives of VHE may uncover vastly different understanding of the VHE, as well as how this influences coping and recovery. As it has been identified that external influences play a significant role in shaping understanding of voice hearers, and therefore influencing coping around VHE (Holt & Tickle, 2015), examining the understanding of voice hearers who have experienced approaches informed by the HVM is critical to informing current clinical mental health service provision. The aim of the current study was to understand the essence of how adults with lived experience of voice hearing who participated in a clinically based Hearing Voices Group understand their VHE.

Methods

A phenomenological approach was used to guide the current study. Phenomenological approaches seek to explore the essence of lived experiences (Grbich, 2007). To date, no evidence exists describing how voice hearers who have been exposed to the unique approaches of the HVM, understand their VHE. A phenomenological approach was used to elicit detailed insights to expand the current understanding of this population within an Australian context.

Phenomenological approaches purport to accessing key informants with lived experiences of the phenomenon under investigation (Grbich, 2007). Convenience sampling was thus employed amongst consumers from the Hearing Voices Recovery Support Group (HVRSG). The HVRSG is a nine-week group series, co-facilitated by a consumer worker and mental health clinician. Based on HVM approaches, the HVRSG

aims to support voice hearers to make sense of their VHE and provide peer support with coping. Ethical approval was obtained from the Northern Sydney Local Health District Human Research Ethics Committee.

Recruitment

Potential participants were identified via a database search conducted by staff of the service. Inclusion criteria required participants to: self-identify as hearing voices; have completed at least one HVRSG series; and, be aged 18 years or over. Participation in one HVRSG series was required to provide adequate introduction to the approaches of the HVM regarding coping strategies and exploring voices. Participants were excluded if they were unable to communicate in English. Thirty-four potential participants were identified as meeting the inclusion criteria. Potential participants were notified of the study by staff of the service who had established relationships with participants.

Potential participants were notified of the study through several means: flyers were mailed out to participants of the group; announcements about the study were made at the current groups; and, staff conducted phone calls. Participants were briefed regarding the process of the study by the researcher upon initial contact. The participant information sheet and consent form were sent to participants prior to the interview. A copy of the interview guide was offered to participants before their scheduled interview. Participants were screened for signs of acute distress by the researcher at each point of interaction.

Participants

Five participants were recruited, which is consistent with other qualitative studies involving similar participant groups (Anketell, Dorahy & Curran, 2010; Knudson & Coyle, 2002). Participants' ages ranged from 30 to 63. The average duration of voice hearing was 28 years. Most participants self-identified as being in the later stages of psychological recovery of rebuilding or growth (see Table 1).

Data Collection

Semi-structured in-depth interviews were used as the data collection method for this study. Semi-structured interviews provide participants with the flexibility to explore topics that are personally meaningful to them (Minichiello et al., 2004). An interview guide was developed by the first and second researchers as a prompt to guide participants' thinking processes. The interview guide covered topics such as the participants' interpretation of their VHE at initial onset and over time, influences to understanding, coping strategies employed and the impact of the voices on their lives. Open-ended questioning and prompts were employed to further explore participants' responses. An example of an open-ended question was "Tell me the story of your experience of voice hearing from the beginning." Possible probes included: "How did you make sense of your first VHE at the time?" and, "What contributed to this?"

Audio-recorded interviews lasting 70-120 mins were conducted in a private room at a community mental health centre. Prior to interview commencement, participants were re-briefed regarding the conditions of their participation, informed that their participation was voluntary and confidential. Informed written consent was obtained. Demographics data was then collected and participants completed the following questionnaires:

Self-Identified Stages of Recovery Assessment (SISR; Andresen, Caputi, & Oades, 2006). The SISR is a 5-item scale that assesses stage of psychological recovery in terms of identity, meaning, personal responsibility and hope. Findings contributed to demographic information as a measure of participants' mental health recovery which may influence their understanding of VHE.

Beliefs About Voices Questionnaire - Revised (BAVQ-R; Chadwick, Lees, & Birchwood, 2000). The BAVQ-R is a 35-item self-report measure of beliefs about voices, including malevolence, benevolence, omnipotence, and reactions toward voices. BAVQ-R data were included as demographics data to detail the nature of relationships that participants had with their voices.

Analysis

Interviews were transcribed verbatim. Nvivo, a qualitative data organization program (QSR International, 2014), was used to assist data analysis. Thematic analysis was employed to identify and explore the relationships between emerging themes (Braun & Clarke, 2006). Thematic analysis is an inductive process that requires several stages. First, initial ideas were noted in a field diary whilst reading and re-reading the transcripts. Second, transcripts were coded line-by-line in first-level units of meaning (see Table 1). This involved assigning a literal code such as 'associated voice onset with spirituality.' Consensus coding was utilized which involved each transcript being individually coded by the researchers and then collectively comparing codes and interpretations. Third, units of meaning were grouped into second- and third-level categories. Categories and themes were continually checked for consistency with the

original data, as the first author moved backward and forward between the entire data set, coded extracts and the data analysis (Braun & Clark, 2006). The second author monitored and ratified the analysis at each stage. As required by phenomenological approaches, themes were refined and examined to ensure they captured the essence of participants' understanding of VHE. Consensus was reached between all authors, resulting in the identification of one overarching theme and five interrelated themes.

[Insert Table 1 – Coding sample]

Study findings represent the researchers' interpretations of participants' understanding of their experiences. Since taking an objective stance is not possible, researchers must be aware of, and reflect upon how personal biases may influence the research process (Braun & Clarke, 2006; Curtin & Fossey, 2007). The first author, who undertook data collection and analysis, was required to bracket assumptions and reflect upon their potential influences to the research context, process and content (Braun & Clarke, 2006). To accomplish this, a field diary and reflexive journal were kept throughout the study.

Results

Understanding the VHE was characterized by an overarching theme of 'tension and recalibration'. This overarching theme permeated each of five sub-themes: beliefs about voices; navigating the relationship with my voices; learning to live with my voices; rediscovering myself with my voices; and, influences to understanding my voices.

[Insert Table 2 – Participant Demographics here]

Overarching theme: Tension and recalibration

Each participant experienced a recurrent cycle of tension and recalibration during their journey of understanding voices. Tension acted as a driving force for participants to explore their VHE and find ways of readjusting their lives to restore equilibrium. Ella described her attempt to uncover the meaning behind a malevolent message:

It's hard to [understand] in that situation, cause you're still “*me torturing and killing my family?*” [emphasis added]” Like that one's just too much...red flagging. Which is the whole voice's point...It's just got it coming through a really confusing filter.

Theme 1: Beliefs about voices

Beliefs about voice origin. Each participant described feeling confused following the onset of voices, leading to an active search for understanding. Some participants found it necessary to “identify it over a long period of time...what these voices could be” (Daniel). Each participant experienced difficulty making sense of voices, and developed multiple theories to help with this sense-making. Theories included “high stress”, drug use, heredity, mental illness, telepathy, and spirituality.

Learning new perspectives challenged participants’ original beliefs about voices, resulting in participants either altering, or incorporating these perspectives into their

understanding of voices. For example, after learning that trauma is commonly linked to VHE, Daniel combined multiple perspectives and associated his voices with an experience of parental neglect:

[Voices are] either from a traumatic episode where you're just becoming your own best friend...I believe that they're people watching me. But I believe it all started off as a traumatic experience.

Initial beliefs about voices influenced participants' responses toward them and resulted in the use of varied coping strategies. Participants who explained voices through illness perspectives tended to be more fearful of them:

I was scared...It was new to me, the whole idea of hearing voices, and I was a little bit petrified that I was going mad. (Alex)

Conversely, those adopting spiritual perspectives tended to have more positive responses, and were more likely to interact with their voices:

I'd act on [the voices] straight away, one after the other. I thought God was looking after me. (Ben)

Beliefs about voice identity. All participants described their voices as sounding like 'real-life voices', while some participants also experienced hearing sounds other than human language. Participants personified their voices to varying degrees by naming the voices, or identifying their gender, age or personality characteristics, such as being "bubbly and friendly" (Ella). Personifying the voices was found to help participants

distinguish between their voices, though some noted that “know[ing] whose voice was what” (Alex) became more definitive over time. Participants described intimately knowing their voices by distinguishing between their voices by their different personalities. Voices were perceived as ranging from benevolent, with a “beautiful loving quality” (Ella) to malevolent and “dogmatic” (Alex).

Four participants described almost immediately recognising the identity of their voices as representing someone within their social world. Voices were identified as personifications of real-life friends, relatives or acquaintances (see Table 1). Two participants described the resemblance was so similar that they had difficulty distinguishing the voice from its real-life counterpart.

The nature of the voice’s identity determined participants’ response to their voices. Participants were more likely to engage with positive voices. Participants described different relationships with their voices based on their perceived utility:

When I’m making decisions...John Smith and Christopher Hinds are not quite up to it. Kenneth...has useful comments, whereas the other two, they can be a bit annoying at times...I take much more notice of Kenneth. (Alex)

Tension existed in participants’ beliefs as to whether their voices were separate from, or part of themselves. To make this distinction, participants questioned the nature of the voices’ identities, such as tone or “emotional quality” (Ella) from their own sense of self:

My whole tone of voice would change from when they speak, to when I speak. So it gets pretty confusing...but you get to notice that it's just not your voice... (Daniel)

Beliefs about power and control of voices. Each participant described their voices as being powerful. The power and control of voices was considered along a spectrum, from “vulnerability” (Ella) to being comparable to “uranium” (Ben). The perceived power of the voice depended on two factors: the characteristics of the voice; and, how participants responded to the voice. When voices were dominating, participants felt “plagued” (Alex) or “overwhelmed” (Ella):

When it gets scary...it's this experience of victimhood...of having that powerlessness. (Ella)

Participants described more positive relationships with voices when they felt they had more control:

There's almost a celebration when I hear the voices, and I manage the voices to be available at appropriate times. (Alex)

Theme 2: Navigating the relationship with my voices

Participants described that their relationships with voices evolved over time. Four participants improved relationships with voices as a result of more intimately understanding and knowing them. Participants described developing mutually beneficial

relationships with voices founded on trust and respect, as participants discovered how voices could provide help and fulfil their needs. For example, Cooper explained “if I didn't hear the voices, I probably wouldn't have kept my job.” Useful encouragements led to Cooper interacting with the voices for other purposes, such as asking for advice.

Interacting with voices in a way that acknowledged the needs of voices appeared crucial in supporting positive relationships. Alex described initially ignoring his first voice, which resulted in it coming “harder and faster” at him. Conversely, when he did “cooperate, it reduced in severity and frequency.” Alex described “one day I asked the voice...a question, and he replied with a very sensible reply. And I thought, I can actually interact with my voices.” This understanding marked a turning point in his relationship with his voices.

Knowing how to listen, interact and acknowledge voices allowed participants to mediate their own needs with those of their voices and assert boundaries:

If a voice comes to me at an inopportune moment...I'll say “I acknowledge you, I understand you're there, please give me two hours and we'll speak again in two hours' time.” (Alex)

When needs of the voice and participant clashed, tension arose from being unsure of how to “please them and yourself” (Cooper).

Knowing when to act or not act on the voices were described. Participants were more likely to disregard voices when they caused distress, when they disagreed with them or when they were untrustworthy:

I actually had these voices that said they were people I know...it got to the point where that's the process of learning to distrust the voice. (Ella)

When trust and respect were broken, participants reported losing the collaborative potential of the relationship:

I've asked them many a time "give me an hour break." But no they wouldn't...so I basically just abused them so much that basically they just gave me a break...if I was to be aggressive towards them it would end the friendship... (Daniel)

Theme 3: Learning to live with my voices

Participants described a process of “learning to live with your voices” (Cooper) over time that involved accepting the voices and discovering their meaning and purpose.

Accepting the voices. All participants needed to accept their voices to begin to get along with them. Some participants accepted that the voices weren't “going away”, making it necessary to “learn to relate to them a bit better” (Cooper). One participant described needing to find and accept the trauma-related meaning and origins of the voices to move on:

You've just gotta accept it and not stress about it...having that as a topic of your stress in life...you're going to get worse...Sometimes you have to

accept it and actually deal with and put in precautions of what you're going to do to overcome it. (Daniel)

Discovering the meaning and purpose of voices. Each participant attempted to discover meaning or purpose for the voices, so that they could integrate them into their lives. Relating the voices to life events, people or trauma allowed all participants to unearth significant personal lessons:

[the voices are] showing parts of me... that have been repressed, or traumas or parts that are trying to deal with different things in my life... (Ella)

Understanding the meaning or messages to voices was “thought provoking” (Alex) in supporting participants to cope with challenges:

It just takes a lot of time with overcoming the problem... identifying the problem... When it may have occurred, like here or in the past, and how to deal with the problem. (Daniel)

Participants described diverse benefits of hearing voices: being a friend or companion through periods of isolation; replacing the role of lost ones; and guiding decision-making or growth.

Voices were found to play a helpful role in overcoming or resolving the issues they embodied. Voices also supported emotional expression, or provided ‘fulfilment,’ or a way of healing oneself:

The songs that I sung [with the voices] was to actually...heal my inner self...the songs would actually make me express my emotions out. (Daniel)

Theme 4: Rediscovering myself with my voices

A dynamic interplay emerged between participants' VHE and self-identity. Four participants adopted illness identities, labelling themselves as "schizophrenic," "mad" or "psycho." Ella commented that it was often difficult to resist assuming the "societal...archetype of the crazy one. The insane person who is, by definition, defective and inferior". She emphasised that "getting clearer" on her identity was a crucial supporting factor for her recovery. Participants described how approaches that encouraged exploration and understanding and VHE empowered them and promoted a positive sense of self.

Two participants identified having voices that embodied and reinforced negative perceptions of self such as "feeding off" "shame," "self-hatred" and "worthlessness" (Ella). This sometimes negatively affected sense of self that increased participants' distress: "the voices sometimes kick you while you're down, and it's bad for your self-esteem" (Cooper).

Although most participants described experiencing "ups and downs", they each described the VHE as a pathway for "personal growth", rediscovery and transformation. This journey involved tension for each participant. Despite this, four participants expressed no desire to eliminate the voices from their lives:

Sometimes you don't want your voices cause they're driving you nuts and sometimes you need them to get through daily life...I've been through hell since I was about 18...but at the same time, it's helped to shape me as a person...it's been worth it 'cause I've come out a different person. (Cooper)

Theme 5: Influences to understanding my voices

First response. Initial responses from others had profound influences on how participants understood their VHE. Two participants noted that they “had not heard of anyone hearing voices before” (Alex), which led them to believe that voice hearing was an abnormal experience that signified madness. Mental health professionals and social supports reinforced this belief that often cause distress for participants:

I said "yeah, I'm hearing voices and it's weird."...didn't really get anything back from them [family members]...I felt like I was on my own. (Cooper)

It is important to note that no participant reported experiencing positive or affirming initial responses to their voice hearing from anyone.

Mental health clinician approaches. Four participants described their clinical management as having profound influences to their understanding of VHE. They described that pathological discourses of voice hearing invalidated their perspectives and had negative influences on identity:

I'll say "I hear a presence that's a divinity..." And my...medical person is sitting there going "crazy box". There's a filter that rejects that experience.
(Ella)

Participants described this approach as destructive as they enforced an "absolute" diagnosis and gave little hope for recovery: "suppress[es]...a lot of the fuel that you need for change" (Ella).

Conversely, positive experiences of clinical management were reported by participants whose medical professionals were "starting to think 'ok, maybe there is sense in the voices'" (Cooper).

Hearing Voices Recovery Support Group (HVRSG). Participants described many "gifts" from the HVRSG that supported understanding of VHE and recovery. Two participants "began to see more and more, the links to trauma" (Ella) which enabled them to understand "where the voices come from" (Daniel). Each participant emphasised the significance of the Hearing Voices approach in facilitating respect and empowerment in the VHE that differed from the medical discourse that participants had "endured":

I...had that ah-ha moment, understanding that I'm not unwell when I'm hearing voices. And that whole model of hearing voices from the sickness model to the celebrated model. (Alex)

The HVRSG provided a platform for participants to explore their VHE by sharing their stories. This aspect of the group was highly valued and marked a turning point in participants' understanding:

Learning to tell my story [a different] way shifted...so much for me... So I'm not telling an illness story. I'm telling a story of opportunity or learning. (Ella)

Participants emphasised the purpose of sharing in reducing the feelings of isolation and hopelessness they had experienced for many years: “It was a real ‘I’m not alone in this situation anymore’” (Ben).

Each participant highlighted how the HVRSG taught them that they could “recover from the voices” (Daniel). Many had not considered recovery possible, given the prognosis they had previously received. Learning that other voice hearers could lead normal lives gave participants confidence: “I thought if this person is having voices and they're doing this and that...why can't I?” (Cooper). This understanding inspired hope for recovery. Each participant attempted management strategies they had learnt from the HVRSG to navigate their relationships with voices:

I really started getting some real traction in managing the voices...taught me how to interact with my voices, how to make time for them to come at a different time. (Alex)

Social supports. Each participant pursued support from family members for their VHE, which either enhanced or hindered their understanding. Some participants described feeling isolated by their family’s lack of understanding. This left participants feeling unsupported and isolated:

As a child, you don't know how to explain it to your family, or no one's listening to you. Or, like, you don't have anyone to talk to. So you bottle it up within yourself. (Daniel)

Participants described the importance of receiving support from family and friends for their VHE, particularly during periods of unwellness or distress:

He'll help me keep perspective. You know, "[the voices] might've said you were gonna hurt your mum, but you didn't."

Discussion

This study aimed to explore how voice hearers who participated in the Hearing Voices Recovery Support Group understand their VHE. Participants offered insight into how this understanding changed as they progressed through the psychological stages of recovery. The findings presented here are relevant to participants of a peer support group that is informed by the philosophy of the HVM. A key theme of this study is the role that beliefs play in voice hearers' understanding of VHEs. As such, comparing understandings from voice hearers who have not had this exposure would be beneficial to extrapolate further influences to understanding. Whilst the small sample size and lack of gender and cultural diversity limits generalisability, the depth of interviews promoted significant insight into the understanding of each participant.

The findings of this study constitute three key implications to the current evidence base.

First, this study identified voice hearers' assertions that VHE may contribute positively to their lives. The current evidence base is dominated by studies examining the distress and disability caused by negative VHE. However, many personal testimonies (Romme et al., 2009) and a small number of qualitative studies (Holt & Tickle, 2015; Fenekou & Georgaca, 2010) have established that VHE are a profound and all-encompassing experience that can involve tension, from which personal growth emerges, as much as distress and disability. Each participant of this study described a non-linear journey that, in hindsight, offered them an opportunity for growth. Recovery was defined as learning to navigate the relationship with voices in a more positive and helpful manner. This study highlights the usefulness of voices that is understood when the hearer learns to live with their voices, rather than eliminating or suppressing them. This supports evidence from HVM approaches which indicate that recurrences and relapses may present an opportunity for learning and growth. Thus, difficult VHE may be a crucial part of the individual's recovery, rather than an adverse outcome (Corstens et al., 2014).

Second, a key theme of the study illuminated the intrinsic relationship between voice hearing and identity. Onset of voice hearing was marked by a period of overwhelm, heightened emotion and, most importantly, a state of confused identity. Participants demonstrated their identity being negatively affected by voices that were critical or derogatory in nature, as well as unhelpful responses from family or health professionals. This led some participants to adopt an 'illness identity'. Identity is a critical element of personal recovery, with multitudes of consumers' recovery testimonies articulating the crucial process of recovering self and identity, along with other aspects of well-being (Anthony, 1993; Deegan, 1988). As the vision and plan for mental health service transformation, the NSW Mental Health Commission's (2014) *Living Well: A Strategic Plan for Mental Health in NSW* calls for service provision to be better integrated and

more holistic in meeting the needs of consumers. This finding presents an avenue for opportunity in identifying *how* mental health services can helpfully respond to people who experience voice hearing. First onset support is as critical to promoting well-being, and hopefulness, as support and therapy.

Third, the overarching theme of tension and recalibration gave rise to participants deepening understanding of their voices and navigating interactions with them.

Participants identified sense-making as a key mechanism of navigating interactions; that is, making sense of one's own needs versus the needs of the voices, and making sense of meaning in the voices' messages. Participants articulated the opportunity provided through the HVRSG to engage in sense-making, and in doing so, to strengthen understanding. Exploring and understanding voices further influenced the ways participants went about their relationships with voices; for example, acknowledging, negotiating and boundary-setting. The process of sense-making aligns with strategies advocated by Romme and Escher (1989) as part of the 'Organisation phase' of recovery, which includes finding meaning and acceptance, and developing coping. These processes are crucial to living with voices, which defines the final phase of recovery, the 'Stabilisation phase.' All participants identified that the opportunity to engage in sense-making around their VHE had not previously been afforded within their interactions with mental health services. Participants' average length of duration of voice hearing was 28 years, with engagement with mental health services having occurred for the majority of this duration. Therefore, the question must be considered as to why such an opportunity to explore VHE is not more commonplace within mental health services. These findings emphasise the need for mental health services to re-evaluate how and when they intervene with people at first onset of voice hearing, beyond medication management. The evidence for approaches that support sense-making as a first line

response to distress and unwellness already exists. One such approach is the Finnish model, Open Dialogue which is founded on the principles of: immediate support (within 24 hours of assistance being sought); within voice hearers' familial context; and, integrated pharmacological coupled with psychological treatment guided by voice hearers themselves (Seikkula et al., 2006). Preliminary outcomes at five-year follow-up are promising: 82% of participants did not have any residual psychotic symptoms, 86% had returned to full-time work or studies, and only 29% had received neuroleptic medication at some point of treatment. Earlier intervention and support for voice hearers to more readily navigate through the early phases of VHE could lead to the achievement of better outcomes in recovery and well-being for voice hearers.

Conclusion

The current study offers a distinct contribution to the literature of the importance and therapeutic benefit of supporting voice hearers to explore their VHE, and in doing so, derive personal meaning. Supporting individuals to navigate their relationships with voices, has the potential to promote mutually beneficial, lifelong relationships and interpersonal and intrapersonal skill development. Future qualitative research into the utility and effectiveness of unorthodox and alternative approaches to working with voice hearers is warranted in supporting the recovery of people with VHE. This is especially pertinent for individuals who find themselves placed within a clinical mental health framework.

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Tables

Table 1. Coding Sample

Excerpt from interview transcript	“I thought God was looking after me. I was 19, I felt well this is a passage of life.” (Ben)
Individual unit of meaning	Associating VHE with spirituality
Second level category	Explanation for VHE
Third level category/sub-theme	Beliefs about voice origin
Theme	Beliefs about voices

Table 2: Participant Demographics

Participant Code	Alex	Ben	Cooper	Daniel	Ella	
Gender	Male	Male	Male	Male	Female	
Age (years)	62	54	43	30	38	
Diagnosis	Schizophrenia	Schizophrenia	Schizoaffective Disorder	Schizophrenia	Undifferentiated schizophrenia	
Current number of voices	5	1	2 or 3	Multiple	5	
Identities of voices	'Kenneth' (Movie character), 'Jen' (own mother), unnamed (7-year old self), 'Christopher' (real-life lawyer), 'John' (stranger)	Unknown	Own conscience	Artificial Intelligence (members of criminal internet gang), Own conscience	'Dane' (Ex-boyfriend), 'Clara,' friend, 3 strangers	
Hearing voices within the last week?	Yes	Yes	Yes	Yes	Yes	
Approximate duration of voice-hearing (years) (mean = 27 years)	37	36	27	26	9	
Number of HVRSG series participated in	2	2	12	1	13	
Self-identified stage of recovery (SISR) (Stages 1-5)*	4; Rebuilding	4; Rebuilding	4; Rebuilding	2; Awareness	5; Growth	
Beliefs About Voices Questionnaire - Revised (BAVQ-R) item scores	Malevolence (0-18)	2	4	8	1	5
	Benevolence (0-18)	16	10	14	10	14
	Omnipotence (0-18)	9	8	13	5	7
	Resistance (0-27)	7	14	19	9	10
	Engagement (0-24)	20	17	17	14	22

* Self-identified stage of recovery (SISR; Andresen, Caputi & Oades, 2010): (1) **Moratorium** - A time of withdrawal characterized by a profound sense of loss and hopelessness; (2) **Awareness** - Realization that all is not lost, and that a fulfilling life is possible; (3) **Preparation** - Taking stock of strengths and weaknesses regarding recovery, and starting to work on developing recovery skills; (4) **Rebuilding** - Actively working towards a positive identity, setting meaningful goals and taking control of one's life; and, (5) **Growth** - Living a full and meaningful life, characterized by self-management of the illness, resilience and a positive sense of self.

Appendices

Appendix A – Ethics Approval: Northern Sydney Local Health District Human Research Ethics Committee

Research Office
Kolling Building, Level 13
Royal North Shore Hospital
St Leonards NSW 2065
Tel (02) 9926 4590 Fax (02) 9926 6179



8 July 2015

Ms Francesca Coniglio
Mental Health Drug & Alcohol
Cameron Building
Macquarie Hospital, Coxs Road
North Ryde NSW 2113

Dear Francesca

NSLHD reference: RESP/15/91

Title: Hearing voices and understanding what they say: Lessons from the Hearing Voices Recovery Support Group

HREC reference: HREC/15/HAWKE/136

SSA reference: SSA/15/HAWKE/216

Thank you for submitting an application for authorisation of this project. I am pleased to advise that the delegate of the Chief Executive for Northern Sydney Local Health District on **6 July 2015** has granted authorisation for the above project to commence at **Northern Sydney Local Health District, Mental Health Drug and Alcohol, Specialist Rehabilitation Service**.

The version of the SSA reviewed by NSLHD RGO was: **AU/2/6D8F116**.

Ethical approval for this study was granted by the **Northern Sydney Local Health District HREC** at a meeting of the Executive Committee held on **15 June 2015**.

The documents authorised for use at this site are:

Document	Version	Date
Study Protocol	2	1 June 2015
Participant Information Sheet and Consent Form	2	1 June 2015
Recruitment advertisement	2	1 June 2015
Interview Guide	1	27 April 2015
Demographics Collection Sheet	1	27 April 2015
Self-Identified Stages of Recovery (SISR)	1	27 April 2015
Beliefs and Values Questionnaire (BAVQ-R)	1	27 April 2015
Distress Protocol Guide	1	27 April 2015
Research Safety Protocol	1	27 April 2015

Site authorisation will cease on the date of HREC expiry **15 June 2020**

You are reminded that, in order to comply with the Guidelines for Good Clinical Research Practice (GCRP) in Australia, and in accordance with additional requirements of NSLHD, the Chief Investigator is responsible for ensuring the following:

1. The HREC is notified of anything that might warrant review of the ethical approval of the project, including unforeseen events that might affect the ethical acceptability of the project.
2. The HREC is notified of all Serious Adverse Events (SAEs) or Serious Unexpected Suspected Adverse Reactions (SUSARs) in accordance with the Serious Adverse Event Reporting Guidelines.
3. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and are submitted to the lead HREC for review, are copied to the Research Governance Officer.

4. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project are to be submitted to the Research Governance Officer.
5. The annual report acknowledgment from the Lead HREC should be submitted to the Research Governance Officer.

Standard forms and additional guidance documents are available on the Research Office Website:
<http://www.nslhd.health.nsw.gov.au/AboutUs/Research/Office>

Yours sincerely



Sarah McNeill
Research Governance Officer and Compliance Manager
Research Office
Northern Sydney Local Health District

cc. Stephanie Clements
TRIM RESD/15/4385

Appendix B - Participant Information Statement and Consent Form



PARTICIPANT INFORMATION SHEET AND CONSENT FORM

NON-INTERVENTIONAL STUDY

HEARING VOICES AND UNDERSTANDING WHAT THEY SAY: LESSONS FROM THE HEARING VOICES RECOVERY SUPPORT GROUP

Invitation

You are invited to take part in a research study about hearing voices. This study aims to understand how adults who experience voice hearing make sense of their experiences, and how their participation in the Hearing Voices Recovery Support Group has influenced their understanding.

The study is being conducted by a team of researchers from the Faculty of Health Sciences, University of Sydney in collaboration with Northern Sydney Local Health District. The research team consists of Francesca Coniglio, Stephanie Clements and Dr Lynette Mackenzie.

The results of this research will be used by the Associate Researcher, Stephanie Clements to form the basis of her research study to obtain a Masters of Occupational Therapy.

This research has been initiated by Principal Researcher, Francesca Coniglio.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

1. 'What is the purpose of this study?'

The purpose is to investigate how adults make sense of their voice hearing experiences. We are also interested to know about how the Hearing Voices Recovery Support Group influences the understanding or sense making process of individuals who experience voice hearing.

2. 'Why have I been invited to participate in this study?'

You are eligible to participate in this study because you are an adult aged 18 years or over, you have participated in a Hearing Voices Recovery Support Group run by the Northern Sydney Local Health District Specialist Rehabilitation Service, and you identify as having voice hearing experiences.

3. 'What if I don't want to take part in this study, or if I want to withdraw later?'

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the

staff caring for you within Northern Sydney Local Health District or with the University of Sydney.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, and without there being any consequences of doing so. In the event of you withdrawing from the study, any information e.g. demographics or interview data, provided by you will be removed from the study.

4. 'What does this study involve?'

You will be asked to participate in an interview lasting 60-90 minutes, depending on how much you wish to share. You will also be asked to complete the Self-Identified Stages of Recovery Assessment and Beliefs About Voices Questionnaire during your interview time. If you agree to be re-contacted, you may also be asked to attend a follow-up interview within two months. You are welcome to take breaks during the interview, or to suspend the interview and continue at another time if needed.

Interviews will take place in a private room at a local community health facility at a time convenient to you. The interviews will be audio recorded to allow Stephanie to type a transcript afterwards. No names or other identifying information will be used in the transcript. You will be offered a copy of your typed interview.

Discussion topics will include:

- Your experiences of voice hearing;
- How you make sense of these experiences in relation to life events;
- How you believe the Hearing Voices Recovery Support Group has influenced your understanding of your voice hearing experiences.

5. 'How is this study being paid for?'

This study is being conducted as part of Stephanie's Masters of Occupational Therapy research program at the University of Sydney. No funding has been provided for this study.

6. 'Are there risks to me in taking part in this study?'

There is always a small risk that discussions around people's experiences of voice hearing may elicit feelings or memories of discomfort or distress. Should you experience discomfort or distress during the interview, you are free to take a break from the interview, or to terminate the interview. Stephanie will also be observing for signs of discomfort or distress and may suggest that the interview be stopped.

If you become distressed during the interview, Stephanie will contact a clinician from the Specialist Rehabilitation Service located on site to provide you with the opportunity for counselling and support as needed. With your permission, the clinician from the Specialist Rehabilitation Service can contact your Community Mental Health Team to provide support around your wellness plan and address the distress experienced.

7. 'Will I benefit from the study?'

There are no direct benefits from participating in this study. The benefits of this study for the broader community may include assisting clinicians to improve their understanding of how to better support voice hearers to cope with their voice hearing experiences. It is hoped that you will find the opportunity to explore your experiences worthwhile.

8. 'Will taking part in this study cost me anything, and will I be paid?'

Participation in this study will not cost you anything. You will be given a \$20 shopping voucher as a small thank you for sharing your time and experiences. Refreshments will also be provided during your interview.

9. 'How will my confidentiality be protected?'

Of the people involved in your care, only Stephanie and Francesca will know whether or not you are participating in this study. Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Interview recordings will be stored in a password protected file that only Francesca and Stephanie will have access to. Any identifiable information such as names of people or places will be de-identified in written records of your interview. Only the researchers and the Northern Sydney Human Research Ethics Committee (HREC) for monitoring purposes will have access to your details and results that will be held securely at Mental Health Drug and Alcohol, Northern Sydney Local Health District.

10. 'What happens with the results?'

If you give us your permission by signing the consent document, we plan to discuss/publish the results in a thesis and in peer-reviewed journals.

In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish.

11. 'What should I do if I want to discuss this study further before I decide?'

When you have read this information, Stephanie or Francesca will discuss it with you and answer any queries you may have. If you would like to know more at any stage, please do not hesitate to contact Stephanie on 0434 323 128 or scle5803@uni.sydney.edu.au or Francesca on 0408 980 602 or Francesca.Coniglio@health.nsw.gov.au

12. 'Who should I contact if I have concerns about the conduct of this study?'

This study has been approved by the Northern Sydney Local Health District HREC. Any person with concerns or complaints about the conduct of this study should contact the Research Office who is nominated to receive complaints from research participants. You should contact them on 02 9926 4590 and quote HREC reference number: HREC/15/HAWKE/136.

**Thank you for taking the time to consider this study.
If you wish to take part in it, please sign the attached consent form.
This information sheet is for you to keep.**

CONSENT FORM
NON-INTERVENTIONAL STUDY

HEARING VOICES AND UNDERSTANDING WHAT THEY SAY:
LESSONS FROM THE HEARING VOICES RECOVERY SUPPORT GROUP

1. I,.....of..... agree to participate as a subject in the study described in the Participant Information Sheet set out above (or: attached to this form).
2. I acknowledge that I have read the Participant Information Sheet, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.
3. Before signing this consent form, I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation and I have received satisfactory answers.
4. I understand that I can withdraw from the study at any time without prejudice to my relationship to the investigators, the Northern Sydney Local Health District or the University of Sydney.
5. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.
6. I understand that if I have any questions relating to my participation in this research, I may contact Stephanie Clements on 0434 323 128 or scl5803@uni.sydnev.edu.au or Francesca Coniglio on 0408 980 602 or Francesca.Coniglio@health.nsw.gov.au who will be happy to answer them.
7. I acknowledge receipt of a copy of this Consent Form and the Participant Information Sheet.

Complaints may be directed to the Research Office on Level 13, Kolling Building, Royal North Shore Hospital, St Leonards NSW 2065
Phone 02 9926 4590 | email NSLHD-research@health.nsw.gov.au

Signature of participant	Please PRINT name	Date
Signature of witness	Please PRINT name	Date
Signature of investigator	Please PRINT name	Date

NON-INTERVENTIONAL STUDY

HEARING VOICES AND UNDERSTANDING WHAT THEY SAY: LESSONS FROM THE HEARING VOICES RECOVERY SUPPORT GROUP

REVOCACTION OF CONSENT

I hereby wish to **WITHDRAW** my consent to participate in the study described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with the Northern Sydney Local Health District or University of Sydney, or my medical attendants

Signature of participant

Please PRINT name

Date

The section for Revocation of Consent should be forwarded to:

Francesca Coniglio

Cameron Building

Macquarie Hospital

Wicks Rd, North Ryde

NSW 2113 AUSTRALIA

Telephone: 0408 980 602

Email: Francesca.Coniglio@health.nsw.gov.au

Appendix C - Demographics Data Collection Sheet

Participant Demographics Collection Sheet

Participant Code: _____

Age: _____

What is your gender? _____

Suburb/State: _____

What is your living arrangement?

- Live alone
- Live with my partner
- Live with housemates
- Live with my parents
- Live with my partner and family
- Live with my children

Do you have a partner/spouse? Yes No

Do you have children? Yes No

Are you of Aboriginal or Torres Strait Islander origin? Yes No

Do you identify as being from a Culturally and Linguistically Diverse Background?

Yes If yes, what is your background? _____

No

Do you identify as lesbian, gay, bisexual, transgender, or intersex? Yes No

Do you agree to being re-contacted by the researcher for a further interview if required?

I give permission for the researcher to contact me for further interview or information.

I do not give permission for the researcher to contact me for further information.

Would you like to receive a copy of your transcript? Yes No

Would you like to receive a lay-summary of findings? Yes No

Would you like to receive copies of any publications? Yes No

Where would you like these sent to e.g. email, postal address?

Email/Postal address: _____

Appendix D - Recruitment Advertisement



Researchers from the University of Sydney and the Northern Sydney Local Health District are conducting a study to understand how people with voice hearing experiences make sense of their experiences, and how they believe the Hearing Voices Recovery Support Group has influenced their recovery.

We want to hear about...

1. What it's like to hear voices and how you make sense of this experience
2. Your experiences with the Hearing Voices Recovery Support Group

Findings from this study may assist clinicians to better support individuals to understand their voice hearing experiences.

What will participation involve?

- An interview will take around 60-90 minutes, depending on how much you would like to share. Interviews will be held at a place and time that suits you. Refreshments and breaks will also be offered.
- You will be given a \$20 shopping voucher as a small thank you for sharing your time and experiences.

If you are interested in being involved or would like further information please contact Stephanie Clements:

Phone: 0434 323 128

Email: scle5803@uni.sydney.edu.au

Recruitment advertisement: **Hearing Voices**

Version 2 01/06/15

This study has been approved by the Northern Sydney Local Health District Human Research Ethics Committee, reference: HREC/15/HAWKE/136

Appendix E - Interview Guide

“We want to learn more about how people make sense of their voice-hearing experiences in relation to their life. We also want to understand how the Hearing Voices Recovery Support Group may have supported or influenced the recovery of voice hearers.”

- Tell me the story of your experience of voice hearing from the beginning.

Possible probes may include:

- When was your first experience of voice hearing?
- What did the voice(s) sound like? What did it/they say?
- How did your first voice hearing experience make you feel?
- How did you make sense of your first voice hearing experience at the time?
- What contributed to this?
- Do you see any significant events relating to your first voice hearing experience?
- What did you do following your first voice hearing experience?
- Did you tell anyone/seek professional support?
- What support did you receive?

- Can you tell me about your current experiences of voice hearing?

Possible probes may include:

- Has/have your voice(s) changed? If so, how have they changed?
- What sense do you make of these changes?

- What influence have your voice hearing experiences had on your life?
- Can you tell me about how you make sense of your voice hearing experiences?
- What has contributed to this understanding?
- What would/does recovery look like for you?
- What have you learnt from your voice-hearing experiences?

- Tell me about your participation in the Hearing Voices Recovery Support Group (HVRSG).

Possible probes may include:

- When did you begin participating in the group?
- How many groups have you participated in?
- How has the group influenced your understanding of your voice hearing experiences?
- What things about the group have influenced your understanding?
- What have you learnt from the group?

- Is there anything else you think I should know to better understand your voice hearing experiences, or your experience of the HVRSG?

Appendix F - Self-Identified Stages of Recovery (SISR) (Andresen, Caputi & Oades, 2010).

Self-Identified Stages of Recovery (SISR)

PART A

People who are told they have a serious illness can feel differently about life with the illness at different times. Below are five statements describing how people may feel at times when living with a mental illness.

Please read **all five** statements (A-E) before answering the question that follows.

- A. "I don't think people can recovery from mental illness. I feel that my life is out of my control, and there is nothing I can do to help myself."
- B. "I have just *recently* realised that people can recover from serious mental illness. I am *just starting* to think it may be possible for me to help myself."
- C. "I am starting to learn how I can overcome the illness. I've decided I'm going to start getting on with my life."
- D. "I can manage the illness reasonably well now. I am doing OK, and feel fairly positive about the future."
- E. "I feel I am in control of my health and my life now. I am doing very well and the future looks bright."

PART B

Below are four statements about how people can feel about aspects of their lives.

For the **past month**, how much would you agree with each statement?

Please circle the appropriate number.

1) I am confident that I will find ways to attain my goals in life.

Disagree Strongly	Disagree	Disagree Somewhat	Agree Slightly	3	Agree Slightly	4	Agree Somewhat	5	Strongly	6
1		2								6

2) I know who I am as a person, and what things in life are important to me.

Disagree Strongly	Disagree	Disagree Somewhat	Agree Slightly	3	Agree Slightly	4	Agree Somewhat	5	Strongly	6
1		2								6

3) The things I do in my life are meaningful and valuable.

Disagree Strongly	Disagree	Disagree Somewhat	Agree Slightly	3	Agree Slightly	4	Agree Somewhat	5	Strongly	6
1		2								6

4) I am completely responsible for my own life and wellbeing.

Disagree Strongly	Disagree	Disagree Somewhat	Agree Slightly	3	Agree Slightly	4	Agree Somewhat	5	Strongly	6
1		2								6

Appendix G - Beliefs about Voices Questionnaire – Revised (BAVQ-R)
(Chadwick et al., 2000)

There are many people who hear voices. It would help us to find out how you are feeling about your voices by completing this questionnaire. Please read each statement and tick the box which best describes the way you have been feeling in the past week.

If you hear more than one voice, please complete the form for the voice which is dominant.

Thank you for your help.

		Disagree	Unsure	Agree slightly	Agree strongly
1	My voice is punishing me for something I have done				
2	My voice wants to help me				
3	My voice is very powerful				
4	My voice is persecuting me for no good reason				
5	My voice wants to protect me				
6	My voice seems to know everything about me				
7	My voice is evil				
8	My voice is helping to keep me sane				
9	My voice makes me do things I really don't want to do				
10	My voice wants to harm me				
11	My voice is helping me to develop my special powers or abilities				
12	I cannot control my voices				
13	My voice wants me to do bad things				
14	My voice is helping me to achieve my goal in life				
15	My voice will harm or kill me if I disobey or resist it				
16	My voice is trying to corrupt or destroy me				
17	I am grateful for my voice				

18	My voice rules my life				
19	My voice reassures me				
20	My voice frightens me				
21	My voice makes me happy				
22	My voice makes me feel down				
23	My voice makes me feel angry				
24	My voice makes me feel calm				
25	My voice makes me feel anxious				
26	My voice makes me feel confident				

When I hear my voice, usually ...

		Disagree	Unsure	Agree slightly	Agree strongly
27	I tell it to leave me alone				
28	I try to take my mind off it				
29	I try to stop it				
30	I do things to prevent it talking				
31	I am reluctant to obey it				
32	I listen to it because I want to				
33	I willingly follow what my voice tells me to do				
34	I have done things to start to get in contact with my voice				
35	I seek the advice of my voice				

Scoring Guidelines

All items have a four-point response range, Disagree (score 0), Unsure (score 1), Agree slightly (score 2) and Agree strongly (score 3).

The questionnaire has three scales measuring meaning given to the voice:

Malevolence (items 1, 4, 7, 10, 13, 16)

Benevolence (items 2, 5, 8, 11, 14, 17)

Omnipotence (items 3, 6, 9, 12, 15, 18)

These three scales therefore have a range of possible scores 0–18.

Following the original BAVQ, the questionnaire also measures Resistance and Engagement, two ways of relating to voices. Resistance and Engagement both contain emotional and behavioural items.

Resistance

- Emotion (items 20, 22, 23, 25): range 0–12
- Behaviour (items 27, 28, 29, 30, 31): range 0–15

Engagement

- Emotion (items 19, 21, 24, 26): range 0–12
- Behaviour (items 32, 33, 34, 35): range 0–12

Emotion and behaviour scores can either be totalled to give one overall score for Resistance (range 0–27) and Engagement (range 0–24), or looked at separately, or both.

Appendix H - Psychiatric Rehabilitation Journal Author Guidelines

Journal Aims and Scope

Psychiatric Rehabilitation Journal® (*PRJ*) publishes original contributions related to the rehabilitation, psychosocial treatment, and recovery of people with serious mental illnesses. *PRJ's* target audience includes psychiatric rehabilitation practitioners and researchers, as well as recipients of mental health and rehabilitation services.

PRJ encourages submissions regarding mechanisms of change in rehabilitation and psychosocial treatment programs, as well as evaluation studies of model programs, and investigations of effectiveness and cost-effectiveness of programs conducted in "real world" settings. Descriptive studies of "cutting edge" programs, especially those informed by the lived experience of mental illness, are also welcome.

Topics within the purview of *PRJ* include:

- studies of the development, refinement, or evaluation of psychiatric rehabilitation or psychosocial treatment programs, including rigorous case studies, open pilot studies, quasi-experimental designs, and randomized controlled trials
- research on the implementation of rehabilitation or psychosocial treatment programs, including studies of organizations and organizational change
- studies of peer support or other peer provided interventions for persons living with serious mental illness
- qualitative or quantitative research addressing important domains of functioning for psychiatric rehabilitation, such as employment, education, parenting, housing, social relationships, community inclusion, health, and well-being
- studies of evidence-based interventions, recovery-based care, and their integration
- research on special populations of people with serious mental illnesses, such as persons with co-occurring substance use disorders, older individuals, people with intellectual disability or other developmental disabilities, persons with a recent onset of mental illness, or people with co-morbid medical disorders
- studies focusing on special needs or disparities in access to, or outcomes from rehabilitation or psychosocial treatments for minority populations based on characteristics such as ethnicity, race, religion, culture, or sexual orientation

- research on the development or psychometric evaluation of instruments designed to measure outcomes relevant to rehabilitation or psychosocial treatment
- studies aimed at better understanding the nature of recovery from serious mental illness, including research focusing on hope, empowerment, self-determination, and resiliency
- studies utilizing participatory action approaches to research design, implementation, and evaluation

Manuscript Submission

Prior to submission, please carefully read and follow the submission guidelines detailed below. Manuscripts that do not conform to the submission guidelines may be returned without review.

1. ***Submission***

Manuscripts must be submitted electronically (.rtf or .doc) through the Manuscript Submission Portal.

Judith A. Cook
 University of Illinois at Chicago
 Center on Mental Health Services Research and Policy
 Chicago, IL
 Kim T. Mueser
 Boston University
 Center for Psychiatric Rehabilitation
 Boston, MA



We strive to ensure that articles and brief reports published in the journal include implications for practice to promote the translation of research findings into useful applications for the field. *Psychiatric Rehabilitation Journal*[®] (*PRJ*) also promotes the U.S. Psychiatric Rehabilitation Association goal of improving the quality of services designed to support positive community adjustment and integration.

PRJ gives priority to submissions that are clearly applicable to the development, administration, and delivery of psychiatric rehabilitation and other mental health-related services. Data-driven articles that report on the results of rigorous research are especially welcome. Qualitative studies are welcome if they follow established procedures for qualitative research including well-justified sample sizes, and clearly documented analytic strategies.

Pre-post evaluations of services are welcome if they are adequately powered and especially if they include comparison groups. Measurement development or testing research is welcome if the measures pertain to recovery, psychiatric rehabilitation, or mental health more broadly. Comprehensive literature reviews, policy studies, and theoretical manuscripts are also accepted for review depending on their originality, timeliness, and importance to the field.

PRJ welcomes submissions from mental health and psychiatric rehabilitation researchers, service providers, administrators or policy makers; persons with lived experience of psychiatric disability; and family members. We also welcome submissions for the “Speaking Out” section, which have a focus on advocacy and suggest some type of system change or a new perspective that could improve service delivery and outcomes.

Manuscripts are evaluated by the *PRJ* editorial team according to the following criteria:

- material is original and timely,
- writing is clear and concise,
- appropriate study methods are used,
- data are valid,
- conclusions are reasonable and supported by study results,
- information is important, and
- topic has relevance to the field of psychiatric rehabilitation and mental health services.

From these criteria, the editors select papers for peer review. Papers of insufficient priority are promptly rejected.

2. ***Masked Review***

This journal has a policy of masked review for all submissions.

A title page should include all authors’ names and institutional affiliations and a complete mailing and e-mail address for the Corresponding Author. The manuscript should omit this information but should include the title of the manuscript and an abbreviated title to serve as the running head on each page of the manuscript.

Authors must make every effort to see that the manuscript itself contains no clues to the authors’ identities. This includes removing the names of academic or other institutions from

human subjects assurance statements, and references to authors' prior publications that include citations revealing their identities.

Manuscripts are sent for peer review to at least two independent reviewers.

A separate statistical review is obtained when a reviewer or the editors request it. Authors are informed about the review decision after the review process is completed.

Manuscripts that are not rejected after the first round of peer review usually require revision and re-review by one or more of the original reviewers. Revised manuscripts must conform to the general requirements listed below, including specified word counts, and word counts must be adhered to in revised submissions.

3. ***Manuscript Preparation***

Prepare manuscripts according to the *Publication Manual of the American Psychological Association* (6th edition). Manuscripts should be copyedited for bias-free language (see Chapter 3 of the *Publication Manual*)

Follow US Psychiatric Rehabilitation Association (USPRA) Language Guidelines. These guidelines are based on the fundamental values of the psychiatric rehabilitation field: respecting the worth and dignity of all persons and groups, as well as honoring and advocating for individual rights and interests, and opposing discrimination in services and in society.

Review APA's Checklist for Manuscript Submission before submitting your article.

Use 12-point Times New Roman font with consistent headings and subheadings and omit underlining. All references should be included in the reference list in APA format. Use of Endnotes is not permitted.

All research manuscripts should include a structured abstract containing a maximum of 250 words. Abstracts that are incomplete or do not conform to the following structure will be returned to the authors for revision.

- **Objective:** the primary purpose of the article should be clearly stated.
- **Methods:** this section must state the sample size and nature of subjects, data sources, study design, how dependent variables were measured and the specific analytic techniques (statistical tests, qualitative analysis strategy) that were used.
- **Results:** primary findings should be stated clearly and concisely, describing statistical results as appropriate.

- **Conclusions and Implications for Practice:** implications of the findings for the field of psychiatric rehabilitation, mental health, or recovery should be clearly stated and future directions may be described.

All theoretical manuscripts should include a structured abstract with the following required sections:

- Objective: the primary purpose of the article should be clearly stated.
- Method: this section should describe the methodology used and type of analysis conducted.
- Findings: primary findings should be stated clearly and concisely.
- Conclusions and Implications for Practice: implications of the findings for the field of psychiatric rehabilitation, mental health, or recovery should be clearly stated and future directions may be described.

Abstracts for brief reports should not exceed 150 words.

Please supply up to five keywords or brief phrases after the abstract.

4. ***Manuscript Length***

Articles should not exceed 5,000 words, excluding tables, figures, and references. Manuscripts submitted for the “Speaking Out” section, as well as Brief Reports, should not exceed 1,500 words. Letters to the Editor should not exceed 300 words. All revisions must adhere to these word limits.

Authors must review and use the Guidelines for Nonhandicapping Language in APA Journals.

5. ***Formatting***

Double-space all copy. Other formatting instructions, as well as instructions on preparing tables, figures, references, metrics, and abstracts, appear in the *Manual*.

Below are additional instructions regarding the preparation of display equations, computer code, and tables.

i. **Display Equations**

We strongly encourage you to use MathType (third-party software) or Equation Editor 3.0 (built into pre-2007 versions of Word) to construct your equations, rather than the equation support that is built into Word 2007 and Word 2010. Equations composed

with the built-in Word 2007/Word 2010 equation support are converted to low-resolution graphics when they enter the production process and must be rekeyed by the typesetter, which may introduce errors.

To construct your equations with MathType or Equation Editor 3.0:

- Go to the Text section of the Insert tab and select Object.
- Select MathType or Equation Editor 3.0 in the drop-down menu.

If you have an equation that has already been produced using Microsoft Word 2007 or 2010 and you have access to the full version of MathType 6.5 or later, you can convert this equation to MathType by clicking on MathType Insert Equation. Copy the equation from Microsoft Word and paste it into the MathType box. Verify that your equation is correct, click File, and then click Update. Your equation has now been inserted into your Word file as a MathType Equation.

Use Equation Editor 3.0 or MathType only for equations or for formulas that cannot be produced as Word text using the Times or Symbol font.

ii. **Computer Code**

Because altering computer code in any way (e.g., indents, line spacing, line breaks, page breaks) during the typesetting process could alter its meaning, we treat computer code differently from the rest of your article in our production process. To that end, we request separate files for computer code.

In Online Supplemental Material

We request that runnable source code be included as supplemental material to the article. For more information, visit [Supplementing Your Article With Online Material](#).

In the Text of the Article

If you would like to include code in the text of your published manuscript, please submit a separate file with your code exactly as you want it to appear, using Courier New font with a type size of 8 points. We will make an image of each segment of code

in your article that exceeds 40 characters in length. (Shorter snippets of code that appear in text will be typeset in Courier New and run in with the rest of the text.) If an appendix contains a mix of code and explanatory text, please submit a file that contains the entire appendix, with the code keyed in 8-point Courier New.

iii. **Tables**

Use Word's Insert Table function when you create tables. Using spaces or tabs in your table will create problems when the table is typeset and may result in errors.

6. ***Submitting Supplemental Materials***

APA can place supplemental materials online, available via the published article in the PsycARTICLES® database. Please see Supplementing Your Article With Online Material for more details.

7. ***References***

List references in alphabetical order. Each listed reference should be cited in text, and each text citation should be listed in the References section. Please do not use Endnotes in submissions. All references should be included in the reference list in APA format.

Examples of basic reference formats:

- **Journal Article:**

Hughes, G., Desantis, A., & Waszak, F. (2013). Mechanisms of intentional binding and sensory attenuation: The role of temporal prediction, temporal control, identity prediction, and motor prediction. *Psychological Bulletin*, *139*, 133–151.
<http://dx.doi.org/10.1037/a0028566>

- **Authored Book:**

Rogers, T. T., & McClelland, J. L. (2004). *Semantic cognition: A parallel distributed processing approach*. Cambridge, MA: MIT Press.

- **Chapter in an Edited Book:**

Gill, M. J., & Sypher, B. D. (2009). Workplace incivility and organizational trust. In P. Lutgen-Sandvik & B. D. Sypher (Eds.), *Destructive organizational communication: Processes, consequences, and constructive ways of organizing* (pp. 53–73). New York, NY: Taylor & Francis.

8. *Figures*

Graphics files are welcome if supplied as Tiff or EPS files. Multipanel figures (i.e., figures with parts labeled a, b, c, d, etc.) should be assembled into one file.

The minimum line weight for line art is 0.5 point for optimal printing.

For more information about acceptable resolutions, fonts, sizing, and other figure issues, please see the general guidelines.

When possible, please place symbol legends below the figure instead of to the side.

APA offers authors the option to publish their figures online in color without the costs associated with print publication of color figures.

The same caption will appear on both the online (color) and print (black and white) versions. To ensure that the figure can be understood in both formats, authors should add alternative wording (e.g., "the red (dark gray) bars represent") as needed.

For authors who prefer their figures to be published in color both in print and online, original color figures can be printed in color at the editor's and publisher's discretion provided the author agrees to pay:

- \$900 for one figure
- An additional \$600 for the second figure
- An additional \$450 for each subsequent figure

9. *Permissions*

Authors of accepted papers must obtain and provide to the editor on final acceptance all necessary permissions to reproduce in print and electronic form any copyrighted work, including test materials (or portions thereof), photographs, and other graphic images (including those used as stimuli in experiments).

On advice of counsel, APA may decline to publish any image whose copyright status is unknown.

- [Download Permissions Alert Form \(PDF, 13KB\)](#)

10. *Publication Policies*

APA policy prohibits an author from submitting the same manuscript for concurrent consideration by two or more publications.

See also APA Journals® Internet Posting Guidelines.

APA requires authors to reveal any possible conflict of interest in the conduct and reporting of research (e.g., financial interests in a test or procedure, funding by pharmaceutical companies for drug research).

- Download Disclosure of Interests Form (PDF, 38KB)

Authors of accepted manuscripts are required to transfer the copyright to APA.

- For manuscripts not funded by the Wellcome Trust or the Research Councils UK Publication Rights (Copyright Transfer) Form (PDF, 83KB)
- For manuscripts funded by the Wellcome Trust or the Research Councils UK Wellcome Trust or Research Councils UK Publication Rights Form (PDF, 34KB)

11. *Ethical Principles*

It is a violation of APA Ethical Principles to publish "as original data, data that have been previously published" (Standard 8.13).

In addition, APA Ethical Principles specify that "after research results are published, psychologists do not withhold the data on which their conclusions are based from other competent professionals who seek to verify the substantive claims through reanalysis and who intend to use such data only for that purpose, provided that the confidentiality of the participants can be protected and unless legal rights concerning proprietary data preclude their release" (Standard 8.14).

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