

## Chapter 4

### **Investigating the lived experience of recovery in people who hear voices:**

#### **A narrative inquiry**

The following chapter is a replication of material contained in the manuscript:

D., McCarthy-Jones, S. & Hayward, M. (2014). *(Submitted to Qualitative Health Research)*.

Investigating the lived experience of recovery in people who hear voices.

Minor changes to the manuscript have been made to maintain consistency in format with the overall thesis. Some information not included in the article due to the constraints of brevity is nonetheless informative and is included in appendices. This includes information about participants' voice-hearing experiences, demographic and diagnostic information (Appendices E and F) and more detail regarding the development of the model of recovery over time (Appendix G).

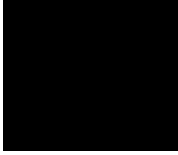
Ms Adèle de Jager took the primary lead in the study's design, data collection, data analysis and interpretation and the writing of the drafts.



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Dr. Paul Rhodes assisted with the study's design, data analysis and data interpretation and provided critical revisions of the manuscript.



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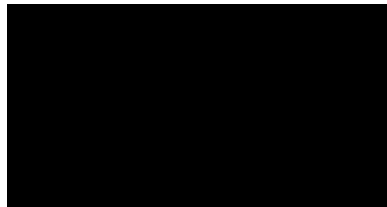
Dr. Mark Hayward assisted with the study's design, data analysis and data interpretation and provided critical revisions of the manuscript.



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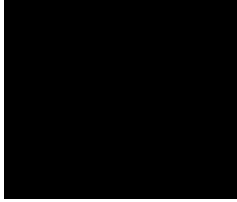
Dr. Vanessa Beavan supported recruitment through the Hearing Voices Network, assisted in data analysis and interpretation, took part in the focus group, and provided critical revisions of the manuscript.



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Date: 30/04/2014

Douglas Holmes assisted with the study's design and ethics application, and supported recruitment through the Hearing Voices Network.



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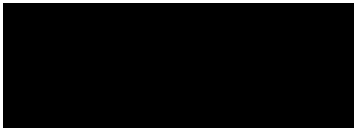
Dr. Kathryn McCabe assisted in the study's design and ethics application to the Australian Schizophrenia Research Bank, as well as training the Candidate in the use of the Diagnostic Interview for Psychoses and analysis of data generated from it. She also proof-read the submitted manuscript.



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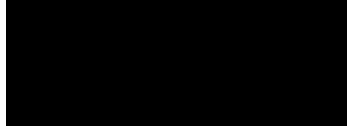
Dr. Neil Thomas provided assistance in analysis and interpretation of the data, took part in the reference group and provided critical revisions of the manuscript.



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Date: 29/04/2014

Debra Lampshire took part in the focus group which involved critiquing the model of recovery generated.



Signature:

Date: 30/04/2014

Dr. Simon McCarthy-Jones took part in the focus group which involved critiquing the model of recovery generated. He also provided a critical revision of the manuscript.



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Date: 30/04/2014

## **Investigating the lived experience of recovery in people who hear voices**

Adèle de Jager<sup>1</sup>, Paul Rhodes<sup>1</sup>, Vanessa Beavan<sup>2</sup>, Douglas Holmes<sup>3</sup>, Kathryn McCabe<sup>4</sup>, Neil Thomas<sup>5</sup>, Debra Lampshire<sup>6</sup>, Simon McCarthy-Jones<sup>7</sup> and Mark Hayward<sup>8</sup>.

<sup>1</sup>The University of Sydney, NSW, Australia.

<sup>2</sup>Australian College of Applied Psychology, Sydney, NSW, Australia.

<sup>3</sup>St Vincent's Hospital, Sydney, NSW, Australia.

<sup>4</sup>Brain & Mind Research Institute, University of Sydney, Sydney, Australia.

<sup>5</sup>Swinburne University, Melbourne, Australia.

<sup>6</sup>University of Auckland, Auckland, New Zealand.

<sup>7</sup>Macquarie University, Sydney, Australia.

<sup>8</sup>The University of Sussex, Brighton, UK.

**Abstract**

Although there is evidence of both clinical and personal recovery from distressing voices, the process of recovery over time is unclear. Narrative inquiry was employed to investigate eleven voice-hearers' lived experience of recovery. After a period of despair/exhaustion, two recovery typologies emerged: 1) *turning toward/empowerment*, which involved developing a normalised account of voices, building voice-specific skills, integration of voices into daily life and a transformation of identity and 2) *turning away/protective hibernation*, which involved harnessing all available resources to survive the experience, with the importance of medication in recovery being emphasised. Results indicated the importance of services being sensitive and responsive to a person's recovery style at any given time and their readiness for change. Coming to hold a normalised account of voice-hearing and the self, and witnessing of preferred narratives by others, were essential in the more robust *turning toward* recovery typology.

**Keywords:**

Illness and disease, experiences; interviews, semistructured; mental health and illness; narrative inquiry; psychology; recovery; schizophrenia; stories / storytelling

Voice-hearing, referred to in the clinical literature as having auditory hallucinations, is commonly experienced in the context of schizophrenia and other psychological disorders, as well as in the general population (Beavan, Read & Cartwright, 2011; Choong, Hunter & Woodruff, 2011; Waters, 2010). The experience is highly stigmatised and associated with poor mental health, distress, and isolation (APA, 2000; Thornicroft, 2006). The predominant approach to treating distressing voices in the context of a psychiatric diagnosis is defined by the medical model, which aims to eliminate symptoms, primarily by administration of antipsychotic medication (Drake, Bond, & Essock, 2009; Read, Bentall, & Fosse, 2009; Sachs, Printz, Kahn, Carpenter & Docherty, 2000). The definition of recovery varies between dominant medical model discourse versus consumer / survivor discourse, with the former focussing on symptom resolution and a return to a former state of functioning (*clinical recovery*), whereas the latter emphasises living a “fulfilling and satisfying life, in the presence or absence of symptoms” (Carlton & Bradstreet, 2006, p16) (*personal recovery*) (Bellack, 2006; Slade et al., 2012). The medical model approach has been criticised for a narrow definition of recovery and pessimism regarding prognosis (Breeding, 2008; Fleming & Martin, 2011; Read et al., 2009). General population surveys indicate that a proportion of people who hear voices are not negatively affected by them (Beavan & Read, 2007; Johns & van Os, 2001; Tien, 1991). Thus, hearing voices in and of itself does not necessarily cause distress (Peters, Williams, Cooke & Kuipers, 2012). In addition, a substantial proportion of people who experience distressing voices functionally recover to a degree which would be considered ‘normal’ by most people, with approximately 50% meeting criteria for clinical recovery over a 20-year period (Harding et al., 1987; Harrison et al., 2001; Slade, Amering & Oades, 2008).

In contrast to clinical recovery, which has quite clear criteria, personal recovery is a

deeply personal process and its definition varies from person to person (Brown, 2008). It is possible, however, to identify common threads in recovery processes and identify factors that support well-being (Brown, 2008). Recovery in this broader sense involves developing or regaining a positive sense of self, agency, hope, meaningful occupation, making sense of or reframing experiences, accepting the limitations associated with the illness and creating a satisfying life within those limitations, and improved quality of life (Andresen, Oades & Caputi, 2003; Leamy, Bird, Le Boutillier, Williams & Slade, 2011; Perkins & Slade, 2012). Others emphasise having the same work and living opportunities as other community members (Kirkpatrick & Byrne, 2009). A pivotal tenet of recovery-orientated approaches is that recovery is possible (Anthony, 1993, 2000; White, 2005). Influenced by consumer/survivor groups, interest in recovery-orientated mental health services and treatment has grown over the past twenty years (Anthony, 2000).

One of the most prominent strands of the consumer/recovery movement has been the hearing voices movement. This was born out of collaboration between consumers, clinicians and researchers (e.g. Romme & Escher, 1989; Romme, Escher, Dillon, Corstens & Morris, 2009), leading to establishment of extensive national and state networks which facilitate the running peer-support *hearing voices groups* (HVGs) and promote connection between voice hearers, referred to collectively as the Hearing Voices Network (HVN; Corstens, Longden, McCarthy-Jones, Waddingham & Thomas, 2014). Principles adopted within the HVN align with both consumer definitions of recovery and the need for a more holistic treatment model which normalises voices and takes into account contextual factors (Fischer, 2003). Distressing voices are understood as a manifestation of solvable emotional problems which may present in a figurative or literal manner (McCarthy-Jones & Longden, 2013). Derived from personal accounts



of voice hearing discussed at the first major voice hearer congress in 1987, Romme and Escher (1989,1993) proposed three phases of recovery: *startling*, which involves initial feelings of shock and being overwhelmed by voice-hearing experiences and trying to push voices away, *organisation*, whereby the person starts to employ some strategies in relation to their voices and place boundaries around their interactions and *stabilisation*, wherein the hearer comes to integrate voices into their life, recognise them as ‘part of me’ and no longer wishes to be rid of them.

Although evidence to date indicates that recovery from distressing voices – both clinical and personal – is possible, there a lack of research into the recovery process in relation to hearing voices. Although many first-person accounts of recovery exist and are valuable in and of themselves (e.g. Romme & Escher, 1993), they were not generated using a qualitative method that allows for analysis of narrative genres or typologies of recovery over time. It is therefore unclear whether recovery processes align with the HVN approach. In addition, diagnoses and stage of recovery were not confirmed. This article addresses this gap in the literature, employing Narrative Inquiry to examine recovery and including quantitative and diagnostic measures.

## **Method**

Narrative analysis is the analysis of text, in this case interview transcripts, in ‘storied’ form (Riessman, 2005). A narrative text involves the telling of a sequence of events, which, in the act of narrating are organised by the narrator. The narrator interprets the text, selecting information to include, how to describe it, and how various elements are connected (Riessman, 2005).

Therefore, narrative analysis focuses on the narrator’s construction of meaning: in other words,

not only what happened but how they understand or make sense of these events. It privileges knowledge gained from personal experience as opposed to master narratives or dominant discourse surrounding a given topic. The notion that meaning is partly or entirely socially constructed is implicit in the philosophical underpinnings of narrative analysis. It acknowledges the role of the researcher in the process of meaning-making. Researchers must organise information generated from narrative interviews and interpret it (Riessman, 2005). Research output represents how the researcher has made sense of how the participant has made sense of their experiences. Taking an objective stance is not considered possible; instead, the researcher is required to be aware of and reflect on their subjective response to the research context, process and content (Braun & Clarke, 2008; Hall, 2009, 2011; Oke, 2008). The first author, who undertook interviews, collection of questionnaire data and lead data analysis, was aware of their tendency to understand voice-hearing as meaningful in context of a person's life history, and expectation that active engagement and making sense of voices would be involved in recovery. Bracketing these assumptions during the research process allowed information which was not in keeping with expectations to be reflected on and acknowledged, rather than obscured (Fischer, 2009; Tufford & Newman, 2012).

In keeping with trends in psychosis research (Schrader, 2013) and because of the advantages it affords, a single complaint approach was employed (Bentall, 2003), examining voice-hearing rather than broader diagnostic constructs. However, it is important to confirm whether or not participants met criteria for a diagnosis during their life-time. This allows comparison with research utilising diagnostic constructs and also confirms that recovery has occurred from a clinically significant degree of distress. In addition to semistructured interviews regarding recovery over time, participants completed the Diagnostic Interview for Psychoses

(DIP; Castle et al., 2006) to ascertain whether diagnostic criteria were met during the person's lifetime. To comprehensively characterize individuals' stage of recovery, measures of stage of recovery, distress and quality of life were also obtained. Participants were actively involved in the generation of narrative summaries and narratives were member-checked. Finally, an expert panel was involved in refining typologies of recovery over time.

### *Participants*

Of the total eleven participants (seven women), six were recruited from the Hearing Voices Network NSW (HVNNSW) and five from the Australian Schizophrenia Research Bank (ASRB). The mean age of the sample was 47 years ( $SD=12.6$ ; range 23-63), with ten White and one Asian participant. Five were engaged in paid employment, one in full-time tertiary study, three were retired and two received a Disability Support Pension. Three participants were married or in de facto relationships, one was divorced and the remainder were single. The aim was to gain depth rather than breadth of understanding. The small number of participants was therefore considered sufficient.

### *Materials*

*Self-report measures.* The Stages of Recovery Instrument (STORI; Andresen et al., 2006) is a 50-item self-report measure designed to identify a person's stage of recovery from serious mental illness based on consumer accounts: 1) Moratorium, 2) Awareness, 3) Preparation, 4) Rebuilding and 5) Growth. It taps into a process of change across four domains known to change during the process of recovery (hope, identity, meaning and responsibility). The Manchester Short Assessment of Quality of Life (MANSA; Priebe,

Huxley, Knight & Evans, 1999) is a self-report measure of subjective quality of life which assesses satisfaction with various domains including friendships, finances, leisure activities, safety and health (both physical and mental). The Kessler Psychological Distress Scale (K10; Kessler et al., 2002) is a 10-item self-report measure of global psychological distress based on items concerning depression and anxiety symptoms over four weeks prior to assessment.

*Diagnostic interview.* The DIP (Castle et al., 2006) is a structured interview employed to generate DSM-IV and ICD-10 diagnoses for research purposes. Responses are analysed to produce a diagnosis.

*Semistructured interview.* A semistructured interview was conducted with a view to eliciting information about participants' experiences of voice-hearing and recovery over time. A time-line was used to indicate when voices first started, when they were at their worst and how participants progressed from that point toward recovery.

### *Procedure*

Ethical approval for the research was obtained from the University of Sydney Human Ethics Committee. This research was advertised through the HVNNSW and ASRB. Reimbursement was offered for travel expenses and time spent taking part. Interested participants contacted the researcher and the Participant Information Sheet was provided. Informed consent was obtained from all participants in writing. Inclusion criteria were 1) current or historical experience of distressing voices 2) self-identified as recovered or recovering 3) adequate English language skills. People experiencing acute levels of distress were excluded. Interviews were conducted at a mental health centre in Sydney and took between sixty and ninety minutes, with breaks as

required.

Lifetime diagnosis was derived either by administering the DIP or by obtaining DIP data held on the ASRB databank. All participants completed the self-report measures. This data provided triangulation regarding recovery.

Semistructured interviews concerning participants' recovery over time were conducted and audio-recorded. Interviews were transcribed and narratives of recovery over time generated by the first author. Participants were given pseudonyms and identifying details removed or in one case changed to protect participants' confidentiality. Narratives were sent to participants for member-checking to ensure that they were an authentic and accurate representation of participants' experiences. Information gleaned from interviews was used to inform subsequent interview questions (Connelley & Clandinin, 2006).

A preliminary model of recovery over time and typologies (types of recovery over time) was generated. A panel of four consultants who were experts by profession and / or experience (VB, NT, DL and SM) were asked to read the narratives and critique this model, providing feedback and suggestions for improvement. The model was revised incorporating four main critiques: 1) the need to exercise caution in producing models of recovery which suggest linear progression not in keeping with reality and the danger of clinicians applying such models in a prescriptive manner 2) inclusion of disconnection from others 3) noting factors which inhibited as well as encouraged recovery and 4) checking the data to confirm the identified period of exhaustion / despair as well as proximal and distal stressors.

## Results

The results of the DIP indicated that during their lifetimes, participants had met DSM-IV diagnostic criteria for schizophrenia (4), schizoaffective disorder (4) or psychosis not otherwise specified (3). Self-report measures showed that nine participants were in stage 5 (growth) of recovery and the remaining two were in stage 4 (rebuilding). Participants reported mixed (5) or mostly satisfied (6) ratings of quality of life, and a broad range of global psychological distress (4 low, 2 moderate and 5 high distress). One participant with a self-reported diagnosis of schizoaffective disorder did not consent to taking part in the diagnostic interview. Their diagnosis is thus based on self-report.

Participants' accounts indicated that recovery was not a neat, linear progression over time. They did not move through each stage progressively. Instead, stages were cyclical in nature, with participants repeating or re-engaging in processes associated with recovery several times or in an ongoing manner. Processes occurred simultaneously rather than discretely and influenced each other. Participants also took time to rest and consolidate the progress they had made.

Given the shortfalls of any model of recovery over time in capturing the essence of individual narratives, as well as the capacity of models to oppress such narratives, one may well ask why production of such a model is advisable or indeed of value. However, to consider what type of story a person is involved in and which stories are being overlooked is to consider how their lives are defined (Frank, 2010). Identifying recover typologies allows us to elucidate and reflect on the (usually obscured) power and function of such narratives and the concrete impact they have on people's lives (Frank, 2010; Madigan, 1992). The description of recovery over time

presented in Figure 1 is thus an approximation of what participants described and included to provide a rubric through which to consider recovery.

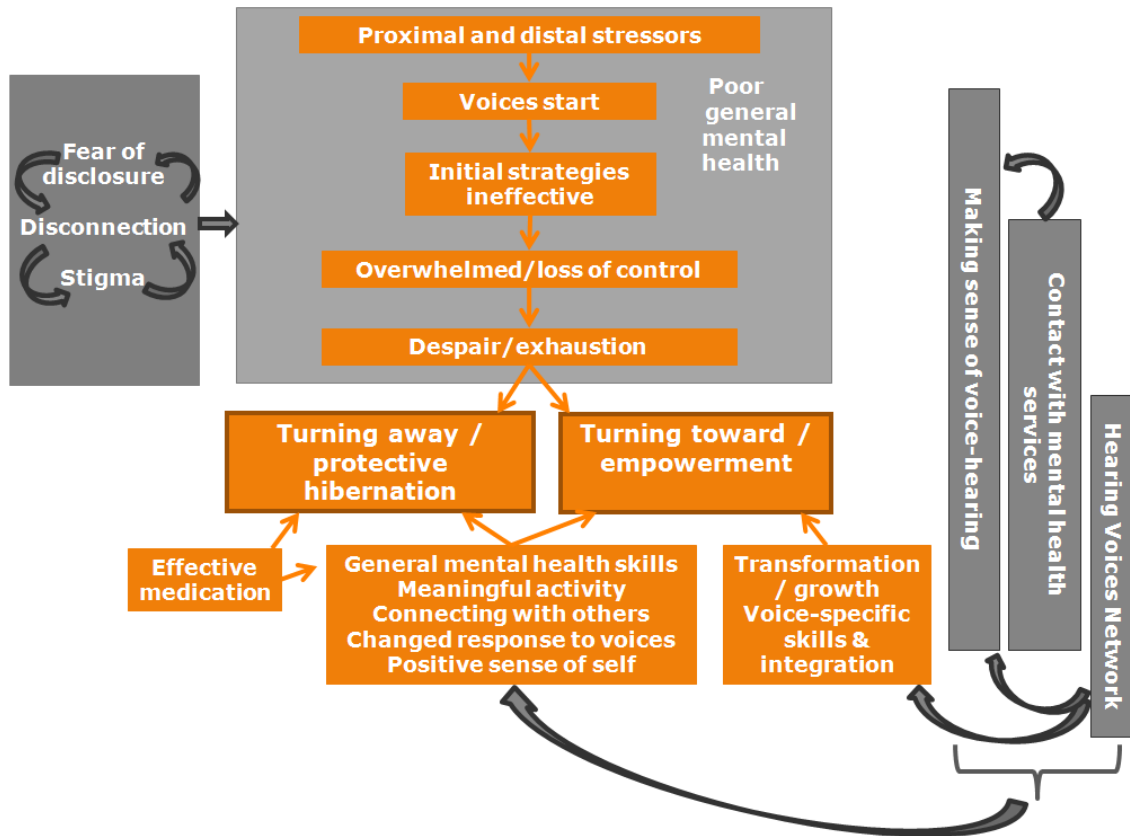


Figure 2: Diagrammatic representation of recovery trajectories over time.

### *Context of Voice Onset and Initial Responses*

Most participants described poor general mental health, distal and proximal stressors and disconnection from others prior to voice onset. Participants feared the consequences of disclosing their experiences to others, expressing concern that they would be judged negatively because of stigma. They were acutely aware of the risk involved in disclosing that they were hearing voices to mental health professionals, fearing that disclosure may result in invasive treatments or involuntary admission to a psychiatric hospital:

*As soon as you mention voices – and you pick it up really early – is they want to fill you up with medication. So it became quite secretive for me . . . I never told people about them . . . it wasn't until . . . I went to a workshop with . . . other voice-hearers that I actually – that I started to talk about them – because I was too embarrassed about telling people what was going on.*

### *Reaching a Point of Despair / Exhaustion*

Overall, strategies initially trialled for dealing with voices including resisting them, avoiding feared situations and people related to voices, were ineffective. Participants often described ongoing poor general mental health. In this context, participants became increasingly overwhelmed by their voices, which typically became louder and more intrusive after initial onset:

*They gave me some medicine and told me it would get rid of it, but they only just kept getting worse and worse and worse . . . until a week or two later, it was virtually non-stop, these two guys talking to each other about me.*

Participants were generally less able to disengage from their voices or resist their instructions, as a result sometimes behaving in ways that were not in line with their values:

*When I was in trouble with hearing voices, I didn't know myself . . . I lost my feeling, lost my self-knowledge . . . With the voice telling me to do things I just lost my self-control . . . I behaved toward people . . . just aggressively.*

Participants described trying everything they could think of to improve their situation, to no avail. Although many had supportive friends or family members, participants felt disconnected



from others, which was often encouraged by their voices. After enduring intolerable situations for months or years, participants became increasingly fatigued and/or reached a point of despair:

*I couldn't see any hope . . . basically I suppose I felt if things didn't get better then what's the point of living? I was at my lowest level then. I prayed . . . deeply as to what was my purpose, what was the point of having a mental illness? How could I contribute (to society) if I had this prognosis? I think my self-esteem and everything was the lowest it could be.*

#### *Divergent Recovery Typologies: Turning Toward Versus Turning Away*

Following this period of despair and exhaustion, two divergent recovery typologies were identified: 'turning away/protective hibernation' and 'turning toward/empowerment'. Five out of six participants with *turning toward* narratives were recruited from the HVNNSW, whereas four out of five with *turning away* narratives were recruited from the ASRB and had had no contact with the HVNNSW.

#### *Turning Away*

In turning away narratives, participants did not all reach an identifiable point of despair, however, clearly became fatigued as a result of ongoing difficulties. They responded by harnessing all available resources to batten down the hatches and weather the storm of voice-hearing experiences. This task demanded all of their attention and energy. Participants survived their experiences and generally noticed a turning point when they were prescribed effective medication. Medication contributed to recovery by enabling them to function better, communicate with others, engage in activities and think more clearly:

*I can function better and I can think better and I've been able to pass my courses.*

These effects meant that participants felt more hopeful about their future:

*I started to see the light at the end of the tunnel more and more it was not a train coming from the other way but a light outside.*

Medication also eliminated voices in some cases or allowed participants to change their response to their voices, enabling them to hold a more comfortable distance from them. For example, instead of being overwhelmed, participants were able to listen to voices for a few minutes and then distract themselves from them.

Overall, for participants with a dominant turning away narrative, reflecting on their experiences and how they were able to survive and recover was a great deal more effortful than for turning toward participants. They gave sparser, less detailed information and appeared to be unused to telling their stories. These participants, for whom medication was effective, were perhaps unsurprisingly more accepting of a medical model explanation for their voices as symptoms of an illness. These narratives were told stoically, with little or no reflection on the meaning of voice-hearing or curiosity about voices or how to interact with them. Instead, there was a strong sense of wanting to put the experience behind them and get on with their lives.

### *Turning Toward*

Turning toward narratives were characterised by a tendency to turn to face problems, active engagement with voices and curiosity about what the experience meant, testing beliefs about voices and shifting one's relationship with voice(s) over time. Participants described an essential transformation of self through voice-hearing and challenges associated with it. Participants

learned how to interact with their voices in healthier ways over time, similar to changing a relationship with a social other.

It is of note that five out of six participants with this typology were recruited through the HVNNSW. The impact of involvement with the HVN on recovery trajectories was evident. Participants reported that the HVNNSW facilitated recovery by normalising voice-hearing, exposing people to the notion that it is possible to live a fulfilling life with or without voices and encouraging consideration of alternative understandings voices. For example, some came to understand voices as communicating something valuable, albeit in a distressing manner. It also provided exposure to other voice-hearers' ways of dealing with voices, social connection and opportunities to contribute to others. Participants noted that each person's process in coming to deal with their voices is different and that it is preferable to be supportive rather than prescriptive:

*Yeah (this is) my story, some things that work for some do not work for others, because we are excellent, you know, we all have own experience, no one can understand us same as us ourselves . . . I can't say (the voices) are untrue, it's not real, to other people with the voices, because . . . it just depends on how long they've been dealing with the voices and how much experience they have. Same as me.*

Participants moved beyond developing a positive sense of self to describe an essential transformation in identity as a result of becoming unwell and hearing voices. They reported becoming less angry and more empathic toward others, becoming more communicative about their emotions rather than keeping their feelings to themselves, and having a stronger sense of self as a result of their voice-hearing experience:

*In a way it's been good that I got sick because I'm a lot less angry . . . It gives me heaps of empathy for other people too.*

Turning toward narratives were characterised by a shift in response to voices that went well beyond distraction or disengagement. Experiences of despair and exhaustion gave rise to participants challenging their voices or testing their beliefs about them. These acts often required a great deal of courage, particularly given that participants often strongly believed that their voices could harm them:

*Challenging the voices . . . they might say the whole world will end and your mother will die or people will come round and kill you. But I actually learnt if I said no, no one would come round and kill me.*

The ability to challenge voices and test them developed slowly over time, with participants feeling incrementally stronger in relation to their voices. Those with turning toward narratives tended to integrate even very challenging voices into their lives. For example, one participant responded to his voices' criticisms that he was stingy by donating an affordable amount to charity each month. Another had formal monthly meetings with her voices, however, she found this model too rigid and therefore supplemented it with less formal ad hoc discussions. Challenging commentary was interpreted as a metaphorical expression of her voices' concerns, which were deserving of her attention. For example, she responded to threatening comments by framing her debate with her voices as a series of poetry:

*It was a way to be able just to listen to them in an artistic way. So rather than take it at face value . . . it sort of was speaking in a more metaphorical sense. They weren't necessarily out to get me, it was more like they were concerned about something and I wanted to make sense of what was going on at the time.*

Another described a shift in her relationship with her voices from them being in control to her helping them understand themselves:

*My voices are now quite curious about who they are – they don't know who they are, why they are.*

Participants tended to grant their voices the status of meaningful beings. Interacting with them in the context of a generally respectful relationship became a valued part of participants' lives. This respect developed over time, facilitated by a stronger sense of self and ability to place boundaries around interactions with voices. Listening to what voices were saying and responding in a moderate and reasonable manner was characteristic of recovery. Voices were understood as being part of the person and therefore learning more about voices and engaging with them also meant learning more about oneself. Finally, participants described transferring skills with social others to their interactions with their voices:

*I think having a social life really helps in developing my other skills and that in the way helps me; I can transfer those skills over to my conversation with the voices.*

Learning to nourish general mental health was much more strongly linked to learning about voices in turning toward compared to turning away narratives, with many commenting on the two being intertwined. For example, participants became acutely aware that their voices were likely to become problematic during times of heightened anxiety and vice versa, thus becoming a 'litmus test' for psychological well-being:

*It's got to do with when I've got myself under pressure . . . it only comes in now if I get over-tired, so I've got a fairly rigid . . . routine around sleeping and doing a range of stuff. Because what happens is, I know as soon as she appears that I'm really over-tired.*

Finally, coming to hold a normalised account of what it means to hear voices was pivotal in *turning toward* recovery narratives, opening up the possibility of a normal, non-pathologized identity:

*It really opened up my mind to this as an experience that was normal in the world . . .  
Whereas before that I thought it was my shame. My shame, my fault, my illness. You know, it was all about me and me broken.*

Overall, the importance of medication in recovery was not emphasised in turning toward narratives and many participants commented that it was ineffective or associated with significant side-effects which out-weighed its benefits. They were characterised by a tone of empowerment, and at times, defiance. There was a commitment to advocacy for the rights of other voice-hearers. Participants described significant changes within themselves and their world view as a result of their voice-hearing experiences and recovery.

#### *Common Processes Across Typologies*

Across typologies, participants emphasised the importance of learning about how to nourish general mental health. For example, many participants commented that voices amplified existing anxieties or vulnerabilities:

*The voices always played on what was your vulnerable point.*

Learning how to manage anxiety meant that when voices attempted to amplify concerns they had less traction or believability and participants were less distressed by their comments. This was a strong theme across narratives. Participants also learned how to manage their mood, balance activity levels to ensure that they were not over- or under-active, manage stress, ensure they got enough sleep and developed communication and assertiveness skills. Although at times mental

health professionals played a role, it was also common for these skills to be developed without external assistance. Many participants used mindfulness and distraction techniques to create some space between themselves and their voices:

*(Mindfulness) is really helpful . . . even if I think I do hear someone swearing at me, I don't have to take it on board for myself.*

As shown in Figure 1, engaging in meaningful activities, connecting with others and (re-) developing a positive sense of self were key recovery processes common to both typologies. These processes were centred around meeting needs to feel competent, valued, purposeful and connected to others. They were strongly inter-related. For example, engaging in meaningful activities – whether paid work, unpaid caring duties, domestic activities or voluntary work – provided routine, a sense of purpose and some distraction from voices. Participants felt more valued by themselves and others when they were able to contribute to others:

*It makes me feel as though I'm contributing to something. And I want to feel valuable, I want to feel that I can contribute.*

For many, it also provided regular, structured activity:

*I had a structure in the day and I used to do mum's house work and cook dinner for the family. I enjoyed all my activities . . . that really got me activated and out of all that sedation. I felt I could do things and enjoy them . . . My life was good.*

Similarly, developing supportive, non-judgemental relationships with others was invariably associated with recovery:

*It's good . . . sometimes I say 'I don't feel like talking for five minutes or at the moment, just feeling a bit stressed.' And she more than understands.*

*We've got a lot in common and help each other . . . she's a good friend to me . . . It's very comforting that she can be a friend, whereas my family is quite cold.*

Being related to and perceived by others first and foremost as a human being and for who participants are, and not based on stereotypes about people who hear voices, was particularly valued. Most participants likewise rejected stigma surrounding voice-hearing, commenting that they had to be strong people to achieve what they had in life and that they need not be ashamed of their experiences. However, most remained cautious about disclosing their experiences and only did so with trusted others. The importance of these processes emphasizes that recovering from distressing voices is not only about learning how to deal with voices; indeed, it was influenced by the hearer's entire life context. It should be noted that the positive sense of self common to both typologies did not involve the transformation in self noted in *turning toward* narratives.

Participants' experiences of mental health services and treatment varied. Mental health services were perceived as helpful when medication was effective and professionals worked with participants to develop strategies for dealing with mental health difficulties generally and voices specifically, and who spoke about voices without panicking. Access to housing, financial support, rehabilitation and mental health services as well as anti-discrimination laws facilitated recovery.



## Discussion

### *Turning Away and Turning Toward*

This narrative research aimed to investigate recovery trajectories and critically appraise and further develop Romme, Escher and colleagues' seminal work on recovery from distressing voices, in particular the suggested *startling*, *organisation* and *stabilisation* phases of recovery (Romme & Escher, 1989; Romme & Morris, 2013). In keeping with prior research, participants in the current research understood negative life events to be causally related to voice onset (e.g. Romme et al., 2009). They described an initial response of shock, confusion and fear in response to voices, loss of sense of self, and becoming overwhelmed. This is in keeping with the *startling* phase. However, from this point, the research identified two typologies of recovery, rather than just one: turning toward and turning away. Turning toward narratives involved a transformation of self, active engagement with voices, adopting a normalised view of voices and integrating them into one's life. This provides support for Romme et al.'s (2009) organisation and stabilisation phases. These narratives align with McGlashan, Levy and Carpenter's (1975) integrative recovery style, which involves curiosity about psychotic experiences, striving to make sense of them and integrating them into one's life, as well as Frank's (1995) quest auto-mythology narratives, which are characterised by a transformation in identity in response to physical illness. This also resonates with the Māori concept of voices as a 'difficult gift' which are nonetheless an ordinary part of daily life (NiaNia & Bush, 2013).

Participants who were seen to 'turn away', however, had also recovered according to our objective criteria, in terms of symptoms, quality of life and psychological distress. The focus was on the resolution or management of symptoms and leaving these experiences behind, rather than integration. This finding indicates a different type of recovery which does not involve active

engagement, negotiation, acceptance and meaning-making characteristic of the suggested organisation and stabilisation phases. Instead, this typology bears parallels to McGlashan et al.'s (1975) *sealing over* recovery style, characterized by cordoning off psychotic experiences from the rest of one's life, and Frank's (1995) *quest memoir* narratives, which involve acceptance of illness with trials told stoically and no special insight gained (France, Hunt, Dow & Wyke, 2013). In considering this narrative, it is critical that these participants are not pathologized when compared to those who 'turned towards.' The latter group had the benefit of HNV groups and professionals who supported them to normalise and respond to their voices. Turning away participants can perhaps be seen as more remarkable because they did not have access to such discursive resources.

While taking care not to pathologize either recovery typology, the stories that participants told about themselves were more restrictive in turning away narratives and more liberative for those who turned towards. Indeed, there is evidence that in the long term, an integrative approach towards psychotic experiences confers better psychological health, predicting remission at one-year follow-up (Staring, van der Gaag & Mulder, 2011). This raises the question of how clinical services should respond to people with different recovery styles. There is evidence that people's recovery style can change over time (Tait, Birchwood & Trower, 2004). Consequently, periodic assessment of a person's recovery mode would allow services to match their approach to the person's natural inclination at that time. If someone persists in using a turning away style and this is perceived as limiting recovery, how should services respond: acknowledge that a limited recovery has sufficient meaning to the individual, or seek to facilitate the adoption of a turning toward style? Longitudinal studies examining recovery style would allow further clarification of this issue.

It is of note that despite significant differences between typologies, many recovery processes were common across typologies. These provided the foundations for further progress. They were centred around meeting participants' needs for connectedness, positive identity, agency, opportunities to contribute to the community and participate in meaningful activities (Andresen, Oades & Caputi, 2003; Reis, Sheldon, Gable, Roscoe & Ryan, 2000; Slade et al., 2012). This indicates a need to shift from the traditional mode of treatment focussing on the individual to inclusion of family, social networks and broader community and social contexts (Sibitz et al., 2011; Tew, Ramon, Slade, Bird, Melton & Boutillier, 2012; Williams & Collins, 2002).

### *Voices, Self & Others*

Many people experience an initial sense of their identity being subsumed by that of being a patient or voice-hearer and losing their sense of self because of the overwhelming nature of voice-hearing experiences (McCarthy-Jones, 2012; Romme & Escher, 2011; Tew et al., 2012). Reclaiming a positive sense of self appears critical to recovery (Goodliffe, Hayward, Brown, Turton & Dannahy, 2010; May, Strauss, Coyle & Hayward, 2014). Indeed, in the current research, participants described being less distressed by critical or threatening voices when they had developed a stronger sense of self. Recognition of the importance of people's self-esteem in mediating their affective response to negative voices has led to this becoming a specific target of psychological interventions, with promising initial results (van der Gaag, Oosterhout, Daalman, Sommer & Korrelboom, 2012).

Reclaiming one's sense of self, however, is a social as well as individual process: the antithesis to personal diminishment which can result from stigma (Livingston & Boyd, 2010). As

participants reconnected with others and developed supportive relationships, they were more able to deal with their voices in an adaptive manner. This is in keeping with research demonstrating significant parallels between how people relate to others and how they relate and respond to their voices (Chin, Hayward & Drinnan, 2009; Hayward, Berry & Ashton, 2011; Paulik, 2011). It is plausible that as people accumulated more positive experiences with others, their beliefs about others and perception of relative social rank changed, positively impacting on their style of relating to their voices. The tendency of people with turning toward narratives to engage with their voices rather than attempt to distance themselves is consistent with research indicating that relating to voices from a position of distance is associated with significantly higher distress (Vaughn & Fowler, 2004; Hayward et al., 2011). Engaging with voices and setting appropriate boundaries has been implicated in developing a positive relationship with voices (Jackson, Hayward & Cooke, 2011). Indeed, in keeping with recent research, mindfully noticing voices contributed to a less distressing relationship with them (May et al., 2014; Newman-Taylor, Harper & Chadwick, 2009).

#### *Discursive Resources and Making Sense of Voices*

The narratives people tell define how they understand themselves and their problems (Lock, Epston, Maisel & de Faria, 2006; Weingarten, 1998). In the context of hearing voices, the dominant narrative, based in Foucauldian terms on ‘global’ (privileged) rather than ‘local’ knowledge, is that it is a symptom of a disease best treated by anti-psychotic medication (Madigan, 1992; Schrader, 2013). Implicitly, this narrative promotes the notion of the person as the problem (Ben-Zeev, Young & Corrigan, 2010; Lock et al., 2006; Madigan, 1992; van Os, 2010). Those who ‘turned towards’ in this research also ‘turned away’ from the dominant

medical model discourse. This act of resistance was conducted in solidarity with others in HVN groups, allowing for the ‘thickening’ of alternative stories (Adame & Knudson, 2007; White & Epston, 1990). For example, participants described voices as a manifestation of distress understandable within their life context (e.g. Beavan & Read, 2007; Schrader, 2013). Although some participants still used aspects of a medical model explanation and vocabulary, they emphasised that voice-hearing is a normal variation in human experience, opening up the possibility of a non-pathologized self. This suggests that exposure to alternative understandings of voice-hearing, which might compliment rather than necessarily replace the dominant medical model narrative, might be helpful.

#### *Parallels in Professional-Driven Treatments*

Despite the impact of consumer-driven HVN groups in this research it is important to recognise that promising professional-driven treatments are also coming to similar conclusions regarding the value of direct engagement with voices and a focus on the person, not just the problem, particularly in the field of clinical psychology. Turning towards voices by exploration of continuities with broader life experiences has long been a key element of therapies such as cognitive behavioural therapy for psychosis (CBTp; see Farhall & Thomas, 2013).

Contemporary therapy developments have gone further to more explicitly engage with voices, including role playing interactions with voices (Hayward, Overton, Dorey, & Denney, 2009), the use of computer generated avatars to represent voices (Leff, Williams, Huckvale, Arbuthnot & Leff, 2013) and direct verbal engagement of voices by the therapist (Corstens, Longden & May, 2012).

As a cautionary note, findings of the current research suggest that timing is critical. Turning toward participants reached a tipping point where doing something differently, although still frightening, was evaluated as a better option than continuing to tolerate their unbearable situation. This is similar to the crisis-induced change noted by Milligan, McCarthy-Jones, Winthrop and Dudley (2013). In addition, those engaged in a turning away style of response might find such treatments unhelpful and require some time to be ready to undertake such work. These caveats aside, the critical role of interpersonal dialogue and solidarity is also becoming recognised in the network therapy of Seikkula and colleagues (e.g. Seikkula, 2002, 2008, 2011; Seikkula, Alakare & Aaltonen, 2011). This approach involves intensive engagement with the client, the entire family and any other loved ones and professional stakeholders involved. Treatment is based on the notion that psychotic reactions are pre-narrative or metaphorical; attempts to make sense of experiences that are so difficult that they have not yet been situated in spoken discourse (Seikkula, 2002).

Despite the evidence for the efficacy of these treatments, however, several barriers to accessing them remain, resulting in significant unmet need (e.g. Farhall & Thomas, 2013; Mojtabai et al., 2009; National Collaborating Centre for Mental Health, 2009). It is important to emphasise that not one single participant reported receiving psychological intervention that was specifically aimed at dealing with voices. Those who engaged in behavioural experiments and other CBT strategies did so without the help of a psychologist.

### *Role of Hearing Voices Groups in Recovery*

Results indicate that the hearing voices groups (HVGs) played a significant role in normalising voice-hearing, exposing participants to different interpretations of what it means to hear voices,

disseminating strategies for dealing with voices, and providing a sense of community. This is in keeping with other research reporting on the experiences of group members both in the HVNNSW and overseas (Dos Santos, 2014; Ngo Nkouth, St-Onge, & Lepage, 2010; Ruddle, Mason & Wykes, 2010; Sørensen, 2013). However, current findings and the research mentioned are based on the experiences of participants who had chosen to attend HVGs and found them helpful. Choosing not to attend an HVG might be part of a turning away response and it is unclear from the current research whether people with this style of response would find attending a group helpful.

In addition, although the flat hierarchy and member-driven agenda of groups are valued by group members (Dos Santos, 2014), this results in significant variation between groups in how they are run (Corstens et al., 2014). It is therefore unclear whether the positive experiences reported by this sample would generalise to all groups and attendees. Finally, the aspects of the HVGs which participants found helpful might also be accessible through peer workers, spiritual groups, structured group therapy or individual therapy. Indeed, some people report that they benefit from the structured nature of group therapy (May et al., 2014). Of course, people might choose to attend both types of groups. The issue is that currently, only limited research (e.g. Dos Santos, 2014; Sørensen, 2013) is available on the impact of HVGs, suggesting that further investigation is required to clarify how they influence recovery in people who hear voices, how helpful they are and for whom they are most useful. Some might reject the notion that such forms of evaluation would be helpful. However, the relative paucity of research means that such approaches are not as well-recognised and accepted by clinicians as might otherwise be the case. More quantitative and qualitative research is required to build a bridge between consumer- and professional-driven approaches, facilitating greater acceptance of HVGs in main-stream services.

*Limitations and Directions for Future Research*

This research is limited by its retrospective design, because retrospective recall is less accurate than recording events as they occur (e.g. Schröder & Börsch-Supan, 2008). However, given that narrative research aims to elicit how participants understand their experience, and this involves their subjective recollection of experiences, this is in a sense not problematic. Nonetheless, prospective, longitudinal investigation of recovery style would allow examination of whether there are any people who initially turn away and then turn towards, and if so, what might contribute to this change. It would also be useful to examine whether regular assessment of recovery style and adjustment of treatment style to match patients' needs lead to better treatment outcomes. A second limitation is the nature of the sample, which was small, involved self-selection and was more likely to attract people who had positive experiences of HVGs.

Strengths of the study include the rigour employed in generating narratives, which were member-checked by participants, and the focus group's critique of the model of recovery generated. The use of reflection on the subjective values and expectations of the primary researcher was another strength. Through bracketing assumptions and remaining open to the data, it was possible to allow the turning away typology to be identified. Given the bias of the researchers towards understanding recovery as involving active engagement with voices and making sense of them, this finding was unexpected.



## References

- Adame, A. L. & Knudson, R. M. (2007). Beyond the counter-narrative: Exploring alternative narratives of recovery from the psychiatric survivor movement. *Narrative Inquiry, 17*(2), 157-178.
- Andresen, R., Caputi, P. & Oades, L. (2006). Stages of recovery instrument: Development of a measure of recovery from serious mental illness. *Australian and New Zealand Journal of Psychiatry, 40*, 972–980. doi:  
<http://dx.doi.org.ezproxy2.library.usyd.edu.au/10.1111/j.1440-1614.2006.01921.x>
- Andresen, R., Oades, L., & Caputi, P. (2003). The experience of recovery from schizophrenia: Towards an empirically validated stage model. *Australian and New Zealand Journal of Psychiatry, 37*(5), 586-594. doi: 10.1046/j.1440-1614.2003.01234.x
- Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal, 16*(4), 11–23. doi:  
 10.1037/h0095655
- Anthony, W. A. (2000). A recovery-orientated service system: setting some system standards. *Psychosocial Rehabilitation Journal, 24*(9), 159-168.
- American Psychiatric Association (2000). *Diagnostic and statistical manual*, 4<sup>th</sup> edition. Washington, DC.
- Beavan, V. & Read, J. (2007). Hearing voices and listening to what they say: the importance of voice content in understanding and working with distressing voices. *The Journal of Nervous and Mental Disease, 198* (3), 201-205.
- Beavan, V., Read, J., & Cartwright, C. (2011). The prevalence of voice-hearers in the general population: A literature review. *Journal of Mental Health, 20*, 281-292.

- Bellack, A. S. (2006). Scientific and consumer models of recovery in schizophrenia: concordance, contrasts, and implications. *Schizophrenia Bulletin*, 32, 432-442.  
doi:10.1093/schbul/sbj044
- Bentall, R. P. (2003). *Madness explained: psychosis and human nature*. London: Penguin Books.
- Ben-Zeev, D., Young, M. A. & Corrigan, P. W. (2010). DSM-V and the stigma of mental illness. *Journal of Mental Health*, 19(4), p318-327. doi: 10.3109/09638237.2010.492484
- Braun, V. & Clarke, V. (2008). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi: 10.1191/1478088706qp063oa
- Breeding, J. (2008). To see or not to see “schizophrenia” and the possibility of full recovery. *Journal of Humanistic Psychology*, 48, 489-504.
- Brown, W. (2008). Narratives of mental health recovery. *Social Alternatives*, 27(4), 42-48.
- Castle, D. J., Jablensky, A., McGrath, J. J., Carr, V., Morgan, V., Waterreus, A., Valuri, G., Stain, H., McGuffin, P. & Farmer, A. (2006). The diagnostic interview for psychoses (DIP): development, reliability and applications. *Psychological Medicine*, 36, 69–80.  
doi:10.1017/S0033291705005969
- Carlton, T. & Bradstreet, S. (2006). Sharing the positives. *Mental Health Today*. doi: 10.1080/14780880701826101
- Chin, J. T., Hayward, M. & Drinnan, A. (2009). ‘Relating’ to voices: Exploring the relevance of this concept to people who hear voices. *Psychology and Psychotherapy: Theory, Research and Practice*, 82, 1-17
- Choong, C., Hunter, M. D. & Woodruff, P. W. R. (2007). Auditory hallucinations in those populations that do not suffer from schizophrenia. *Current Psychiatry Reports*, 9, 206-212.

- Connelly, F. M., & Clandinin, D. J. (2006). *Narrative inquiry*. In J. L. Green, G. Camilli, & P. Elmore (Eds.), *Handbook of complementary methods in education research* (3rd ed., pp.477–487). Mahwah, NJ: Lawrence Erlbaum.
- Corstens, D., Longden, E. & May, R. (2012). Talking with voices: Exploring what is expressed by the voices people hear. *Psychosis*, 4(2), 95-104. doi: 10.1080/17522439.2011.571705
- Corstens, D., Longden, E., McCarthy-Jones, S., Waddingham, R., & Thomas, N. (2014). Emerging perspectives from the Hearing Voices Movement: implications for research and practice. *Schizophrenia Bulletin* (in press). doi: 10.1093/schbul/sbu007
- Drake, R. E., Bond, G. R., & Essock, S. M. (2009). Implementing evidence-based practices for people with schizophrenia. *Schizophrenia Bulletin*, 35 (4), 704-713.  
doi:10.1093/schbul/sbp041
- Dos Santos, B. (2014). *Experiences of attending the Hearing Voices Network New South Wales Peer Support Groups* (Unpublished master's thesis). Australian College of Applied Psychology. Sydney, NSW, Australia.
- Fischer, C. T. (2009). Bracketing in qualitative research: conceptual and practical matters. *Psychotherapy Research*, 19(4-5), 583-590. doi: 10.1080/10503300902798375
- Fischer, D. (2003). People are more important than pills in recovery from mental disorder. *Journal of Humanistic Psychology*, 43, 65-68. doi: 10.1177/0022167802250568
- Fleming, M. P. & Martin, C. R. (2011). Genes and schizophrenia: a pseudoscientific disenfranchisement of the individual. *Journal of Psychiatric and Mental Health Nursing*, 18, 469-478. doi: 10.1111/j.1365-2850.2011.01690.x
- Frank, A. W. (1995). *The wounded storyteller—Body, illness and ethics*. Chicago: University of Chicago Press.

- Frank, A. W. (2010). *Letting stories breathe: A socio-narratology*. Chicago: University of Chicago Press.
- France, E. F., Hunt, K., Dow, C. & Wykes, E. (2013). Do men's and women's accounts of surviving stroke conform to Frank's narrative genres? *Qualitative Health Research*, 23 (12), p1649-1659. doi: 10.1177/1049732313509895
- Goodliffe, L., Hayward, M., Brown, D., Turton, W. & Dannahy, L. (2010). Group Person-Based Cognitive Therapy for distressing voices: Views from the hearers. *Psychotherapy Research*, 20, 447-461.
- Hall, J.M., Roman, M. W., Thomas, S. P., Brown T. C., Powell, J., Tennison, C. R., . . . & McArther, P. M. (2009). Thriving as becoming resolute in narratives of women surviving childhood maltreatment. *American Journal of Orthopsychiatry*, 79(3), 375-386. doi: 10.1037/a0016531
- Hall, J. M. (2011). Narrative methods in a study of trauma recovery. *Qualitative Health Research*, 21(1), 3-13. doi: 10.1177/1049732310377181
- Harding, C. M., Brooks, G. W., Ashikaga, T., Strauss, J. S. & Breier, A. (1987). The Vermont longitudinal study of persons with severe mental illness II: Long-term outcome of subjects who retrospectively met DSM-III criteria for schizophrenia. *American Journal of Psychiatry*, 144 (6), 727-735. doi: 10.1037/t01554-000
- Harrison, G., Hopper, K., Craig, T., Laska, E., Siegel, C., Wanderling, J...& Wiersma, D. (2001). Recovery from psychotic illness: a 15- and 25-year international follow-up study. *British Journal of Psychiatry*, 178, 506-517. doi: 10.1192/bjp.178.6.506

- Hayward, M., Berry, K. & Ashton, A. (2011). Applying interpersonal theories to the understanding of and therapy for auditory hallucinations: A review of the literature and directions for future research. *Clinical Psychology Review, 31*, 1313-1323.
- Hayward, M., Overton, J., Dorey, T. & Denney, J. (2009). Relating therapy for people who hear voices: A case series. *Clinical Psychology and Psychotherapy, 16*, 216-227.
- Jackson, L., Hayward, M. & Cooke, A. (2011). Developing positive relationships with voices: A preliminary grounded theory. *International Journal of Social Psychiatry, 57*, 487-495.
- Johns, L. C. & Van Os, J. (2001). The continuity of psychotic experiences in the general population. *Clinical Psychology Review, 21* (8), 1125-1141. doi: 10.1016/S0272-7358(01)00103-9
- Kessler, R.C., Andrews, G., Colpe, L. J., Hiripi, E., Mroczek, D. K., Normand, S.-L. T., Walters, E. E. & Zaslavsky, A. M. (2002). Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological Medicine, 32*, 959-956. doi: 10.1017/S0033291702006074
- Kirkpatrick, H. & Byrne, C. (2009). A narrative inquiry: Moving on from homelessness for individuals with a major mental illness. *Journal of Psychiatric and Mental Health Nursing, 16*, 68-75. doi: 10.1111/j.1365-2850.2008.01331.x
- Kuipers, E., Garety, P., Fowler, D., Freeman, D., Dunn, G. & Bebbington, P. (2006). Cognitive, emotional, and social processes in psychosis: Refining Cognitive Behavioral Therapy for persistent positive symptoms. *Schizophrenia Bulletin, 32* (1), p24-31. doi:10.1093/schbul/sbl014

- Leamy, M., Bird, V., Le Boutillier, C., Williams, J. & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *British Journal of Psychiatry*, *199*, 445-452. doi: 10.1192/bjp.bp.110.083733
- Leff, J., Williams, G., Huckvale, M. A., Arbutnot, M. & Leff, A. P. (2013). Computer-assisted therapy for medication-resistant auditory hallucinations. *British Journal of Psychiatry*, *202*(6), 428-433. doi: 10.1192/bjp.bp.112.124883
- Livingston, J. D. & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science & Medicine*, *71* (12), 2150-2161. doi: 10.1016/j.socscimed.2010.09.030
- Lock, A., Epston, D., Maisal, R. & de Faria, M. (2006). Resisting anorexia/bulimia: Foucauldian perspectives in narrative therapy. *British Journal of Guidance and Counselling*, *33*(3), p315-332. doi: 10.1080/03069880500179459
- Madigan, S. P. (1992). The application of Michel Foucault's philosophy in the problem externalizing discourse of Michael White. *Journal of Family Therapy*, *14*, p265-279. doi: 10.1016/j.socscimed.2010.09.030
- May, K., Strauss, C., Coyle, A. & Hayward, M. (2014). Person-based cognitive therapy groups for distressing voices: A thematic analysis of participant experiences of the therapy. *Psychosis*, *6*, 16-26.
- McCarthy-Jones, S. (2012). *Hearing voices: The histories, causes and meanings of auditory verbal hallucinations*. Cambridge: Cambridge University Press.
- McCarthy-Jones, S. & Longden, E. (2013). The voices others cannot hear. *The Psychologist*, *26*(8), p570-574.

- McGlashan, T. H., Levy, S. T., & Carpenter, W. T. (1975). Integration and sealing over: Clinically distinct recovery styles from schizophrenia. *Archives of General Psychiatry*, 32, p1269-1272.
- Milligan, D., McCarthy-Jones, S., Winthrop, A. & Dudley, R. (2013). Time changes everything? A qualitative investigation of the experience of auditory verbal hallucinations over time. *Psychosis*, 5(2), p107-118.
- Mojtabai, R., Fochtmann, L., Chang, S.-W., Kotov, R., Craig, T. J. & Bromet, E. (2009). Unmet need for mental health care in schizophrenia: An overview of the literature and new data from a first-admission study. *Schizophrenia Bulletin*, 35(4), p679-695.  
doi:10.1093/schbul/sbp045
- National Collaborating Centre for Mental Health (2009). *Schizophrenia: The NICE Guideline on Core Interventions in the Treatment and Management of Schizophrenia in Adults in Primary and Secondary Care (National Clinical Practice Guideline) (updated edition)*. London: Royal College of Psychiatrists and British Psychological Society.
- Newman-Taylor, K., Harper, S. & Chadwick, P. (2009). Impact of mindfulness on cognition and affect in voice-hearing: Evidence from two case studies. *Behavioural and Cognitive Psychotherapy*, 37(4), 397-402. doi: 10.1017/S135246580999018X
- NiaNia, W. & Bush, A. (2013, 20 November). *New Zealand Māori traditional healing approaches to voice-hearing*. Article presented at the World Hearing Voices Congress, Melbourne, Australia.
- Ngo Nkouth, B., St-Onge, M. & Lepage, S. (2010). The group as a place of training and universality of the experience of voice-hearers. *Groupwork*, 20 (2), 45-64. doi: 10.1921/095182410X552693

- Oke, M. (2008). The value of narrative in understanding Mongolian and Australian women's journeys of survival recovery and remaking of self, through and beyond domestic violence. *Women's Studies International Forum*, 31, 415-423. doi: 10.1375/anft.29.3.148
- Paulik, G. (2011). The Role of Social Schema in the Experience of Auditory Hallucinations: A Systematic Review and a Proposal for the Inclusion of Social Schema in a Cognitive Behavioural Model of Voice Hearing. *Clinical Psychology and Psychotherapy*, p768. 10.1002/cpp.768
- Perkins, R. & Slade, M. (2012). Recovery in England: Transforming statutory services? *International Review of Psychiatry*, 24(1), p29–39. doi: 10.3109/09540261.2011.645025
- Priebe, S., Huxley, P., Knight, S. & Evans, S. (1999). Application and results of the Manchester Short Assessment of Quality of Life (MANSA). *International Journal of Social Psychiatry*, 45(1), p7-12. doi: 10.1177/002076409904500102
- Read, J., Bentall, R. P., & Fosse, R. (2009). Time to abandon the bio-bio-bio model of psychosis: Exploring the epigenetic and psychological mechanisms by which adverse life events lead to psychotic symptoms. *Epidemiologia e Psichiatria Sociale*, 18 (4), 299-310. doi: 10.1111/j.1600-0447.2005.00634.x
- Priebe, S., McCabe, R., Junghan, U., Kallert, T., Ruggeri, M., Slade, M. & Reininghaus, U. (2011). Association between symptoms and quality of life in patients with schizophrenia: A pooled analysis of changes over time. *Schizophrenia Research*, 133, 17-21. doi: 10.1177/002076409904500102
- Reis, H. T., Sheldon, K. M., Gable, S. L., Roscoe, S. L. & Ryan, R. M. (2000). Daily Well-Being: The Role of Autonomy, Competence, and Relatedness. *Personality and Social Psychology Bulletin*, 26(4), 419-435. doi: 10.1177/0146167200266002



- Riessman, C. K. (2005). Narrative Analysis. In: *Narrative, Memory & Everyday Life*.  
Huddersfield: University of Huddersfield.
- Romme, M. A. J., & Escher, A. D. M. A. C. (1989). Hearing voices. *Schizophrenia Bulletin*, 15, 209-216.
- Romme, M. & Escher, S. (1993). *Accepting voices*. London: MIND publications.
- Romme, M. & Escher, S. (Eds.) (2011). *Psychosis as a personal crisis: An experience-based approach*. East Sussex / New York: Routledge.
- Romme, M. Escher, S., Dillon, J., Corstens, D. & Morris, M. (2009). *Living with Voices: 50 Stories of Recovery*. Herefordshire, UK: PCCS Books.
- Romme, M. & Morris, M. (2013). The recovery process with hearing voices. *Psychosis*, 5(3), 250-260. doi: 10.1080/17522439.2013.830641
- Ruddle, A., Mason, O. & Wykes, T. (2010). A review of hearing voices groups: Evidence and mechanisms of change. *Clinical Psychology Review*, 31, 757-766.  
doi:10.1016/j.cpr.2011.03.010
- Sachs, G. S., Printz, D. J., Kahn, D. A., Carpenter, D. & Docherty, J. P. (2000). Medication treatment of bipolar disorder. *Expert consensus guideline series: A postgraduate medicine special report*.
- Schrader, S. R. (2013). Illuminating the heterogeneity of voices in a multiple perspectives research paradigm. *Psychosis*, 5(3), p216-225. doi: 10.1080/17522439.2013.845593
- Schröder, M. & Börsch-Supan, A. (2008). Retrospective data collection in Europe. *Manheim Institute for the Economics of Aging*. Retrieved from:  
[http://mea.mpisoc.mpg.de/uploads/user\\_mea\\_discussionpapers/1jxcvniw0vcuwcvva\\_DP%20172-08.pdf](http://mea.mpisoc.mpg.de/uploads/user_mea_discussionpapers/1jxcvniw0vcuwcvva_DP%20172-08.pdf)

- Seikkula, J. (2002). Open dialogues with good and poor outcomes for psychotic crises: Examples from families with violence. *Journal of Marital and Family Therapy*, 28(3), 263-274. doi: 10.1111/j.1752-0606.2002.tb01183.x
- Seikkula, J. (2008). Inner and outer voices in the present moment of family and network therapy. *Journal of Family Therapy*, 30, 478-491. doi: 10.1111/j.1467-6427.2008.00439.x
- Seikkula, J. (2011). Becoming dialogical: Psychotherapy or a way of life? *The Australian and New Zealand Journal of Family Therapy*, 32(2), 179-193.
- Seikkula, J., Alalkare, B. & Aaltonen, J. (2011). The comprehensive Open-Dialogue approach in Western Lapland: II. Long-term stability of acute psychosis outcomes in advanced community care. *Psychosis*, 3(3), 192-204. doi: 10.1080/17522439.2011.595819
- Sibitz, I., Amering, M., Unger, A., Seyringer, M. E., Bachmann, A., Schrank, B., Benesch, T., Schulze, B., Woppmann, A. (2011). The impact of the social network, stigma and empowerment on the quality of life in patients with schizophrenia. *European Psychiatry*, 26, 28–33. doi:10.1016/j.eurpsy.2010.08.010
- Slade, M., Amering, M. & Oades, L. (2008). Recovery: an international perspective. *Epidemiologia e Psichiatria Sociale*, 17(2), p128-137.
- Slade, M., Leamy, M., Bacon, F., Janosik, M., Le Boutillier, C., Williams, J., & Bird, V. (2012). International differences in understanding recovery: systematic review. *Epidemiology and Psychiatric Sciences*, 21, 353-364. doi:10.1017/S2045796012000133
- Sørensen, T. H. (2013). *The Aarhus Voice Hearing Program – An exploration of a recovery-oriented program* (Unpublished master's thesis). Aarhus University. Aarhus, Denmark.

- Staring, A. B. P., van der Gaag, M. & Mulder, C. L. (2011). Recovery style predicts remission at one-year follow-up in outpatients with schizophrenia spectrum disorders. *The Journal of Nervous and Mental Disease*, 199(5), p295-300. doi: 10.1097/NMD.0b013e3182174e97
- Tait, L., Birchwood, M. & Trower, P. (2004). Adapting to the challenge of psychosis: personal resilience and the use of 'sealing over' (avoidant) coping strategies. *British Journal of Psychiatry*, 185, p410-415.
- Tew, J., Ramon, S., Slade, M., Bird, V., Melton, J. & Le Boutillier, C. (2012). Social factors and recovery from mental health difficulties: A review of the evidence. *British Journal of Social Work*, 42, 443–460. doi:10.1093/bjsw/bcr076
- Thomas, N., Hayward, M., Peters, E., van der Gaag, M., Bentall, R. P., Jenner, J.... & McCarthy-Jones, S. (2014). Psychological therapies for auditory hallucinations (voices): current status and key directions for future research. *Schizophrenia Bulletin*, in press.
- Thornicroft, G. (2006). *Shunned: Discrimination against people with mental illness*. Oxford: Oxford University Press.
- Tien, A. Y. (1991). Distributions of hallucinations in the population. *Social Psychiatry and Psychiatric Epidemiology*, 26, 287– 292. doi: 10.1007%2F00789221
- Tufford, L. & Newman, P. (2012). Bracketing in qualitative research. *Qualitative Social Work: Research and Practice*, 11(1), 80-96. doi: 10.1177/1473325010368316
- Vaughn, S. & Fowler, D. (2004). The distress experienced by voice hearers is associated with the perceived relationship between the voice hearer and the voice. *British Journal of Clinical Psychology*, 43, 143-153. doi: 10.1348/014466504323088024
- Van der Gaag, M., Oosterhout, B., Daalman, K., Sommer, I. E., & Korrelboom, K. (2012). Initial evaluation of the effects of competitive memory training (COMET) on depression in

- schizophrenia-spectrum patients with persistent auditory verbal hallucinations: A randomised controlled trial. *British Journal of Clinical Psychology*, 51, 158-171. doi: 10.1111/j.2044-8260.2011.02025.x
- Van Os, J. (2010). Are psychiatric diagnoses of psychosis scientific and useful? The case of schizophrenia. *Journal of Mental Health*, 19(4), p305-317. doi: 10.3109/09638237.2010.492417
- Waters, F. (2010). Auditory hallucinations in psychiatric illness. *Psychiatric Times*. Retrieved from: <http://www.psychiatrictimes.com/schizophrenia/auditory-hallucinations-psychiatric-illness>
- Weingarten, K. (1998). Accounting for narrative therapy's success: The small and the ordinary: The daily practice of a postmodern narrative therapy. *Family Process*, 37, 3-15. doi: 10.1111/j.1545-5300.1998.00003.x
- White, M. & Epston, D. (1990). *Narrative means to therapeutic ends*. New York / London: W. W. Norton & Company.
- White, R. F. (2005). An empowerment model of recovery from severe mental illness: An expert interview with Daniel B. Fisher, MD, PhD. *Medscape Psychiatry*.  
retrieved from: <http://www.medscape.com/viewarticle/496394>.

## Chapter 5

### Discussion

#### Turning Away and Turning Toward

This narrative study aimed to investigate recovery trajectories and critically appraise and further develop Romme, Escher and colleagues' seminal work on recovery from distressing voices, in particular the suggested *startling*, *organisation* and *stabilisation* phases of recovery (e.g. Romme & Escher, 1989; Romme & Morris, 2013). Romme and his patient Patsy Hague appeared on a Dutch television program, inviting other voice-hearers to contact them. The response was significant: approximately 450 voice-hearers contacted them, 300 of whom reported that they were not able to cope with their voices, with the remaining 150 indicating that they were able to cope (Romme & Escher, 1989). The discovery that such a significant proportion of people were able to function and cope with their voices challenged the notion that experiencing auditory hallucinations was necessarily disabling and associated with mental ill-health. This motivated Romme, Escher and Hage to organize the first world hearing voices congress. The congress provided an opportunity for voice-hearers to share their experiences and ways of coping with voices. All understandings of voices, whether medical, psychological, spiritual, or trauma-based, were welcomed. Romme and Escher (1989, 1993) noticed a common pattern of recovery across voice-hearers' accounts, suggesting three phases of recovery. Most people described being initially frightened and shocked by the onset of voices (*startling phase*), followed by starting to investigate what their voices meant, communicating with them, placing boundaries around their communication and accepting voices as independent beings (*organisation phase*) and finally coming to accept themselves, understand what function the voices might play in their lives and accepting them.

Participants in the current study described an initial response of shock, confusion and fear in response to voices, loss of sense of self, and becoming overwhelmed. This is in keeping with the *startling* phase. However, from this point, the study identified two typologies of recovery, rather than just one: *turning toward* and *turning away*. *Turning toward* narratives involved a transformation of self, active engagement with voices, adopting a normalised view of voices and integrating them into one's life. This provides support for Romme et al.'s (2009) *organisation* and *stabilisation* phases. These narratives align with McGlashan, Levy and Carpenter's (1975) integrative recovery style, which involves curiosity about psychotic experiences, striving to make sense of them and integrating them into one's life, as well as Frank's (1995) quest mythology narratives, which are characterised by a transformation in identity in response to physical illness. This also resonates with the Māori concept of voices as a 'difficult gift' which are nonetheless an ordinary part of daily life (NiaNia & Bush, 2013).

Participants who were seen to '*turn away*', however, had also recovered according to our objective criteria, in terms of symptoms, quality of life and psychological distress. The focus was on the resolution or management of symptoms and leaving these experiences behind, rather than integration. This finding indicates a different type of recovery which does not involve active engagement, negotiation, acceptance and meaning-making characteristic of the suggested *organisation* and *stabilisation* phases. Instead, this typology bears parallels to McGlashan et al.'s (1975) *sealing over* recovery style, characterized by cordoning off psychotic experiences from the rest of one's life, and Frank's (1995) quest memoir narratives, which involve acceptance of illness with trials told stoically and no special insight gained (France, Hunt, Dow & Wyke, 2013). In considering this narrative, it is critical that these participants are not pathologized when compared to those who 'turned towards.' The latter group had the benefit of

HNV groups and professionals who supported them to normalise and respond to their voices.

*Turning away* participants can perhaps be seen as more remarkable because they did not have access to such discursive resources (Lock, Epston, Maisal & de Faria, 2005). It is also important to note the sense in which withdrawal can be an active means of protecting oneself rather than a passive action, as pointed out by consumers/survivors (e.g. Andresen, Oades & Caputi, 2003).

While taking care not to pathologize either recovery typology, the stories that participants told about themselves were more restrictive in *turning away* narratives and more liberative for those who *turned towards*. Indeed, there is evidence that in the long-term, an integrative approach towards psychotic experiences confers better psychological health, predicting remission at one-year follow-up (Staring, van der Gaag & Mulder, 2011). A ‘sealing over’ style has been associated with poor attachment, depression and low self-esteem (Drayton, Birchwood & Trower, 1998).

This raises the question of how clinical services should respond to people with different recovery styles. There is evidence that people’s recovery style can change over time (Tait, Birchwood & Trower, 2004). Consequently, periodic assessment of a person’s recovery mode would allow services to match their approach to the person’s natural inclination at that time. If someone persists in using a *turning away* style and this is perceived as limiting recovery, how should services respond – acknowledge that a limited recovery has sufficient meaning to the individual, or seek to facilitate the adoption of a *turning toward* style? Longitudinal studies examining recovery style would allow further clarification of this issue. Assuming that encouraging a *turning toward* style over the long-term is possible and desirable, identifying mechanisms that support this change would be helpful. For example, Leonard, Jones and Cupitt (2014) found that stronger positive beliefs about worry were associated with an increased

tendency to ‘seal over’. Addressing beliefs about worry in therapy may facilitate decreased avoidance of difficult emotions and images, encouraging increased emotional processing and therefore recovery.

### **Role of HVN in Recovery**

Five out of six participants who *turned towards* were recruited from the HVNNSW. However, before considering the impact of the HVN on recovery, it is worth clarifying its dual role as both a radical social movement focused on human rights and advocacy at a systems level and a user-led organization offering support and therapeutic intervention (Corstens, Longden, McCarthy-Jones, Waddingham & Thomas, 2014). Although related, these will be discussed separately below for the sake of clarity.

### ***Hearing Voices Groups***

Results indicate that the HVN groups and approach played a significant role in normalising voice-hearing, exposing participants to different interpretations of what it means to hear voices, disseminating strategies for dealing with voices, and providing a sense of community. This is in keeping with the experiences of group members both in the HVNNSW and overseas (dos Santos, 2014; Ngo Nkouth, St-Onge, & Lepage, 2010; Sørensen, 2013; Ruddle, Mason & Wykes, 2010). Ngo Nkouth et al.’s (2010) participants emphasized the group’s importance to their identity and sense of belonging and connectedness. Through discussing experiences with other group members, they were exposed to different ideas about how to cope with voices and how voices were experienced by other people. Participation in the group gave them hope and destigmatised the experience. Similarly, dos Santos’s (2014)



participants reported that they valued the social connections formed in the group as well as the opportunity to receive feedback about themselves. They also described a shift from being too uncomfortable to talk about voice-hearing experiences within the group to gradually gaining confidence within what was experienced as a safe environment. For some, this extended to talking about their experiences outside of the group.

Increased openness on the part of voice-hearers about their voices may contribute to voice-hearing being better understood and less stigmatized in the community generally. Increased contact between the general public and people with mental health difficulties has been shown to decrease negative attitudes and perceptions of dangerousness (Scheffer, 2003). In addition, psychosocial rather than biological explanations are associated with decreased stigma (Read, Haslam, Sayce & Davies, 2006). Given that in the current study secrecy and fear inhibited recovery, decreased stigma is likely to support recovery. Of course, decisions regarding disclosure should be left to individual choice, particularly given the risk of negative consequences, including discrimination.

An important issue is that currently, only limited research (e.g. dos Santos, 2014; Sørensen, 2013) supports the helpfulness of HVN groups. One randomized controlled trial on peer support groups for psychosis generally (not specifically related to hearing voices) indicated a significant positive effect on social network and support (Castelein et al., 2008). Current findings and the research mentioned are based on the experiences of participants who found HVN groups helpful. Choosing not to attend an HVN group may be part of a *turning away* response and it is unclear from the current study whether attending a group would be helpful for people with this style of response. While participants in our study reported positive experiences of the HVN, however, it is possible that other people have had a different experience. The

aspects of the HVN which participants found helpful may also be accessible through peer workers, spiritual groups, structured group therapy or individual therapy. Indeed, some people report that they benefit from the structured nature of group therapy (May et al., 2014). Ruddle et al. (2009) suggested attempts to identify common helpful processes across group type (structured, HVG, CBT) would be more helpful than attempting to determine which type of group is more effective. Thus, further research into HVGs is urgently required.

Some within the survivor movements may reject the notion that such forms of evaluation would be helpful. However, the relative paucity of research means that such approaches are not as well-recognised and accepted by clinicians as might otherwise be the case. Clinicians, working from a scientist-practitioner model, are more likely to feel comfortable recommending therapeutic groups which have been shown to be effective. More quantitative and qualitative research is required to build a bridge between consumer- and professional-driven approaches, facilitating greater acceptance of approaches such as the HVN in main-stream services.

The efficacy of HVGs is not, however, amenable to being researched using traditional research designs, including randomized controlled trials. Participants in dos Santos's (2014) research emphasized that they valued that the group agenda is determined by group members. They did not wish for it to become a therapy group led by a therapist, which would result in a loss of power and autonomy. However, while the flat hierarchy and member-driven agenda of groups are valued by group members (dos Santos, 2014), this means that they are not standardised. Standardized delivery of a treatment via session by session manuals which specify content is required in randomized controlled trials. While the essential elements of an HVG group could be identified, it is unclear whether such distillation would capture the true nature and processes of a naturally occurring HVG (Corstens et al., 2014). Another issue is how to define

effectiveness – in terms of symptom reduction associated with clinical recovery, or with personal recovery outcomes including subjective well-being, the nature of people’s relationship(s) with their voice(s), sense of self and ability to function and live a valued life (Corstens et al., 2014). Inclusion of voice-hearers in the research process would help to address this issue. Collaboration between the HVM and researchers is required to consider which research questions should be asked as a priority and which research methods would be most appropriate to employ. This is discussed further in the ‘story-telling rights in research’ section.

### ***Hearing Voices Movement***

All participants recruited from the HVNNSW had attended a group at least once. Some did so regularly and three were actively involved in advocacy and peer work. Thus, the degree of participants’ political involvement and alignment with the hearing voices movement (HVM) varied. However, they all tended to take a human rights stance and offered critiques of the mental health system. They viewed themselves through a political lens and questioned the lack of power they and other service users had in the mental health system. This is in keeping with the key concerns of the HVM (Corstens et al., 2014). Participants’ political stance, values regarding issues of power and rights, and advocacy of others was deeply meaningful to them and formed part of their identity. In contrast, in the context of a traditional service framework, five out of six people received diagnoses. This formed part of how professionals, who held an expert position in relation to participants’ experiences at the time, interpreted the experience of distressing voices. Therefore, they also influenced how participants initially understood their experiences, with implications for their sense of self and identity. In most cases, treatment involved being given a diagnosis and prescribed medication. The potentially harmful effects of

diagnosis, for example, encouraging a reductionistic approach and contributing to stigma, continue to be debated (Van Os, 2010). Some argue that the diagnostic system should be changed to incorporate categorical and dimensional classification, which is in keeping with evidence from epidemiological research, and to emphasise that it is a variation in normal human experience (Van Os, 2010). Others have focused on how to minimize the negative impact of communicating a psychotic-spectrum disorder diagnosis (Outram et al., 2014).

Certainly in the current study, while diagnosis brought short-term relief for some participants, recovery generally involved coming to understand voice-hearing as a meaningful response to life events. Indeed, most *turning towards* participants described their treatment within a traditional medical model to be insufficient. They felt that it did not provide an adequate explanation for their experiences in context of their life history and current situation. One participant commented that not being diagnosed, even though she may have met criteria for diagnosis, meant that her experiences were not pathologised and that this was essential to her becoming well. Indeed, the assumption that effective treatment can only be provided in context of diagnosis bears revisiting. In addition to potentially causing stigma and internalised stigma, there are significant concerns regarding the validity of the schizophrenia and schizoaffective disorder diagnoses (e.g. Bentall, 2003; Heckers, 2009). Further, as pointed out by Johnstone (2008), it is feasible to provide formulation-based treatment and avoid diagnosis altogether. Approaching distressing voices as potentially meaningful in the context of one's life history, which is by definition provided in a clinical formulation, is certainly what *turning toward* participants in the current study wished to receive during treatment.

Participants' shift away from a purely medical model explanation and toward the HVM was also therefore an empowering shift toward reclaiming their right to define their own

experiences and critique the treatment which with they were provided. This stance represents a shift from a passive patient role, wherein the person feels they have little valid knowledge, to one of expert by experience, which involves viewing knowledge gained by experience as valid and valuable. This is in keeping with Sørensen's (2013) participants' description that rethinking diagnosis meant relegating their problems to the status of being a part of themselves rather than defining who they were as human beings: the difference between "I am schizophrenic" and "I have schizophrenia."

Similarly, as participants recovered, they were more active in decision-making regarding their treatment. They emphasised the value of psychiatrists who were willing to work collaboratively with them and, in some cases, agree to changes in medication (e.g. lowered dosage) which were not their preference.

There is concern that these key aspects of the recovery-orientated paradigm have been mistranslated – even colonised or hijacked – from their consumer/survivor and recovery movement roots to formal mental health policies and practice (Perkins & Slade, 2012; Slade, 2014). However, while integrating evidence-based and recovery-orientated services remains challenging, it is not impossible. For example, Frese, Stanley, Kress and Vogel-Scibilia (2001) argue that greater autonomy should be afforded to people in mental health services as they recover. Similarly, whichever approach is adopted regarding diagnosis and other relevant clinical practices, it is essential from a consumer rights and advocacy perspective that consumers are included in the debate and that their contributions are given weight and value in such processes. This will be further discussed in the 'story-telling rights' in therapy and research sections below. The notion of 'story-telling rights' is adopted from narrative therapy (e.g. Dulwich Centre, 2014).

### **Story-telling rights in clinical services: Implications for practice**

Results suggest that people have their own resources and expertise regarding what they need to recover and when they need it. Readiness for change emerged as a critical factor in recovery. It is not necessarily something which is likely to occur on the therapists' or hospital's schedule. This is at odds with the demands on funding-pressured services with targets to meet in terms of diminishing length of stay and highlights the importance of out-patient services. In combination with the observed difference in recovery styles, results suggest that a collaborative approach offering different treatments available and encouraging patients to, at the very least, have input into which services they would like to use and when would be advisable. The concept of 'personal budgets' – which allow consumers to choose which services they would like to access – is an example of an approach which recognises patients' expertise regarding what they need (Perkins & Slade, 2013). However, there is some discomfort with this approach among professionals who argue that they, rather than patients, are in the best position to determine optimal treatment (Perkins & Slade, 2013). This position is based on a scientist-practitioner orientation, whereby knowledge of the research literature combined with clinical assessment and formulation skills are used to inform treatment (Jones & Mehr, 2007). Although from a clinical psychology perspective formulation is by definition collaborative, there is still some acknowledgement that the clinician has access to expert knowledge which gives them the right to recommend and in some cases subtly determine what treatment will be undertaken. An important aspect of the scientist-practitioner model is that the evidence-base for a particular treatment is derived from aggregate outcome data rather than individual cases. In contrast, a recovery-oriented way of working would give equal weight to the individual's values and goals (Perkins & Slade, 2013). Indeed, people who have recovered from severe mental health

difficulties report that taking responsibility for recovery is an essential part of the process (Andresen et al., 2003; Anthony, 1993). In keeping with this, a longitudinal, prospective study found that an internal locus of control was positively associated with recovery and negatively associated with depression and psychosis (Harrow et al., 2009).

The question from a clinical perspective is how to support this sense of agency and internality in people distressed by voices while also meeting one's legal responsibilities. This 'dual-role' affects mental health workers, with considerable tension created between institutional demands and the desire to work collaboratively (Borchers, Seikkula & Lehtinen, 2014). The NSW Consumer Advisory Group (2009) identified the following barriers to recovery: consumers becoming passive in relation to their treatment, service providers taking the expert role and tension between clinical and personal views of recovery. However, they also acknowledged the difficulty in following recovery-oriented philosophy, which emphasises increased agency and choice, when faced with a situation where a service user poses a risk to themselves or others.

It is worth bearing in mind that no treatment – whether it is medical, psychological or social – works for everybody or to the same extent (Thomas et al., 2014). The idiosyncratic nature of recovery across participants, differences in recovery style and importance of timing in the current study emphasises differences between people in their recovery and treatment needs. The question of what works for whom and when is fertile ground for further research. A recent review of psychological interventions identified a need to shift away from broad group-based efficacy trials to identifying what individual factors, if any, might predict which type of treatment is likely to be helpful for a particular patient (Thomas et al., 2014). The heterogeneity in response to treatment, as well as the importance of agency in supporting recovery, suggests that a genuinely collaborative stance toward decision-making which balances recommendations

based on existing research with service users' preferences and values is likely to support recovery. In addition, it is not necessarily incompatible with a scientist-practitioner orientation. For example, the Needs Adapted Approach (NAA) practiced in Finland operates very much on tailoring treatment to the individual needs of the person and their social systems and working collaboratively (Alanen, 2009). A subset of NAA, the Open-Dialogue approach, operates on the same principles, with an emphasis on initiating treatment within 24 hours of contact and involving the individual's social networks (Seikkula et al., 2003). It has resulted in excellent outcomes, with 81% of first episode participants reporting no residual psychotic symptoms and 83% having returned to work at two-year follow-up (Seikkula et al., 2003).

The issue may be more about how, as much as what, is done. Indeed, *how* treatment is organised and *how* decisions about the best course of action are made appear to have a very significant impact. Traditionally, professionals would assess the person in distress and create a treatment plan, which is then communicated to the person and possibly their family. In contrast, the Open Dialogue approach mentioned above involves the whole team meeting together with the person and their family from the first point of contact. They collaboratively assess the situation, come to a shared understanding thereof and then decide what to do. As pointed out by Seikkula (2008), traditional forms of treatment delivery trap people in a monological mode, which keeps them stuck in the problem. In contrast, encouraging dialogue, which is done drawing on the principles of systemic and family therapies, encourages the mobilisation of the family's resources to deal with the problem. Open Dialogue also focuses on understanding the person's distress within their life context and situates the problem as separate to the person, as in narrative therapy. This avoids the profoundly harmful effects of diagnosis as discussed above. In contrast, paternalistic services obscure these resources and inhibit recovery by encouraging



people to remain in a passive role regarding their recovery. Further, while the impact of life experiences and society generally may be considered, the problem is conceptualised as being within the person.

### **Story-telling rights in research**

The question of who holds the expert position or has access to expert knowledge in research has important implications for how research is conducted, what knowledge is generated and which perspectives of voice-hearing are reinforced by research. Traditionally, the researcher, typically someone who has training in research design and is familiar with existing literature on the topic of interest, has held the expert position in conducting further research and generating knowledge. Unfortunately, there is a history within psychiatric and psychological research into voice-hearing of using language which voice-hearers experienced as stigmatizing and ‘othering’ – creating the impression of an essential difference between people who hear voices and those who do not. This is the opposite of the normalizing, continuum-based explanation of voice-hearing espoused by the HVM and reported to facilitate recovery by *turning toward* participants in the current study. Studies have tended to describe differences in terms of deficits within the voice-hearing group compared to controls. Comparatively little research has been conducted into positive outcomes associated with hearing voices or schizotypy more generally. For example, there appears to be an association between schizotypy, psychosis proneness, bipolar traits and creativity (Acar & Sen, 2013; Claridge & Blakey, 2009; Thys, Sabbe & De Hurt, 2011). On a separate but related topic, Pyle and Morrison’s (2013) participants reported that the absence of positive reports about people with psychosis in the media contributed to stigma. While the focus on identifying causes of distress associated with

voice-hearing is understandable, there is a difference between this and trying to identify ‘what’s wrong with’ people who hear voices. Indeed, the idea of voices as necessarily pathological is one of many possible perspectives through which to understand voice-hearing. The notion of voices as both the problem and the solution commonly referred to in the HVM (Corstens et al. 2014) or a ‘difficult gift’ (NiaNia & Bush, 2013) are alternative perspectives. The question is whether re-telling and reinforcing the notion of ‘impairment’ and ‘deficits’ is of benefit to people who hear voices. This question has ethical significance regarding research conducted. As in clinical settings, it is perhaps as much about how as what is done. It is possible that the same findings could be reported in more respectful language. Indeed, from a postmodern perspective, language is a means through which socially constructed reality is expressed (Gergen, 2001). The terms used in research, for example, ‘auditory hallucination’ versus ‘voice-hearing’, ‘symptom’ versus ‘experience’, ‘unusual belief’ versus ‘delusion’ are important because they have the capacity to create and reinforce particular concepts. For example, people who have lived experience of hearing voices often dislike the term ‘auditory hallucination’ because of connotations that voices are ‘not real’, which is contrary to their experience of them as very real indeed (Corstens et al., 2014). Given the constitutive power of language in defining how we understand and interpret the world, it is perhaps unsurprising that it emerged as a critical topic at the World Hearing Voices Congress (2013). Indeed, the NSW Consumer Advisory Group (NSWCAG, 2009) review specifically recommended a shift away from deficit-based language and toward a strengths-based mode of practice.

More broadly, in order for voice-hearers to have story-telling rights in research, they need to be included in the broader research agenda; in other words, they need to have some power in determining which research questions are asked and how research is conducted (Corstens et al.,

2014). Historically, psychiatric and psychological research into voice-hearing has typically not included voice-hearers or service users in the research agenda. This issue is complicated by the reluctance of some voice-hearers to be involved in research given its questionable approach historically. Voice-hearers and their loved ones are in business terms ‘key stakeholders’ in the research process and should therefore be involved in research (Griffiths, Jorm, Christensen, Medway & Dear, 2002). Their inclusion in research makes it more likely that the research will result in a practical benefit to the group it is intended to benefit. For example, research which aims to identify which medication will be effective and less harmful (i.e. have fewer side-effects) for a particular individual has a clear practical benefit for people who hear voices (e.g. Adkins et al., 2013). The same applies to research by Tsuboi et al. (2013) concerning what range of dosage of antipsychotic medication is required for therapeutic effect while avoiding changes in the dopamine system associated with harmful metabolic changes. Consumers and carers are generally in agreement with other stakeholders regarding the importance of research into psychological and social interventions, as well as prevention of mental health difficulties (e.g. Griffiths et al., 2002). Given that various stakeholder groups may rate research priorities differently, it is important that independent consumer and carer reviews be undertaken. For example, the NSW CAG review (2009) identified clearer operationalisation and benchmarking of recovery as a research priority.

From a postmodern perspective, all aspects of the research process, including what questions are conceivable, are determined by social context and existing knowledge (Gergen, 2001). While it is not possible to extricate the production of knowledge from this context, inclusion of voice-hearers and their families in research would strengthen the design through bringing perspectives gained from lived experience to bear on the research agenda and question,

design, process and dissemination of knowledge gained. They have a unique perspective which those in the dominant position cannot fully understand. Clearly, voice-hearers have a unique knowledge not only in what they know, but how they know it. Their inclusion would be a step in the right direction in terms of shifting power toward a disempowered group (Kruger, 2000). It is important that sufficient training in research design and methods is provided if this involvement is to be meaningful rather than tokenistic (Corstens et al., 2014). The concern within a Participatory Action Research (PAR) paradigm on effecting change through research is in keeping with an agenda of empowerment and ensuring benefits to the group being studied (e.g. Khan, Bawani & Aziz, 2013). A broader issue, of course, is that regarding funding, potential conflicts of interest and public availability of research results. The Clinical Antipsychotic Trial of Intervention Effectiveness (CATIE) trial is an example of an attempt to address these issues (Lieberman et al., 2005; Stroup et al., 2003).

The benefits of taking a participatory research action stance are apparent in Neil et al.'s (2013) study. The aim of the research was to create and trial a measure of recovery – the Questionnaire about the Process of Recovery from Psychosis (QPR) – which was in keeping with voice-hearers' definitions and was easy to administer and score. The value of service users' involvement at all stages of the research process was apparent. They had direct input into the wording of items and suggested new items to be included. Further, speaking from the perspective of someone who might be asked to complete the measure, they queried whether filling it in might elicit distress. After discussing this issue with the research team, it was decided to include a visual analogue scale of distress in the trial. Research team members with lived experience also disseminated findings in service user forums which would have been inaccessible to non-service user researchers.

## **Reflections on the research process**

In the context of the current research, there was some tension between traditional clinical psychology and narrative or consumer-driven paradigms when designing, implementing and interpreting this research. The diagnostic interview, for example, was included to address concerns of the research coordinator at the University of Sydney that without confirmation of a diagnosis, it was unclear what participants were recovering from, as hearing distressing voices does not in and of itself constitute a psychological disorder. Inclusion of diagnostic information was intended to address this concern for those readers whose work is informed by this paradigm. However, it is also worth noting that the utility of diagnosis is constantly under debate and some have questioned whether it does more harm than good (e.g. Breeding, 2008).

The current research privileged the knowledge of people with lived experience of recovery from hearing distressing voices. It was designed in collaboration with people who hear voices. Although a power differential will perhaps always exist between researchers and participants, narrative research represents a collaborative endeavour. As part of the research process, participants told their preferred story, which was heard and witnessed by the researcher. Member-checking and co-construction of narrative recognises researcher and participant as equals in meaning-making and in the research process. Narrative method is by its nature in keeping with recognising the expertise of the interviewee. However, given additional time and resources, there are some improvements that could have been made to the method. In this case, the primary researcher collected data and conducted a preliminary analysis. They were the only person in the research team who had been immersed in the data to that extent. The focus group, including people who were experts by experience and profession, was helpful in terms of considering alternative perspectives on the data. However, consulting with people with lived

experience at various points of the research process does not confer the same benefit as their active involvement throughout would. It is possible that other interpretations of the data would have emerged had someone with lived experience been immersed in the data to the same extent that the primary researcher was. This may not always be practical; however, given the demonstrated benefits of this approach, it would be worth considering in future research designs.

### **Recovery trajectories**

Recovery trajectories were non-linear, cyclical and involved periods of rest and consolidation. This pattern is in keeping with narrative research into recovery from childhood sexual abuse, wherein participants emphasised that recovery was not a linear progression and involved many challenges and plateaus in progress (Andersen et al., 2007). Recovery processes interacted with one another and were inter-connected. For example, engagement in meaningful activities was often associated with development of a positive sense of self and vice versa; while for *turning toward* participants, both contributed to the development of voice-specific skills. The complex nature of recovery processes has been documented elsewhere (e.g. Norman, Windell, Lynch & Manchanda, 2013).

### ***General mental health & disconnection from others***

Most participants described poor general mental health, disconnection from others and proximal and distal stressors preceding voice onset. Stressors included bereavement, stressful communication between family members, job loss, excessive work-load due to over-commitment to work and study, turmoil regarding difficult life decisions and in one case historical repeated sexual abuse. Participants' understanding that stressors played a causal role in the onset of their

voices is in keeping with the research literature. People vulnerable to psychosis report increased emotional reactivity to daily hassles and stressors compared to those not vulnerable to such experiences (Myin-Germeys & van Os, 2007). The origins of this elevated reactivity appear to lie in genetic predisposition combined with adverse experiences (Myin-Germeys & van Os, 2007). Indeed, social adversity such as migration and poverty, stressors associated with living in urban areas, as well as childhood trauma play a causal role in the onset of voices for some people (Broome et al., 2005; Read, van Os, Morrison & Ross, 2005). Family interactions characterised by a high degree of criticism and intrusiveness have been associated with an increased risk of relapse (Myin-Germeys & van Os, 2007). People who have been sexually abused as children are significantly more likely to develop voices, with likelihood increasing with repeated or more severe abuse (Read et al., 2005; Whitfield, Dube, Felitti & Anda, 2005). It is at least plausible that in conditions of minimised or absent social stressors and increased coping skills, these predispositions may not develop into distressing voices (Davies & Burdett, 2005).

Participants' understanding that general mental health and disconnection from others preceded and maintained distressing voices is in keeping with existing research. For example, a lengthy (24+ month) period of mood, anxiety and sleep difficulties as well as a decrease in social functioning is common prior to the onset of psychosis (Birchwood, Spencer & McGovern, 2000; Häfner, 2000, Rietdijk et al., 2009; Yung & Jackson, 2004) and these difficulties are frequently co-morbid with psychotic symptoms (Morrison, 2009). An increased degree of depression and lower self-esteem are associated with greater voice severity and negative content (Smith et al., 2006). From a clinical perspective, the rationale for targeting anxiety, mood, sleep, stress difficulties and social difficulties in treatment are two-fold: firstly, they contribute to lowered quality of life and higher distress, and secondly, they appear to exacerbate or act as a trigger for

more distressing voices (Eisner, Drake & Barrowclough, 2013; Krabbendam et al., 2005; Morrison, 2009; Soehner, Kaplan & Harvey, 2013). Indeed, learning about how to nourish general mental health was a strong theme across typologies and was understood to be essential to recovery.

### ***Inhibitors of Recovery: Loss & Stigma***

Participants described a sense of loss and grief regarding identity and future due to onset of voice-hearing. This is a common experience among people who hear distressing voices (Mauritz & von Meijl, 2009). Voice-hearing is often an overwhelming experience in and of itself (Lieberman & Fenton, 2000). In addition to this, participants were fearful of disclosing their voice-hearing experiences to others, particularly mental health professionals, due to concerns about stigma and involuntary or invasive treatment. Secrecy about voices due to fear of alarming loved ones or concern that others would respond negatively was also reported by dos Santos's (2014) and Pyle and Morrison's (2013) participants. Indeed, secrecy is an adaptive response when one possesses a characteristic which is understood by the community to be shameful (Byrne, 2000). In keeping with existing research, stigma was a barrier to accessing treatment, forming social relationships and gaining employment, negatively impacting participants' sense of self (Corrigan, 2004; Franz, Carter, Leiner, Bergner, Thompson & Compton, 2010; McCann, Lubman & Clark, 2011). Thus, secrecy and stigma inhibited recovery mainly through inhibiting processes that supported recovery, keeping participants isolated and unexposed to non-stigmatising views of the self.



### ***Initial Responses & Becoming Overwhelmed***

Given this context, it is perhaps unsurprising that participants typically initially responded to voices by attempting to push them away. This is in keeping with the ‘startling’ phase of recovery described by Romme and Escher (1989), which involves attempts to distance oneself from voices and avoid them. In addition, research indicates that relating to voices from a position of distance is associated with distress (Vaughn & Fowler, 2004). Similarly, Escher, Delespaul, Romme and van Os (2003) found that adolescents who responded defensively toward their voices, were more likely to become depressed. Participants described low self-esteem, low mood and a sense of being overwhelmed and powerless to change their situation for the better. Some acted upon voice commands in ways which were not in keeping with their values, exacerbating their sense of despair. A sense of entrapment is common among those struggling with their voices and is associated with depressed mood (Birchwood, Spencer & McGovern, 2000). At this stage, attempts to cope with distressing voices had been largely unsuccessful. The tone of participants’ narratives was one of defeat and powerlessness, with a sense that their lives were progressing in accordance with factors outside of their control. Understandably, beliefs that voices are powerful and omnipotent is associated with depressed mood (Chadwick & Birchwood, 1994). In addition, an external locus of control is associated with depression in people diagnosed with schizophrenia (Harrow, Hansford & Astrachan-Fletcher, 2009).

### ***Despair / Exhaustion Leading to Change***

Participants described tolerating a state of despair for months and even years before experiencing positive change. The notion of ‘hitting rock bottom’ leading to positive change is part of our cultural vocabulary regarding adversity and transformation. There seems to be some

truth to the idea that people find strength to take action and change their lives for the better when in the midst of despair. For example, Dawson, Rhodes and Touyz (2014) found that women who had recovered from chronic anorexia reached a tipping point after being worn out by the anorexia characterised by externalising the disorder, increased insight and feeling understood by others. These factors combined to provide motivation to act against the anorexia and pursue recovery. Similarly, Oke's participants described a turning point of 'breaking down and breaking through' in their escape and recovery from domestic violence (2008, p152). In the context of responses to distressing voices, Milligan, McCarthy-Jones, Winthrope and Dudley (2013) examined changing responses to voices over time in people who were admitted to an early intervention service. As in the current study, participants initially rejected voices and attempted to distance themselves from them. This strategy appeared ineffective, however, with participants' life situations deteriorating into situations of crisis. Contrary to the studies mentioned above, but in keeping with current results, points of crisis could lead to either positive or negative change. This emphasises that people appear to respond differently to crises depending on the resources available to them and their natural recovery style. Indeed, Milligan et al.'s (2013) participants who entered a phase of curiosity and engagement with voices did so based on internal resources, as well as support from others and services. In keeping with Dawson et al.'s (2013) findings, turning points leading to active pursuit of recovery required several factors to coincide. Critically, they found that shifting from an internalised to externalised perspective of the disorder, and from an external to internal locus of control, were characteristic of participants reaching a turning point in their battle with anorexia. Feeling genuinely understood by and connected to others was also characteristic of this stage. This is in keeping with the results of the current study, whereby participants shifted from a state of despair and

powerlessness to feeling in control of their lives, as well as moving from disconnection to connection with others. Again, this reinforces the importance of considering social support networks and factors outside the individual in supporting recovery (e.g. Tew, Ramon, Slade, Bird, Melton & Boutillier, 2012).

### ***The Small and the Ordinary: Recovering from an Illness versus Recovering a Life***

Despite significant differences between typologies, many recovery processes were common across typologies. They were centred around meeting participants' needs for connectedness, positive identity, agency, opportunities to contribute to the community and participate in meaningful activities (Andresen, Oades & Caputi, 2003; Reis, Sheldon, Gable, Roscoe & Ryan, 2000; Slade et al., 2012). These 'small and ordinary' things were essential to rebuilding a life beyond simply eliminating symptoms (Perkins & Slade, 2012; Weingarten, 1998, p4 & p7). They formed the foundation for further progress and recovery processes. For example, for participants who engaged in challenging their voices, it was only possible for them to do so once they had regained or started to regain a positive sense of self and connection to the community. Being able to participate in the broader community, be it through paid, unpaid or voluntary work, meant that participants felt connected to and valued by society. It also provided an antithesis to the 'passive patient' role (Kelly, Lamount & Brunero, 2010; Tew et al., 2012). Paid work also addressed an important barrier to social inclusion through providing an income (van Niekerk, 2009). Flexible work arrangements or casual/contract work, anti-discrimination workplace laws, vocational services, financial support and access to safe housing were essential to participants' recovery trajectories. Some participants commented that without access to

contract work or protection under anti-discrimination laws, their recovery would have been undermined and their eventual outcomes much poorer.

In keeping with these findings, occupational identity has emerged in qualitative research as an essential aspect of the self, underpinning the ability to live with psychotic experiences (Makdisi et al., 2013). Supported employment has been shown to lead to positive outcomes for people with mental health difficulties including higher pay, increased number of days worked and shorter time to securing paid employment (Marshall et al., 2014). Likewise, in terms of access to housing, Kirkpatrick and Bryne's (2009) participants reported that having stable accommodation allowed them to exit the continuous circuit of movement which characterised their lives while homeless. Increased certainty and control regarding this basic need for shelter meant that they were able to reconnect with others. Importantly, they maintained the ability to choose when and with whom to connect. Their accommodation also made engagement in employment and planning for the future feasible.

Poverty is a significant predictor of who will develop psychosis and is associated with increased psychological distress more generally (Read, 2010). Higher rates of schizophrenia have been found in countries with greater income disparity (Burns, Tomita & Kopadia, 2014) and there is evidence that greater relative poverty rather than poverty per se is associated with poorer mental health, including psychosis (Read, 2010).

In keeping with the broader research literature, results from the current study indicate a need to shift from the traditional mode of treatment focussing on the individual to inclusion of family, social networks and broader community and social contexts (Sibitz et al., 2011; Tew et al., 2012; Williams & Collins, 2002). Interestingly, Dilks, Tasker and Wren (2010) employed grounded theory to examine how engagement in psychological therapy for psychosis supported

personal recovery. They found a clear emphasis by psychologists and patients on therapy facilitating recovery through supporting day-to-day functioning in the social world.

On an individual level, research has focussed on addressing factors such as social cognition, which has been shown to mediate the impact of symptoms on functioning (Marsh, Langdon, Harris & Colthart, 2013). A recent clinical trial targeting specific aspects of social cognition including theory of mind, inferring the emotional states of others and social understanding demonstrated significant improvement in these areas in a sample of 14 people diagnosed with schizophrenia or schizoaffective disorder (Marsh et al., 2013). The authors noted, however, that it appeared to be less effective for people with decreased working memory. Other research has focussed on improving cognition in general, which is strongly associated with the ability to work as well as response to vocational rehabilitation (McGurk & Mueser, 2013).

More broadly, family therapy and the Open Dialogue approach, which involves families and broader social systems, have been shown to be an effective treatment for people with psychotic spectrum disorders (National Collaborating Centre for Mental Health, 2009; Seikkula, Alakare & Aaltonen, 2011). At the level of social policies, anti-discrimination laws in the area of employment and housing, as well as financial support, for example disability pensions, and access to adequate housing, are all recognised in social policies in Australia (Department of Social Services, 2014; Department of Human Services, 2014; Disability Discrimination Act, 1992; Disability Services Act, 1993; NSW Anti-Discrimination Act, 1977; Spender, 1995).

Whether social policies achieve in practice what they set out to in theory is debatable, with the NSWCAG identifying a significant gap between policy and outcomes (2009). While social inclusion has become the focus of social policies regarding mental health in many countries, there is some debate about how to measure it and thereby provide a baseline from

which to evaluate progress (Baumgartner & Burns, 2013). What is clear, however, is that when recovery is considered through a social rather than purely individual lens, a human rights framework is much more commonly evoked and brought into focus. This has partly occurred due to the advocacy of consumer groups and highlights the broader socio-political context within which treatment is provided (Sayce, 2001). Although a broader social perspective and human rights issues are rarely discussed in-depth in the training of most psychologists and psychiatrists, they are worthy of attention, reflection and debate. Indeed, both clinical and personal recovery rates appear to increase in accordance with broader socio-economic factors (Warner, 1994, cited in Tew et al., 2012). Recognition of broader social factors is included in NSW's mental health strategy, which acknowledges the individual's broader social environment both in causing or preventing onset of psychological difficulties, as well as in rehabilitation and recovery (NSW Health, 2007).

### ***Meaningful Activities***

Participants reported that engagement in activities that held meaning for them was essential to their recovery. This is in line with findings that it is associated with higher life satisfaction in people with mental health difficulties (Goldberg, Brintnell & Goldberg, 2002) as well as lower depressive affect and higher self-esteem in a community sample of unemployed persons (Waters & Moore, 2002). Paid employment, volunteer work, social and solitary activities help to meet the need of human beings to feel competent, autonomous and related to others (Reis, Sheldon, Gable, Roscoe & Ryan, 2000; van Niekerk, 2009). In the current study, three participants were actively engaged in providing mental health services in the context of paid or voluntary work, both within the HVN and externally. Helping others with mental health

difficulties is associated with better mental health, less hopelessness and an increased sense of meaning in life (Schwartz, Meisenhelder, Yunsheng & Reed, 2003). It is also the antithesis to the 'passive patient' role. Participants engaged in paid employment within the mental health system were actively engaged in attempts to improve it. They were more likely to talk about mental health issues within a human rights framework (e.g. Perkins & Slade, 2013). Those paid as peer support advocates commented that receiving remuneration for their work indicated to them that they were more than 'token' consumer team-members and that their contributions were valued.

Other participants emphasised the structure and routine which regular activities provided and the enjoyment they derived from their activities. This is in keeping with the literature on the positive impact of behavioural activation on mood in people diagnosed with depression (Turner & Leach, 2012). Of course, what was meaningful to each participant varied, determined by the person's values. Although most participants still experienced hearing voices, they had come to lead lives in keeping with their values and engage in activities that reflected their values despite that.

Supported employment is an effective intervention for people with mental health difficulties (Marshall et al., 2014) and engagement in paid employment is associated with higher self-esteem and quality of life (van Dongen, 1996). Qualitative research indicates that work, despite its challenges, can support well-being for people with mental health difficulties, particularly through providing a sense of purpose, evidence that one is able to contribute to society, forming a positive identity and providing a distraction from symptoms (van Dongen, 1996; van Niekerk, 2009). Indeed, purpose in life is a strong predictor of self-efficacy in people diagnosed with a major mental health disorder (Scott, 2007). It is of note that despite evidence of the positive impact of supported employment programs, several barriers to their

implementation have been observed and availability of these services remains an issue (Marshall et al., 2014).

### ***Voices, Self & Others***

Many people experience an initial sense of their identity being overwhelmed and subsumed by that of being a patient or voice-hearer (McCarthy-Jones, 2012; Romme & Escher, 2011; Tew et al., 2012). Based on an analysis of six case studies, Williams (2011) suggested that voice onset was best understood as developing in response to an existential threat to the self. Other authors have conceptualized the impact of psychosis as disrupting the individual's capacity to create a coherent narrative of the self, with recovery involving the opposite (Lysaker & Lysaker, 2011). Reclaiming a positive sense of self appears critical to recovery (Goodliffe, Hayward, Brown, Turton & Dannahy, 2010; May, Strauss, Coyle & Hayward, 2014). Indeed, in the current study, participants described being less distressed by critical or threatening voices when they had developed a stronger sense of self. This is in keeping with research demonstrating that a reduced capacity to reassure oneself after self-critical thoughts is associated with shaming voice content, while people who report feelings of self-hatred and inadequacy are more likely to experience their voices as controlling and critical (Connor & Birchwood, 2013). Recognition of the importance of people's self-esteem in mediating their affective response to negative voices has led to this becoming a specific target of psychological interventions. For example, van der Gaag, Oosterhout, Daalman, Sommer and Korrelboom (2011) trialled the use of imagery techniques targeted at strengthening positive memories and perceptions of the self. Results were promising, with significant improvements in depression in the treatment condition compared to treatment as usual, mediated by improvements in self-esteem and acceptance of



voices. Similarly, participants who undertook person-based cognitive therapy reported that acceptance of voices and developing a positive sense of self were pivotal to their progress (Goodliffe, Hayward, Brown, Turton & Dannahy, 2010; May, Strauss, Coyle & Hayward, 2014).

Re-building one's sense of self, including developing increased self-esteem, self-efficacy, agency and non-pathologised identity, has been implicated in recovery from domestic violence (Oke, 2008) alcohol abuse (Paris et al., 2001) child sexual abuse (Anderson & Hiersteiner, 2007; Hall et al., 2009) and severe or long-term mental health difficulties including psychosis (Brown et al., 2008; Sells, Topor & Davidson, 2004, Song & Shih., 2009, Thornhill, Claire & May, 2004). Redefining experiences – whether they be of abuse or psychosis – were essential to forming a positive, non-pathologised self.

Reclaiming one's sense of self, however, is a social as well as individual process: the antithesis to personal diminishment which can result from stigma (Livingston & Boyd, 2010). As participants reconnected with others and developed supportive relationships, they were more able to deal with their voices in an adaptive manner. This is in keeping with research demonstrating significant parallels between how people relate to social others and how they relate and respond to their voices (Chin, Hayward & Drinnan, 2009; Hayward, Berry & Ashton, 2011; Paulik, 2011). It is plausible that as people accumulated more positive experiences with others, their beliefs about others and perception of relative social rank changed, positively impacting upon their style of relating to their voices. The tendency of people with *turning toward* narratives to engage with their voices rather than attempt to distance themselves is consistent with research indicating that relating to voices from a position of distance is associated with significantly higher distress (Vaughn & Fowler, 2004; Hayward et al., 2011). Engaging

with voices and setting appropriate boundaries has been implicated in developing a positive relationship with voices (Jackson, Hayward & Cooke, 2011).

### *Discursive Resources and Making Sense of Voices*

The narratives people tell define how they understand themselves and their problems (Lock et al., 2005; Weingarten, 1998). In the context of hearing voices, the dominant narrative, based in Foucauldian terms on ‘global’ (privileged) rather than ‘local’ knowledge, is that it is a symptom of a disease best treated by anti-psychotic medication (Madigan, 1992; Schrader, 2013). Implicitly, this narrative promotes the notion of the person as the problem (Ben-Zeev, Young & Corrigan, 2010; Lock et al., 2006; Madigan, 1992; van Os, 2010). Those who ‘turned towards’ in this study also ‘turned away’ from the dominant medical model discourse. This act of resistance was conducted in solidarity with others in HVN groups, allowing for the ‘thickening’ of alternative stories (White & Epston, 1990). For example, participants described voices as a manifestation of distress understandable within their life context (e.g. Beavan & Read, 2007; Schrader, 2013). Although some participants still used aspects of a medical model explanation and vocabulary, they emphasised that voice-hearing is a normal variation in human experience, opening up the possibility of a non-pathologized self. This is in keeping with the Hearing Voices Movement (HVM) approach and with findings that a stronger belief that psychotic experiences occur on a continuum is associated with lower stigma (Wiesjahn, Brabban, Jung, Gebauer & Lincoln, 2014). Findings suggest that exposure to alternative understandings of voice-hearing, which might compliment rather than necessarily replace the dominant medical model narrative, may be helpful.

### *Effective Medication*

Participants with a dominant *turning away* narrative emphasised the importance of effective medication becoming available, in helping them to survive, think clearly, function and eventually recover. Medication was essential in enabling participants to meet their basic needs. For example, medication was understood by participants to keep them calmer and enable them to manage difficult emotions better, to communicate and build relationships with others, and to engage in activities, including paid work. The benefits of medication for some voice-hearers in terms of decreasing the severity of distressing voices and the intense negative emotions accompanying them has been documented elsewhere (Moncrieff, 2009; NICE, 2009). It is important to note, however, that three out of five *turning away* participants still experienced hearing voices. However, they described medication as enabling them to disengage their attention from voices when they wished to do so and decreasing the intensity of their emotional response. The benefits of medication appeared to be intertwined with other recovery processes. For example, participants used mindfulness skills in combination with medication to deal with distressing voices. In addition, they did so in context of generally improved mental health, which in turn was contributed to by medication. Thus medication formed an essential part of recovery in combination with other processes. The importance of factors above and beyond a decrease in clinical symptoms has been demonstrated in the CATIE findings. While emerging as significant predictors of subjective quality of life (SQOL), depressive, positive and negative symptoms collectively explained only 20% of variance in SQOL (Fervaha, Agid, Takeuchi, Foussias & Remington, 2013). In *turning away* narratives, there was less motivation to seek alternative meanings of voice-hearing. Once symptoms had resolved or became manageable, there was little or no perceived need to reflect any further on the meaning of the experience.

While some participants were uncomfortable with a medical model explanation, they had difficulty generating or making visible alternative interpretations.

In contrast, those with *turning toward* narratives either found medication to be ineffective in decreasing symptoms, or found it somewhat helpful but associated with significant side-effects which outweighed its benefits. Potential side-effects of antipsychotic medications are well-documented and include weight-gain and increased lipids, glucose and heart-rate (Abou-Setta et al., 2012). Many *turning toward* participants reported being disillusioned with a purely medical model approach. This was partly due to medication being ineffective in reducing symptoms. Three had decreased or ceased their medication in consultation with their psychiatrist for this reason, as well as to avoid negative side-effects. The primary reason people report for ceasing medication is that it had no or little effect on positive symptoms (Ascher-Svanum et al., 2010). These issues aside, even during times when *turning toward* participants experienced some benefit from medication (including anti-depressants or Lithium) they reported a strong sense of needing to talk about their experiences and address psychological needs. Within the HVM, the potential benefits of medication in helping people distressed by their voices to sleep and be less emotionally reactive in response to voices are acknowledged (Corstens et al., 2014). However, there is also the idea that medication should be given sparingly, at low doses and for a limited time only (Corstens et al., 2014). Indeed, from the HVM perspective, given an understanding of voices as messengers about an important emotional issue, eliminating them entirely by use of medication is viewed as potentially counter-productive. Similarly, occasions when in medical terms people's 'symptoms' increase, this can be and often is viewed as a learning opportunity within the HVM framework. This highlights some essential differences and

possible points of tension between the two approaches and the need for increased communication among proponents of both views.

The heterogeneity in response to antipsychotic medication is well-documented (e.g. Adkins et al., 2013). It is therefore not surprising that there was a great deal of variability in effectiveness reported by participants in the current study. A relatively new and promising development is the trend in research toward attempts to identify which medication is likely to be effective for a particular individual, or alternatively which individuals are unlikely to respond to any medication (e.g. Ramsey, Liu, Massey & Brennan, 2013). Although in its infancy, this line of research could produce knowledge which would allow psychiatrists to tailor treatment for a particular person based on their genes and ancestry (Adkins et al., 2013). After assessment, this would allow selection of the medication(s) most likely to be of benefit to them and avoid trialling various medications with potentially harmful side-effects and possibly low effectiveness (Adkins et al., 2013).

### **Parallels in Professional-Driven Treatments**

Across typologies, participants described mindfulness skills as an effective way of dealing with distressing voices. Given findings that a resistant style of relating to voices is associated with increased distress, intentionally noticing voices without being drawn in and caught up with them holds promise (Farhall, Greenwood & Jackson, 2007; Thomas et al., 2014). There is evidence that responding mindfully to distressing voices is associated with decreased negative affect (Chadwick, Barnbrook & Chadwick-Taylor, 2007). Evidence from two case studies demonstrated an association between increased mindfulness skills and decreased belief conviction and distress (Newman-Taylor, Harper & Chadwick, 2009). A meta-analysis of pre-

and post-treatment studies demonstrated promising results, with a decrease in positive, negative and affective symptoms and increase in functioning and quality of life (Khoury, Lecomte, Gaudino & Pacquin, 2013). Group-based randomised controlled trials examining the efficacy of mindfulness and acceptance strategies in coping with voices are in progress (e.g. May, Strauss, Coyle & Hayward, 2014). In the current study, participants described the effect of mindfulness skills as providing some space and distance from voices. Participants described being more able to disengage from voices or not take their comments to heart as much as they did before learning how to mindfully notice voices as transient events. This is very much in keeping with the ‘decentred’ relationship with distressing emotions and events which is aimed for in ACT and mindfulness-based therapies.

Despite the impact of consumer-driven HVN groups in this study it is also important to recognise that promising professional-driven treatments are coming to similar conclusions regarding the value of direct engagement with voices and a focus on the person, not just the problem, particularly in the field of clinical psychology. Cognitive Behavioural Therapy for Psychosis (CBTp; Farhall & Thomas, 2013), voice dialogue work, relational therapies, including Avatar and other role-play based interventions, all involve active engagement with voices (Corstens, Longden & May, 2012; Hayward, Overton, Dorey & Denney, 2009; Leff, Williams, Huckvale, Arbuthnot & Leff, 2013; Seikkula, Alakare & Aaltonen, 2011).

As a cautionary note, findings of the current study suggest that timing is critical. *Turning toward* participants reached a tipping point where doing something differently, although still frightening, was evaluated as a better option than continuing to tolerate their situation. This is similar to the crisis-induced change noted by Milligan et al. (2013). In addition, those engaged in a *turning away* style of response may find such treatments unhelpful and require some time to

be ready to undertake such work. These caveats aside, the critical role of interpersonal dialogue and solidarity is also becoming recognised in the network therapy of Seikkula and colleagues (e.g. Seikkula, 2002, 2008, 2011; Seikkula et al., 2011). This approach, involves intensive engagement with the client, the entire family and any other loved ones as well as professional stakeholders involved. Treatment is based on the notion that psychotic reactions are pre-narrative or metaphorical; attempts to make sense of experiences that are so difficult that they have not yet been situated in spoken discourse (Seikkula, 2002).

Despite the evidence for the efficacy of psychological treatments, however, several barriers to accessing them remain, resulting in significant unmet need (Farhall & Thomas, 2013; Mojtabai et al., 2009; National Collaborating Centre for Mental Health, 2009). For example, up to 40% of people diagnosed with schizophrenia reported receiving no psychological intervention over a six to twelve month period (Mojtabai et al., 2009). Barriers to implementation of evidence-based therapies for psychosis include organisational factors such as managerial focus on acute needs, and therapist factors including lack of specific training and supervision in psychological interventions for psychosis (Mojtabai et al., 2009; Farhall & Thomas, 2013). It is important to emphasise that not one single participant in the current study reported receiving psychological intervention that was specifically aimed at dealing with voices. Those who engaged in behavioural experiments and other CBT strategies did so without the help of a psychologist.

### **Limitations and Directions for Future Research**

This study is limited by its retrospective design, as retrospective recall is less accurate than recording events as they occur (e.g. Schröder & Börsch-Supan, 2008; Yoshihama &

Gillespie, 2002). However, given that narrative research aims to elicit how participants understand their experience, and this involves their subjective recollection of experiences, this is in a sense not problematic. Nonetheless, prospective, longitudinal investigation of recovery style would allow examination of whether there are any people who initially *turn away* and then *turn towards*, and if so, what might contribute to this change. It would also be useful to examine whether regular assessment of recovery style and adjustment of treatment style to match patients' needs leads to better treatment outcomes. A second limitation is the nature of the sample, which was small, involved self-selection into the study and was more likely to attract people who had had positive experiences of HVN groups.

Strengths of the study include the rigour employed in generating narratives, which were member-checked by participants, and the focus group's critique of the model of recovery generated. The use of reflection on the subjective values and expectations of the primary researcher was another strength. Through bracketing assumptions and remaining open to the data, it was possible to allow the *turning away* typology to be identified. Given the bias of the researchers towards understanding recovery as involving active engagement with voices and making sense of them, this finding was unexpected.



## References

- Abdul-Rahman, M. F., Qui, A., Woon, P. S., Kuswanto, C., Collinson, S. L. & Sim, K. (2012). Arcuate fasciculus abnormalities and their relationship with psychotic symptoms in schizophrenia. *PLoS ONE*, 7 (1).
- Acar, S. & Sen, S. (2013). A multilevel meta-analysis of the relationship between creativity and schizotypy. *Psychology of Aesthetics, Creativity, and the Arts*, 7(3), 214–228.
- Adame, A. L. & Knudson, R. M. (2007). Beyond the counter-narrative: Exploring alternative narratives of recovery from the psychiatric survivor movement. *Narrative Inquiry*, 17(2), 157-178.
- Allen, P. P., Johns, L. C., Fu, C. H. Y., Broome, M. R., Vythelingum, G. N. & McGuire, P. K. (2004). Misattribution of external speech in patients with hallucinations and delusions. *Schizophrenia Research*, 69, (2-3), 277-287.
- Allen, P. Aleman, A. & McGuire, P. K. (2007). Inner speech models of auditory verbal hallucinations: Evidence from behavioural and neuroimaging studies. *International Review of Psychiatry*, 19 (4), 407-415.
- Anderson, K. M. & Hiersteiner, C. (2007). Listening to the stories of adults in treatment who were sexually abused as children. *Families in Society*, 88(4), 637-644.
- Andreasen, N. C. & Flaum, M. (1991). Schizophrenia: The characteristic symptoms. *Schizophrenia Bulletin*, 49, 1727.
- Andresen, R., Caputi, P. & Oades, L. (2006). Stages of recovery instrument: Development of a measure of recovery from serious mental illness. *Australian and New Zealand Journal of Psychiatry*, 40, 972–980.

- Andresen, R., Oades, L., & Caputi, P. (2003). The experience of recovery from schizophrenia: Towards an empirically validated stage model. *Australian and New Zealand Journal of Psychiatry*, 37(5), 586-594.
- Angermeyer, M. C., & Matschinger, H. (2005). Causal beliefs and attitudes to people with schizophrenia: Trend analysis based on data from two population surveys in Germany. *The British Journal of Psychiatry*, 186(4), 331–334
- Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, 16(4), 11–23.
- Anthony, W. A. (2000). A recovery-orientated service system: setting some system standards. *Psychosocial Rehabilitation Journal*, 24(9), 159-168.
- American Psychiatric Association (2000). *Diagnostic and statistical manual*, 4<sup>th</sup> edition. Washington, DC.
- Ashton, A., Berry, K., Murray, C. & Hayward, M. (2011). Voice hearing within the context of hearers' social worlds: An interpretative phenomenological analysis. *Psychology & Psychotherapy: Theory, Research & Practice*, 84, 256-272.
- Ascher-Svanum H., Nyhuis A. W., Stauffer, V., et al. (2010). Reasons for discontinuation and continuation of antipsychotics in the treatment of schizophrenia from patient and clinician perspectives. *Current Medical Research and Opinion*, 26(10), 2403-10.
- Australian Government Department of Social Services (2014). Retrieved from: <http://www.dss.gov.au/> on 23/04/2014.
- Australian Government Department of Human Services (2014). Retrieved from: <http://www.humanservices.gov.au/> on 23/04/2014.

- Baethge, C., Baldessarini, R. J., Freudenthal, K., Streurwitz, A., Bauer, M. and Bschor, T. (2005). Hallucinations in bipolar disorder: characteristics and comparison to depression and schizophrenia. *Bipolar Disorders*, 7, 136–145.
- Barlow, D. H. (2008). *Clinical Handbook of Psychological Disorders, Fourth Edition*. Guilford Press: New York / London.
- Barnes, T. R. E.; McPhillips, M. A. (1995). How to distinguish between the neuroleptic-induced deficit syndrome, depression and disease-related negative symptoms in schizophrenia. *International Clinical Psychopharmacology*, 10 (3), 115-121.
- Baumgartner, J. N. & Burns, J. K. (2013). Measuring social inclusion – a key outcome in global mental health. *International Journal of Epidemiology*, 1-11.
- Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin*, 117, 497–529.
- Beavan, V. & Read, J. (2010). Angels at our tables: New Zealanders' experiences of hearing voices. *Ph.D. thesis (Psychology) University of Auckland New Zealand*.
- Bellack, A. S. (2006). Scientific and consumer models of recovery in schizophrenia: concordance, contrasts, and implications. *Schizophrenia Bulletin*, 32, 432-442.
- Bentall, R. P. (2003). *Madness explained: psychosis and human nature*. London: Penguin Books.
- Bentall, R. P. (2006). Madness explained: Why we must reject the Kraepelinian paradigm and replace it with a complaint-orientated approach to understanding mental illness. *Medical Hypotheses*, 66, 200-233.
- Bentall (2009). *Doctoring the mind*. London, UK: Penguin.
- Ben-Zeev, D., Young, M. A. & Corrigan, P. W. (2010). DSM-V and the stigma of mental illness. *Journal of Mental Health*, 19(4), 318-327.

- Bernal, B. & Ardila, A. (2009). The role of the arcuate fasciculus in conduction Aphasia. *Brain*, *132*, 2309–2316.
- Birchwood, M., Gilbert, P., Gilbert, J., Trower, P., Meaden, A., Hay, J., Murray, E. & Miles, J. N. V. (2004). Interpersonal and role-related schema influence the relationship with the dominant ‘voice’ in schizophrenia: A comparison of three models. *Psychological Medicine*, *34*, 1571-1580.
- Birchwood, M., Meaden, A., Trower, P., Gilbert, P. (2002). Shame, humiliation and entrapment in psychosis: Subordination and entrapment by voices and significant others. *Psychological Medicine*, *30*, 337-344.
- Braun, V. & Clarke, V. (2008). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.
- Brebion, G., Amador, X. David, A., Malaspina, D., Sharif, Z. & Gorman, J. M. (2000). Positive symptomatology and source-monitoring failure in schizophrenia – an analysis of symptom-specific effects. *Psychiatry Research*, *95* (2), 119-131.
- Breeding, J. (2008). To see or not to see “schizophrenia” and the possibility of full recovery. *Journal of Humanistic Psychology*, *48*, 489-504.
- Brenner, K., St-Hilaire, A., Liu, A., Laplante, D. P., & King, S. (2011). Cortisol response and coping style predict quality of life in schizophrenia. *Schizophrenia Research*, *128*, 23-29.
- Brown, W. (2008). Narratives of mental health recovery. *Social Alternatives*, *27*(4), 42-48.
- Byrne, P. (2000). The stigma of mental illness and ways of diminishing it. *Advances in Psychiatric Treatment*, *6*, 65-72.

- Cabanach, R. G., Arias, A. V., Rodriguez, C. R. & Canedo, M. F. (2012). The relations between perceived self-efficacy and psychological well-being in university students. *Revista Mexicana de Psicología*, 29(1), 40-48
- Carlton, T. & Bradstreet, S. (2006). Sharing the positives. *Mental Health Today*.
- Castle, D. J., Jablensky, A., McGrath, J. J., Carr, V., Morgan, V., Waterreus, A., Valuri, G., Stain, H., McGuffin, P. & Farmer, A. (2006). The diagnostic interview for psychoses (DIP): development, reliability and applications. *Psychological Medicine*, 36, 69–80.
- Chin, J. T., Hayward, M. & Drinnan, A. (2009). ‘Relating’ to voices: Exploring the relevance of this concept to people who hear voices. *Psychology and Psychotherapy: Theory, Research and Practice*, 82, 1-17
- Choong, C., Hunter, M. D. & Woodruff, P. W. R. (2007). Auditory hallucinations in those populations that do not suffer from schizophrenia. *Current Psychiatry Reports*, 9, 206-212.
- Chiovitti, R. F., & Piran, N. (2003). Rigour and grounded theory research. *Journal of Advanced Nursing*, 44 (4), 427-435.
- Citrome, L. & Volavka, J. (2004). The promise of atypical antipsychotics: fewer side effects mean enhanced compliance and improved functioning. *Postgraduate medicine*, 116 (4), 49-63.
- Clandinin, D. J. & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco: Jossey-Bass Publishers.
- Clandinin, D. J., Murphy, M. S., Huber, J. & Orr, A. M. (2011). Negotiating narrative inquiries: Living in a tension-filled midst. *The Journal of Educational Research*, 103 (2), 81-90.

- Claridge, G. & Blakey, S. (2009). Schizotypy and affective temperament: Relationships with divergent thinking and creativity styles. *Personality and Individual Differences, 46*, 820–826.
- Clarke, A. E. (2003). Situational analyses: Grounded theory mapping after the postmodern turn. *Symbolic Interaction, 26*, 4, 553-576.
- Cohen, O. (2005). An analysis of psychiatric survivor oral histories. *Journal of Humanistic Psychology, 45* (3), 333-354.
- Connelly, F. M., & Clandinin, D. J. (2006). *Narrative inquiry*. In J. L. Green, G. Camilli, & P. Elmore (Eds.), *Handbook of complementary methods in education research* (3rd ed., 477–487). Mahwah, NJ: Lawrence Erlbaum.
- Connor, C. & Birchwood, M. (2013). Through the looking glass: self-reassuring meta-cognitive capacity and its relationship with the thematic content of voices. *Frontiers in Human Neuroscience, 7*, 213.
- Copolov, D. L., Seal, M. L., Maruff, P., Ulusory, R., Wong, M. T. H, Tochon-Danguy, H. J. et al. (2003). Cortical activation associated with the experience of auditory hallucinations and perception of human speech in schizophrenia: A PET correlation study. *Psychiatry Research: Neuroimaging, 122*, 139-152.
- Corstens, D., Longden, E. & May, R. (2012). Talking with voices: Exploring what is expressed by the voices people hear. *Psychosis, 4*(2), 95-104.
- Corstens, D., Longden, E., McCarthy-Jones, S., Waddingham, R., & Thomas, N. (2014). Emerging perspectives from the Hearing Voices Movement: implications for research and practice. *Schizophrenia Bulletin* (in press).

- Crisp, A. H., Gelder, M. G., Rix, S., Meltzer, H. I. & Rowlands, O. J. (2000). Stigmatisation of people with mental illness. *British Journal of Psychiatry*, 177, 4-7.
- Denzin, N.K. (1978). *The research act: An introduction to sociological methods*. New York: McGraw-Hill.
- Dixon-Woods M, Fitzpatrick R, Roberts K. (2001). Including qualitative research in systematic reviews: opportunities and problems. *Journal of Evaluation in Clinical Practice*, 7, 125-133.
- Dos Santos, B. (2014). *Experiences of attending the Hearing Voices Network New South Wales Peer Support Groups* (Unpublished master's thesis). Australian College of Applied Psychology. Sydney, NSW, Australia.
- Drake, R. E., Bond, G. R., & Essock, S. M. (2009). Implementing evidence-based practices for people with schizophrenia. *Schizophrenia Bulletin*, 35 (4), 704-713.
- Dulwich Centre (2014). *Narrative therapy charter of story-telling rights*. Retrieved from: <http://www.dulwichcentre.com.au/current-projects.html>
- Ezzy, D. (1993). Unemployment and mental health: A critical review. *Social Sciences and Medicine*, 37(1) 41-52.
- Fan, F. & Fu, J. (2001). Self-concept and mental health of college students. *Chinese Mental Health Journal*, 15(2), 76-77.
- Feiring, C., Taska, L. & Lewis, M. (2002). Adjustment Following Sexual Abuse Discovery: The Role of Shame and Attributional Style. *Developmental Psychology*, 38(1), 79-92.
- Fervaha, G., Agid, O., Takeuchi, H., Foussias, G. & Remington, G. (2013). Clinical determinants of life satisfaction in chronic schizophrenia: Data from the CATIE study. *Schizophrenia Research*, 151, 203-208.

- Fischer, C. T. (2009). Bracketing in qualitative research: conceptual and practical matters. *Psychotherapy Research, 19*(4-5), 583-590.
- Fischer, D. (2003). People are more important than pills in recovery from mental disorder. *Journal of Humanistic Psychology, 43*, 65-68.
- Fleming, M. P. & Martin, C. R. (2011). Genes and schizophrenia: a pseudoscientific disenfranchisement of the individual. *Journal of Psychiatric and Mental Health Nursing, 18*, 469-478.
- Fox, J. R. E, Gray, N. S., & Lewis, H. (2004). Factors determining compliance with command hallucinations with violent content: The role of social rank, perceived power of the voice and voice malevolence. *The Journal of Forensic Psychiatry and Psychology, 15*, 511-531.
- Frank, A. W. (1995). *The wounded storyteller—Body, illness and ethics*. Chicago: University of Chicago Press.
- Frank, A. W. (2010). *Letting stories breathe: A socio-narratology*. Chicago: University of Chicago Press.
- Franck, N., Rouby, P., Daprati, E., Dalery, J., Marie-Cardine, M. & Georgieff, N. (2000). Confusion between silent and overt reading in schizophrenia. *Schizophrenia Research, 21*, 357-364.
- France, E. F., Hunt, K., Dow, C. & Wykes, E. (2013). Do men's and women's accounts of surviving stroke conform to Frank's narrative genres? *Qualitative Health Research, 23* (12), 1649-1659.



- Franz, L., Carter, T., Leiner, A. S., Bergner, E., Thompson, N. J. & Compton, M. T. (2010). Stigma and treatment delay in first-episode psychosis: A grounded theory study. *Early Intervention in Psychiatry*, 4(1): 47–56.
- Frese, F. J., Stanley, J. S., Kress, K. K. & Vogel-Scibilia, S. (2001). Integrating evidence-based practices and the recovery model. *Psychiatric Services*, 52 (11), 1462-1468.
- Frith, C. D. (1987). The positive and negative symptoms of schizophrenia reflect impairments in the perception and initiation of action. *Psychological Medicine*, 17, 631–648.
- Griffiths, K. M., Jorm, A. F., Christensen, H., Medway, J. & Dear, K. B. G. (2002). Research priorities in mental health part 2: An evaluation of the current research effort against stakeholders' priorities. *Australian and New Zealand Journal of Psychiatry*, 36, 327-339.
- Hall, J.M., Roman, M. W., Thomas, S. P., Brown T. C., Powell, J., Tennison, C. R., . . . & McArther, P. M. (2009). Thriving as becoming resolute in narratives of women surviving childhood maltreatment. *American Journal of Orthopsychiatry*, 79(3), 375-386.
- Hall, J. M. (2011). Narrative methods in a study of trauma recovery. *Qualitative Health Research*, 21(1), 3-13.
- Harding, C. M., Brooks, G. W., Ashikaga, T., Strauss, J. S. & Breier, A. (1987). The Vermont longitudinal study of persons with severe mental illness II: Long-term outcome of subjects who retrospectively met DSM-III criteria for schizophrenia. *American Journal of Psychiatry*, 144 (6), 727-735.
- Harrison, G., Hopper, K., Craig, T., Laska, E., Siegel, C., Wanderling, J...& Wiersma, D. (2001). Recovery from psychotic illness: a 15- and 25-year international follow-up study. *British Journal of Psychiatry*, 178, 506-517.

- Harrow, M., Hansford, B. G. & Astrachan-Fletcher, E. B. (2009). Locus of control: Relation to schizophrenia, to recovery, and to depression and psychosis – A 15-year longitudinal study. *Psychiatry Research*, *168*, 186-192.
- Hayward, M., Berry, K. & Ashton, A. (2011). Applying interpersonal theories to the understanding of and therapy for auditory hallucinations: A review of the literature and directions for future research. *Clinical Psychology Review*, *31*, 1313-1323.
- Hayward, M., Denner, J., Vaughan, S. & Fowler, D. (2008). The voice and you: Development and psychometric evaluation of a measure of relationships with voices. *Clinical Psychology & Psychotherapy*, *15*, 45-52.
- Heckers, S. (2009). Is schizoaffective disorder a useful diagnosis? *Current Psychiatry Reports*, *11*, 332-337.
- Hendryx, M., Green, C. A. & Perrin, N. A. (2008). Social Support, Activities, and Recovery from Serious Mental Illness: STARS Study Findings. *Journal of Behavioral Health Services & Research*, *36*(3), 320.
- Henquet, C., Krabbendam, L., Dautzenberg J., Jolles, J. & Merckelbach, H. (2005). Confusing thoughts and speech: source monitoring and psychosis. *Psychiatry Research*, *133*(1), 57–63.
- Hodgekins, J. & Fowler, D. (2010). CBT and recovery from psychosis in the ISREP trial: Mediating effects of hope and positive beliefs on activity. *Psychiatric Services*, *61*(3), 321-324.
- Jackson, L., Hayward, M. & Cooke, A. (2011). Developing positive relationships with voices: A preliminary grounded theory. *International Journal of Social Psychiatry*, *57*, 487-495.

- Johns, L. C. & Van Os, J. (2001). The continuity of psychotic experiences in the general population. *Clinical Psychology Review, 21* (8), 1125-1141.
- Johns, L. C., Gregg, L., Allen, P., Vythelingum, G. M. & McGuire, P. K. (2006). Verbal self-monitoring and auditory verbal hallucinations in psychosis: effects of state, trait and diagnosis. *Psychological Medicine, 36*, 465-474.
- Johnstone, L. (2009). Psychiatric diagnosis. In T. Turner & B. Tummey (Eds.) *Critical Issues in Mental Health* (p1-10). UK: Palgrave Macmillan.
- Jones, J. L. & Mehr, S. L. (2007). Foundations and assumptions of the scientist-practitioner model. *American Behavioral Scientist, 50*, 765-771.
- Jones, K. (2004). Mission drift in qualitative research, or moving toward a systematic review of qualitative studies, moving back to a more systematic narrative review. *The Qualitative Report, 95-112*.
- Juckel, G. & Morosini, P. L. (2008). The new approach: psychosocial function as a necessary outcome criterion for therapeutic success in schizophrenia. *Current Opinion in Psychiatry, 21*, 630-639.
- Kagan, N., & Schauble, P. G. (1969). Affect simulation in Interpersonal Process Recall. *Journal of Counseling Psychology, 16*(4), 309-313.
- Kao, Y.-C., Liu, Y.-P., Chou, M. K. & Cheng, T. H. (2011). Subjective quality of life in patients with chronic schizophrenia: relationships between psychosocial and clinical characteristics. *Comprehensive Psychiatry, 52*, 171–180.
- Keefe, R. S. E., Arnold, M.C., Bayen, U. J. (1999). Source monitoring deficits in patients with schizophrenia; a multinomial modeling analysis. *Psychological Medicine, 29*(4), 903–914.

- Kelly, M., Lamount, S. & Brunero, S. (2010). An occupational perspective of the recovery journey in mental health. *British Journal of Occupational Therapy*, 73(3), 129-135.
- Kessler, R.C., Andrews, G., Colpe, L. J., Hiripi, E., Mroczek, D. K., Normand, S.-L. T., Walters, E. E. & Zaslavsky, A. M. (2002). Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological Medicine*, 32, 959-956.
- Khan, K. S., Bawani, S. A. A. & Aziz, A. (2013). Bridging the gap of knowledge and action: A case for participatory action research. *Action Research*, 11(2), 157-175.
- Kim, J.-H; Ann, J.-H; Kim, M. -J. (2011). Relationship between improvements of subjective well-being and depressive symptoms during acute treatment of schizophrenia with atypical antipsychotics. *Journal of Clinical Pharmacy and Therapeutics*, 36 (2), 172-178.
- Kirkpatrick, H. & Byrne, C. (2009). A narrative inquiry: Moving on from homelessness for individuals with a major mental illness. *Journal of Psychiatric and Mental Health Nursing*, 16, 68-75.
- Krabbendam, L. & Van Os, J. (2005). Schizophrenia and urbanicity: A major environmental influence—conditional on genetic risk. *Schizophrenia Bulletin*, 31(4), 795–799.
- Kruger, A. (2000). Empowerment in social work practice with the psychiatrically disabled: Model and method. *Smith College Studies in Social Work*, 70(3), 427-439.
- Kuipers, E., Garety, P., Fowler, D., Freeman, D., Dunn, G. & Bebbington, P. (2006). Cognitive, emotional, and social processes in psychosis: Refining Cognitive Behavioral Therapy for persistent positive symptoms. *Schizophrenia Bulletin*, 32 (1), 24-31.
- Lader, M. H. (1993). Neuroleptic Induced Deficit Syndrome: old problem, new challenge. *Journal of Psychopharmacology*, 7, 392-393.

- Lakeman, R. (2001). Making sense of the voices. *International Journal of Nursing Studies*, 38, 523–531.
- Lakey, B. & Orehek, E. (2011). Relational regulation theory: A new approach to explain the link between perceived social support and mental health. *Psychological Review*, 118(3), 482–495.
- Lakhani, N. (2009). A first-class recovery: from hopeless case to graduate. *The Independent*. Retrieved from: <http://www.independent.co.uk/news/people/news/a-firstclass-recovery-from-hopeless-case-to-graduate-1808991.html>
- Larson, D., Flesaker, K. & Stege, R. (2008). Qualitative interviewing using Interpersonal Process Recall: investigating internal experiences during professional-client conversations. *International Journal of Qualitative Methods*, 7 (1), 18-37.
- Leamy, M., Bird, V., Le Boutillier, C., Williams, J. & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *British Journal of Psychiatry*, 199, 445-452.
- Leff, J., Williams, G., Huckvale, M. A., Arbutnot, M. & Leff, A. P. (2013). Computer-assisted therapy for medication-resistant auditory hallucinations. *British Journal of Psychiatry*, 202(6), 428-433.
- Lieberman, J. A., Stroup, S., McEvoy, J.P., Swartz, M. S., Rosenheck, R. A., , Perkins, D. O. M.P.H., Keefe, R. S. E., ...& Hsiao, J. K. (2005). Effectiveness of Antipsychotic Drugs in Patients with Chronic Schizophrenia. *New England Journal of Medicine*, 353, 1209-1223.
- Lincoln, T. M., Arens, E., Berger, C. & Rief, W. (2008). Can Antistigma Campaigns Be Improved? A Test of the Impact of Biogenetic Vs Psychosocial Causal Explanations on

- Implicit and Explicit Attitudes to Schizophrenia. *Schizophrenia Bulletin*, 34 (5), 984-994.
- Lindenmayer, J. P. (2000). Treatment refractory schizophrenia. *Psychiatric Quarterly*, 71 (4), 373-384.
- Lindenmayer, J.P., Bossie, C. A., Kujawa, M., Zhu, Y & Canuso, C. M. (2008).Dimensions of psychosis in patients with bipolar mania as measured by the Positive and Negative Syndrome Scale. *Psychopathology*, 41(4), 264-270.
- Livingston, J. D. & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science & Medicine*, 71 (12), 2150-2161.
- Lobban, F., Barrowclough, C. & Jones, S. (2003). A review of the role of illness models in severe mental illness. *Clinical Psychology Review*, 23 (2), 171-196.
- Lobovits, D., Maisel, R. & Freeman, J. (1995). Public practices: An ethic of circulation. In Friedman, S. (Ed.), *The Reflecting Process in Action*. New York: Guilford Press.
- Lock, A., Epston, D., Maisal, R. & de Faria, M. (2006). Resisting anorexia/bulimia: Foucauldian perspectives in narrative therapy. *British Journal of Guidance and Counselling*, 33(3), 315-332.
- Luszczynska, A., Benight, C. C. & Cieslak, R. (2009). Self-efficacy and health-related outcomes of collective trauma. *European Psychologist*, 14(1), 59-62
- Lysaker, P. H. & Lysaker, J. T. (2011). Psychotherapy and recovery from schizophrenia: A model of treatment as informed by a dialogical model of the self experience in psychosis. *Journal of Contemporary Psychotherapy*, 41, 125-133.

- Madigan, S. P. (1992). The application of Michel Foucault's philosophy in the problem externalizing discourse of Michael White. *Journal of Family Therapy, 14*, 265-279.
- Makdisi, L., Blank, A., Bryant, W., Andrews, C., Franco, L. & Parsonage, J. (2013). Facilitators and barriers to living with psychosis: an exploratory collaborative study of the perspectives of mental health service users. *The British Journal of Occupational Therapy, 76*(9), 418-426.
- Marsh, P.J., Langdon, R., Harris, A., & Coltheart, M. (2013). The case for social-cognitive remediation to improve outcomes in schizophrenia: A life well lived is more than remission from psychosis. *Australian and New Zealand Journal of Psychiatry (ANZJP), 47*(6), 512-515.
- Mawson, A., Berry, K., Murray, C. & Hayward, M. (2011). Voice hearing within the context of hearers' social worlds: An interpretative phenomenological analysis. *Psychology and Psychotherapy: Theory, Research and Practice, 84*, 256-272.
- Mawson, A., Cohen, K. & Berry, K. (2010). Reviewing evidence for the cognitive model of auditory hallucinations: The relationship between cognitive voice appraisals and distress during psychosis. *Clinical Psychology Review, 30*, 248-258.
- May, K., Strauss, C., Coyle, A. & Hayward, M. (2014). Person-based cognitive therapy groups for distressing voices: A thematic analysis of participant experiences of the therapy. *Psychosis, 6*, 16-26.
- McCarthy-Jones, S., & Fernyhough, C. (2011). The varieties of inner speech: Links between quality of inner speech and psychopathological variables in a sample of young adults. *Consciousness & Cognition, 20*, 1586-93.

- McGlashan, T. H., Levy, S. T., & Carpenter, W. T. (1975). Integration and sealing over: Clinically distinct recovery styles from schizophrenia. *Archives of General Psychiatry*, 32, 1269-1272.
- McGuire, P. K., Murray, R. M. & Shah, G. M. S. (1993). Increased blood flow in Broca's area during auditory hallucinations in schizophrenia. *Lancet*, 342 (8873), 703-706.
- McIntyre, A. (2008). *Participatory action research*. Thousand Oaks, CA.: Sage Publications.
- Mehta, S. & Farina, A. (1997). Is being 'sick' really better? Effect of the disease view of mental disorder on stigma. *Journal of Social and Clinical Psychology*, 16 (4), 405-419.
- Merleau-Ponty (1962). *Phenomenology of Perception*. London: Routledge.
- Milligan, D., McCarthy-Jones, S., Winthrope, A., & Dudley, R. (2013). Time changes everything? A qualitative investigation of the experience of auditory verbal hallucinations over time. *Psychosis: Psychological, Social and Integrative Approaches*, 5(2), 107-118.
- Mojtabai, R., Fochtmann, L., Chang, S.-W., Kotov, R., Craig, T. J. & Bromet, E. (2009). Unmet need for mental health care in schizophrenia: An overview of the literature and new data from a first-admission study. *Schizophrenia Bulletin*, 35(4), 679-695.
- Morrison, A. P. (2001). The interpretation of intrusions in psychosis: an integrative cognitive approach to hallucinations and delusions. *Behavioural and Cognitive Psychotherapy*, 29, 257-276.
- National Collaborating Centre for Mental Health (2009). *Schizophrenia: The NICE Guideline on Core Interventions in the Treatment and Management of Schizophrenia in Adults in Primary and Secondary Care (National Clinical Practice Guideline) (updated edition)*. London: Royal College of Psychiatrists and British Psychological Society.



- Newman-Taylor, K., Harper, S. & Chadwick, P. (2009). Impact of mindfulness on cognition and affect in voice-hearing: Evidence from two case studies. *Behavioural and Cognitive Psychotherapy*, 37(4), 397-402.
- Noyes, J., Popay, J., Pearson, A., Hanes, K. & Booth, A. (2008). Chapter 20: Qualitative research and Cochrane reviews. In Higgins, J. P. T. & Green, S. (Eds). *Cochrane Handbook for Systematic Reviews of Interventions*. Version 5.0.1 (updated September 2008). The Cochrane, Collaboration, 2008.
- NSW Health (2007). *NSW Community Mental Health Strategy 2007 – 2012. From Prevention and Early Intervention to Recovery*. Retrieved from:  
[www.health.nsw.gov.au/pubs/2008/.../070214\\_cmhs\\_summary.pdf](http://www.health.nsw.gov.au/pubs/2008/.../070214_cmhs_summary.pdf)
- NSW Government (2014). *NSW Anti-Discrimination Act, 1977*. Retrieved from:  
[http://www.austlii.edu.au/au/legis/nsw/consol\\_act/aa1977204/](http://www.austlii.edu.au/au/legis/nsw/consol_act/aa1977204/) on 23/04/2014.
- NSW Government (2014). *Disability Discrimination Act, 1992*. Retrieved from:  
[http://www.austlii.edu.au/au/legis/cth/consol\\_act/dda1992264/](http://www.austlii.edu.au/au/legis/cth/consol_act/dda1992264/) on 23/04/2014.
- NSW Government (2014). *Disability Services Act, 1993*. Retrieved from:  
[http://www.austlii.edu.au/au/legis/nsw/consol\\_act/dsa1993213/](http://www.austlii.edu.au/au/legis/nsw/consol_act/dsa1993213/) on 23/04/2014.
- NiaNia, W. & Bush, A. (2013, 20 November). *New Zealand Māori traditional healing approaches to voice-hearing*. Article presented at the World Hearing Voices Congress, Melbourne, Australia.
- Neden, J. Curating stories in teaching family therapy. *The Australian and New Zealand Journal of Family Therapy*, 32 (3), 220-236.

- Neil, S.T., Price, J., Pitt, L., Welford, M., Nothard, S., Sellwood, W., Mulligan, J. & Morrison, A. P. (2013). Working together: Service Users and researchers in Psychosis research. *Psychosis*, 5(3), 306-316.
- Ngo Nkouth, B., St-Onge, M. & Lepage, S. (2010). The group as a place of training and universality of the experience of voice-hearers. *Groupwork*, 20 (2), 45-64.
- Oke, M. (2008). The value of narrative in understanding Mongolian and Australian women's journeys of survival recovery and remaking of self, through and beyond domestic violence. *Women's Studies International Forum*, 31, 415-423.
- Outram, S., Harris, G., Kelly, B., Cohen, M., Sandhu, H., Vamos, M. et al. (2014). Communicating a schizophrenia diagnosis to patients and families: A qualitative study of mental health clinicians. *Psychiatric Services*, 65(4).
- Pape, B. & Galipeault, J. (2002). Mental Health Promotion for People with Mental Illness: A Discussion Paper. Canada: Mental Health Promotion Unit, Health Canada.
- Patterson, A. (2009). Building the foundations for mental health and well-being: Review of Australian and international mental health promotion, prevention, and early intervention policy. *Department of Health and Human Services*.
- Paris, R. & Bradley, C. L. (2001). The challenge of adversity: three narratives of alcohol dependence, recovery and adult development. *Qualitative Health Research*, 11(5), 647-667.
- Paulik, G. (2011). The Role of Social Schema in the Experience of Auditory Hallucinations: A Systematic Review and a Proposal for the Inclusion of Social Schema in a Cognitive Behavioural Model of Voice Hearing. *Clinical Psychology and Psychotherapy*, 768.

- Perkins, R. & Slade, M. (2012). Recovery in England: Transforming statutory services? *International Review of Psychiatry*, 24(1), 29–39.
- Popay, J. (2005). Moving beyond floccinaucinihilipilification: enhancing the utility of systematic reviews. *Journal of Clinical Epidemiology* 2005, 58: 1079-1080.
- Popay, J., Rogers, A. & Williams, G. (1998). Rationale and standards for the systematic review of qualitative literature in health service research. *Qualitative Health Research*, 8, 341-351.
- Priebe, S., Huxley, P., Knight, S. & Evans, S. (1999). Application and results of the Manchester Short Assessment of Quality of Life (MANSA). *International Journal of Social Psychiatry*, 45(1), 7-12.
- Priebe, S., McCabe, R., Junghan, U., Kallert, T., Ruggeri, M., Slade, M. & Reininghaus, U. (2011). Association between symptoms and quality of life in patients with schizophrenia: A pooled analysis of changes over time. *Schizophrenia Research*, 133, 17-21.
- Pyle, M. & Morrison, A. P. (2013). It's just a very taboo and secretive kind of thing": making sense of living with stigma and discrimination from accounts of people with psychosis. *Psychosis*, 5(3).
- Ramsey, T. L., Liu, Q., Massey, B. W. & Brennan, M. D. (2013). Genotypic variation in the SV2C gene impacts response to atypical antipsychotics the CATIE Study. *Schizophrenia Research*. 149, 21–25.
- Read, J., Agar, K., Argyle, N., & Aderhold, V. (2003). Sexual and physical abuse during childhood and adulthood as predictors of hallucinations, delusions and thought disorder. *Psychology and Psychotherapy: Theory, Research and Practice*, 76, 1-22.

- Read, J., Bentall, R. P., & Fosse, R. (2009). Time to abandon the bio-bio-bio model of psychosis: Exploring the epigenetic and psychological mechanisms by which adverse life events lead to psychotic symptoms. *Epidemiologia e Psichiatria Sociale, 18* (4), 299-310.
- Read, J., Haslam, N., Sayce, L. & Davies, E (2006). A review of the ‘mental illness is an illness like any other’ approach. *Acta Psychiatrica Scandinavica, 114*(5), 303-318.
- Read, J., Mosher, L., & Bentall, R. (2004). *Models of Madness*. London & New York: Routledge.
- Read, J., van Os, J., Morrison, A. P. & Ross, C. A. (2005). Childhood trauma, psychosis and schizophrenia: a literature review with theoretical and clinical implications. *Acta Psychiatrica Scandinavica, 112*, 330-350.
- Read, J. & Gumley, A. (2010). Can attachment theory help explain the relationship between childhood adversity and psychosis? In S. Benamer (Ed.), *Telling Stories? Attachment based approach to the treatment of psychosis* (p51-94). London, England: Karnac Books.
- Reis, H. T., Sheldon, K. M., Gable, S. L., Roscoe, S. L. & Ryan, R. M. (2000). Daily Well-Being: The Role of Autonomy, Competence, and Relatedness. *Personality and Social Psychology Bulletin, 26*(4), 419-435.
- Rhodes, P., Baillee, A., Brown, J. & Madden, S. (2008). Can parent-to-parent consultation improve the effectiveness of the Maudsley model of family-based treatment for anorexia nervosa? A randomized control trial. *Journal of Family Therapy, 30*, 96–108.

- Rhodes, P., Brown, J. & Madden, S. (2009). The Maudsley model of family-based treatment for anorexia nervosa: A qualitative evaluation of parent-to-parent consultation. *Journal of Marital and Family Therapy*, 35 (2), 181-192.
- Rhodes, P. & de Jager, A. (2013). Narrative studies of recovery: A critical resource for clinicians. *Clinical Psychologist*, 1-9.
- Riessman, C. K. (2005). Narrative Analysis. In: *Narrative, Memory & Everyday Life*. Huddersfield: University of Huddersfield.
- Roddenberry, A. & Renk, K. (2010). Locus of control and self-efficacy: Potential mediators of stress, illness, and utilization of health services in college students. *Child Psychiatry and Human Development*, 41, 353-370.
- Romme, M. A. J., & Escher, A. D. M. A. C. (1989). Hearing voices. *Schizophrenia Bulletin*, 15, 209-216.
- Romme, M. & Escher, S. (1993). *Accepting voices*. London: MIND publications.
- Romme, M. & Escher, S. (2000). *Making sense of voices*. London: Mind Publications.
- Romme, M. & Escher, S. (Eds.) (2011). *Psychosis as a personal crisis: An experience-based approach*. East Sussex / New York: Routledge.
- Romme, M. Escher, S., Dillon, J., Corstens, D. & Morris, M. (2009). *Living with Voices: 50 Stories of Recovery*. Herefordshire, UK: PCCS Books.
- Romme, M. & Morris, M. (2013). The recovery process with hearing voices. *Psychosis*, 5(3), 250-260.
- Ruddle, A., Mason, O. & Wykes, T. (2010). A review of hearing voices groups: Evidence and mechanisms of change. *Clinical Psychology Review*, 31, 757-766.

- Rueda, S., Raboud, J., Mustard, C., Bayoumi, A., Lavis, J. N. & Rourke, S. B. (2011).  
Employment status is associated with both physical and mental health quality of life in  
people living with HIV. *AIDS Care*, 23(4), 435-443.
- Sachs, G. S., Printz, D. J., Kahn, D. A., Carpenter, D. & Docherty, J. P. (2000). Medication  
treatment of bipolar disorder. *Expert consensus guideline series: A postgraduate medicine  
special report*.
- Sayce, L. (2001). Social inclusion and mental health. *Psychiatric Bulletin*, 25, 121-123.
- Scheffer, R. (2003). Addressing stigma: increasing public understanding of mental illness.  
*Centre for Addiction and Mental Health*.
- Shergill, S. S., Brammer, M. J., Williams, S. C., Murray, R. M. & McGuire, P. K. (2000).  
Mapping auditory hallucinations in schizophrenia using functional magnetic resonance  
imaging. *Archives of General Psychiatry*, 57 (11), 1033-1038.
- Schrader, S. R. (2013). Illuminating the heterogeneity of voices in a multiple perspectives  
research paradigm. *Psychosis*, 5(3), 216-225.
- Schrank, B. & Slade, M. (2007). Recovery in psychiatry. *Psychiatric Bulletin*, 31,321-325.
- Schröder, M. & Börsch-Supan, A. (2008). Retrospective data collection in Europe. *Manheim  
Institute for the Economics of Aging*. Retrieved from:  
[http://mea.mpisoc.mpg.de/uploads/user\\_mea\\_discussionpapers/1jxcvniw0vcuwcvva\\_DP%20172-08.pdf](http://mea.mpisoc.mpg.de/uploads/user_mea_discussionpapers/1jxcvniw0vcuwcvva_DP%20172-08.pdf)
- Schwartz, C., Meisenhelder, J. B., Ma, Y. & Reed, G. (2003). Altruistic Social Interest  
Behaviors Are Associated With Better Mental Health. *Psychosomatic Medicine*, 65, 778–  
785.

- Scott, R. (2007). The relationship of the components of an authentic life on self-efficacy and perception of stress in persons diagnosed with major mental health disorders. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 68(4-A), 1661.
- Seedat, S., Stein, M. B., Oosthuizen, P. P., Emsley, R. A. & Stein, D. J. (2003). Linking posttraumatic stress disorder and psychosis: A look at epidemiology, phenomenology and treatment. *The Journal of Nervous and Mental Disease*, 191 (10), 675-678.
- Sederer, L. I. (2009). Science to practice: Making what we know what we actually do. *Schizophrenia Bulletin*, 35 (4), 714-718.
- Sells, D., Topor, A. & Davidson, L. (2004). Generating coherence out of chaos: Examples of the utility of empathic bridges in phenomenological research. *Journal of Phenomenological Psychology*, 35(2), 253-271
- Seikkula, J. (2002). Open dialogues with good and poor outcomes for psychotic crises: Examples from families with violence. *Journal of Marital and Family Therapy*, 28(3), 263-274.
- Seikkula, J. (2008). Inner and outer voices in the present moment of family and network therapy. *Journal of Family Therapy*, 30, 478-491.
- Seikkula, J. (2011). Becoming dialogical: Psychotherapy or a way of life? *The Australian and New Zealand Journal of Family Therapy*, 32(2), 179-193.
- Seikkula, J., Alakare, B. & Aaltonen, J. (2011). The comprehensive Open-Dialogue approach in Western Lapland: II. Long-term stability of acute psychosis outcomes in advanced community care. *Psychosis*, 3(3), 192-204.
- Sells, D., Topor, A. & Davidson, L. (2004). Generating coherence out of chaos: Examples of the utility of empathic bridges in phenomenological research. *Journal of Phenomenological Psychology*, 35(2), 253-271.

- Shapiro, D. H., Schwartz, C. E. & Astin, J. A. (1996). Controlling ourselves, controlling our worlds: Psychology's role in understanding positive and negative consequences of seeking and gaining control. *American Psychologist*, *51*(12), 1213-1230.
- Sibitz, I., Amering, M., Unger, A., Seyringer, M. E., Bachmann, A., Schrank, B....& Woppmann, A. (2011). The impact of the social network, stigma and empowerment on the quality of life in patients with schizophrenia. *European Psychiatry*, *26*, 28–33.
- Slade, M., Amering, M. & Oades, L. (2008). Recovery: an international perspective. *Epidemiologia e Psichiatria Sociale*, *17*(2), 128-137.
- Slade, P., & Bentall, R. (1988). *Sensory deception: Towards a scientific analysis of hallucinations*. London: Croom Helm.
- Slade, M., Leamy, M., Bacon, F., Janosik, M., Le Boutillier, C., Williams, J., & Bird, V. (2012). International differences in understanding recovery: systematic review. *Epidemiology and Psychiatric Sciences*, *21*, 353-364.
- Sommer, I. E., Diederer, K. M., Blom, J. D., Willems, A., Kushan, L., Slotema, K., Boks, M. P., Daalman, K., Hoek, H. W., Neggers, S. F., Kahn, R. S. (2008). Auditory verbal hallucinations predominantly activate the right inferior frontal area. *Brain*, *131*(12), 3169-77.
- Song, L.-Y. & Shih, C.-Y. (2009). Factors, process and outcomes of recovery from psychiatric disability: the unity model. *International Journal of Social Psychiatry*, *55*(4), 348-360.
- Sørensen, T. H. (2013). *The Aarhus Voice Hearing Program – An exploration of a recovery-oriented program* (Unpublished master's thesis). Aarhus University. Aarhus, Denmark.
- Sparks, J. (1997). Voices of experience: Inviting former clients to rejoin the therapy process as consultants. *Journal of Systemic Therapies*, *16*, 367–375.



- Spender, L. (Ed.) (1995). *Mental health rights manual: A guide to the legal and human rights of people with a mental illness in NSW*. Sydney: Redfern Legal Centre Publishing.
- Staring, A. B. P., van der Gaag, M. & Mulder, C. L. (2011). Recovery style predicts remission at one-year follow-up in outpatients with schizophrenia spectrum disorders. *The Journal of Nervous and Mental Disease*, 199(5), 295-300.
- Stromwell, L. K., Holley, L. C. & Bashor, K. E. (2011). Stigma in the mental health workplace: Perceptions of peer employees and clinicians. *Community Mental Health Journal*, 47, 472–481.
- Stroup, T.S., McEvoy, J.P., Swartz, M.S., Byerly, M.J., Glick, I.D., Canive, J.M., McGee, M.F., Simpson, G.M., Stevens, M.C., Lieberman, J.A. (2003). The National Institute of Mental Health Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) project: schizophrenia trial design and protocol development. *Schizophrenia Bulletin*, 29 (1), 15–31.
- Sugimori, E., Asai, T. & Tanno, Y. (2011). Sense of agency over thought: External misattribution of thought in a memory task and proneness to auditory hallucination. *Consciousness and Cognition*, 20(3), 688-695.
- Suzuki, M., Amagai, M., Shibata, F. & Tsai, J. (2011). Factors related to self-efficacy for social participation of people with mental illness. *Archives of Psychiatric Nursing*, 25(5), 359-365.
- Tai, S. & Turkington, D. (2009). The Evolution of Cognitive Behavior Therapy for Schizophrenia: Current Practice and Recent Developments. *Schizophrenia Bulletin*, 35 (5), 865–873.

- Tait, L., Birchwood, M. & Trower, P. (2004). Adapting to the challenge of psychosis: personal resilience and the use of ‘sealing over’ (avoidant) coping strategies. *British Journal of Psychiatry*, 185, 410-415.
- Tew, J., Ramon, S., Slade, M., Bird, V., Melton, J. & Le Boutillier, C. (2012). Social factors and recovery from mental health difficulties: A review of the evidence. *British Journal of Social Work*, 42, 443–460.
- Thomas, N., Hayward, M., Peters, E., van der Gaag, M., Bentall, R. P., Jenner, J.... & McCarthy-Jones, S. (2014). Psychological therapies for auditory hallucinations (voices): current status and key directions for future research. *Schizophrenia Bulletin*, in press.
- Thornhill, H., Claire, L. & May, R. (2010). Escape, enlightenment and endurance. *Anthropology & Medicine*, 11(2), 181-199.
- Thornicroft, G. (2006). *Shunned: Discrimination against people with mental illness*. Oxford: Oxford University Press.
- Thornicroft, G., Brohan, E., Rose, D., Sartorius, N. & Leese, M. (2009). Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. *The Lancet*, 373, 408–415.
- Thys, E., Sabbe, B. & De Hurt, M. (2011). Creativity and psychiatric disorders: Recent neuroscientific insights. *Tijdschrift voor Psychiatrie*, 53(12), 905-915.
- Tien, A. Y. (1991). Distributions of hallucinations in the population. *Social Psychiatry and Psychiatric Epidemiology*, 26, 287– 292.
- Tomes, N. (2006). The patient as a policy factor: A historical case study of the consumer/survivor movement in mental health. *Health Affairs*, 25(3), 720-729

- Trower, P., Birchwood, M., Meaden, A., Byrne, S., Nelson, A.I., & Ross, K. (2004). Cognitive therapy for command hallucinations: randomised controlled trial. *The British Journal of Psychiatry*, *184*, 312-320.
- Tufford, L. & Newman, P. (2012). Bracketing in qualitative research. *Qualitative Social Work: Research and Practice*, *11*(1), 80-96.
- Turner-Crowson, J. & Wallcraft, J. (2002). The recovery vision for mental health services and research: A British perspective. *Psychiatric Rehabilitation Journal*, *25*(3), 245-254.
- Turner, J. S. & Leach, D. J. (2012). Behavioural activation therapy: Philosophy, concepts, and techniques. *Behaviour Change*, *29*(2), 77-96.
- Vaughn, S. & Fowler, D. (2004). The distress experienced by voice hearers is associated with the perceived relationship between the voice hearer and the voice. *British Journal of Clinical Psychology*, *43*, 143-153.
- Van den Berg, D. P. G. & Van der Gaag, M. (2014). Treating trauma in psychosis with EMDR: A pilot study. *Journal of Behaviour Therapy and Experimental Psychiatry*, *43*, 664-671.
- Van der Gaag, M., Oosterhout, B., Daalman, K., Sommer, I. E., & Korrelboom, K. (2012). Initial evaluation of the effects of competitive memory training (COMET) on depression in schizophrenia-spectrum patients with persistent auditory verbal hallucinations: A randomised controlled trial. *British Journal of Clinical Psychology*, *51*, 158-171.
- Van Niekerk, L. (2009). Participation in work: A source of wellness for people with psychiatric disability. *Work*, *32*, 455-465.
- Van Os, J. (2010). Are psychiatric diagnoses of psychosis scientific and useful? The case of schizophrenia. *Journal of Mental Health*, *19*(4), 305-317.

- Venning, A., Kettler, L., Zajac, I., Wilson, A., Elliott, J. (2011). Is hope or mental illness a stronger predictor of mental health? *The International Journal of Mental Health Promotion, 13*(2), 32-39.
- Versmissen, D., Janssen, I., Johns, L., McGuire, P., Drukker, M., à Campo, J., Myin-Germeys, I., Van Os J. & Krabbendam, L. (2007). Verbal self-monitoring in psychosis: a non-replication. *Psychological Medicine, 37*(4), 569-576.
- Waters, F. A. V., Badcock, J. C. & Maybery, M. T. (2006). The 'who' and 'when' of context memory: Different patterns of association with auditory hallucinations. *Schizophrenia Research, 82*, 271-273.
- Waters, F. A. V., Badcock, J. C. & Maybery, M. T. & Michie, P. T. (2003). Inhibition in schizophrenia: associations with auditory hallucinations. *Schizophrenia Research, 62*, 275-280.
- Waters, F. (2010). Auditory hallucinations in psychiatric illness. *Psychiatric Times*. Retrieved from: <http://www.psychiatrictimes.com/schizophrenia/auditory-hallucinations-psychiatric-illness>.
- Waters, F., Allen, P., Aleman, A., Fernyhough, C., Woodward, T., Badcock, J., Barkus, E., Johns, L., Varese, F., Menon, M., Vercammen, A. & Larøi, F. (2012). Auditory hallucinations in schizophrenia and non-schizophrenia populations: A review and integrated model of cognitive mechanisms. *Schizophrenia Bulletin, 38*(4), 683-693.
- Weeks, G., Slade, M. & Hayward, M. (2011). A UK validation of the Stages of Recovery Instrument. *International Journal of Social Psychiatry, 57*, 446-454.
- Weingarten, K. (1998). Accounting for narrative therapy's success: The small and the ordinary: The daily practice of a postmodern narrative therapy. *Family Process, 37*, 3-15.

- White, R. F. (2005). An empowerment model of recovery from severe mental illness: An expert interview with Daniel B. Fisher, MD, PhD. *Medscape Psychiatry*. Retrieved from: <http://www.medscape.com/viewarticle/496394>.
- White, M. & Epston, D. (1990). *Narrative means to therapeutic ends*. New York / London: W. W. Norton & Company.
- Whitney, S. D., Sullivan, S. & Herman, K. (2010). Low self-esteem as an early indicator of youth depressive symptoms. *Advances in School Mental Health Promotion*, 3(2), 5-16.
- Whitwell, D. (1999). The myth of recovery from mental illness. *Psychiatric Bulletin*, 23, 621-622.
- Wiesjahn, M., Brabban, A., Jung, E., Gebauer, U. B. & Lincoln, T. M. (2012). Are continuum beliefs about psychotic symptoms associated with stereotypes about schizophrenia? *Psychosis: Psychological, Social and Integrative Approaches*.
- Williams, C. C. & Collins, A. A. (2002). The social construction of disability in schizophrenia. *Qualitative Health Research*, 12, 297-309.
- Wykes, T., Steel, C., Everitt, B. & Tarrier, N. (2008). Cognitive behaviour therapy for schizophrenia: effect sizes, clinical models and methodological rigor. *Schizophrenia Bulletin*, 34, 523-537.
- Zimmermann, G., Favrod, J., Trieu, V. H. & Pomini, V. (2005). The effects of cognitive behavioural treatment on the positive symptoms of schizophrenia spectrum disorders: A meta-analysis. *Schizophrenia Research*, 77, 1-9.

## APPENDIX A: Ethics Approval from the University of Sydney Human Research Ethics Committee



**RESEARCH INTEGRITY**  
**Human Research Ethics Committee**  
 Web: <http://sydney.edu.au/ethics/>  
 Email: [ro.humanethics@sydney.edu.au](mailto:ro.humanethics@sydney.edu.au)

**Address for all correspondence:**  
 Level 6, Jane Foss Russell Building - G02  
 The University of Sydney  
 NSW 2006 AUSTRALIA

Ref: GD/PE

19 July 2012

Dr Paul Rhodes  
 School of Psychology  
 Faculty of Science  
 Mackie Building – K01  
 The University of Sydney  
[p.rhodes@sydney.edu.au](mailto:p.rhodes@sydney.edu.au)

Dear Dr Rhodes

Thank you for your correspondence dated 11 July 2012 addressing comments made to you by the Human Research Ethics Committee (HREC).

On 18 July 2012 the Chair of the HREC considered this information and approved your protocol entitled "Investigating the lived experience of recovered voice hearers".

Details of the approval are as follows:

**Protocol No.:** 15033  
**Approval Date:** 18 July 2012  
**First Annual Report Due:** 31 July 2013  
**Authorised Personnel:** Dr Paul Rhodes  
 Ms Adele de Jager  
 Mrs Kathryn Dorgan  
 Ms Kathryn McCabe

**Documents Approved:**

Document	Version Number	Date
Participant Information Statement – Study 1	2	7/6/2012
Participant Information Statement – Study 2	2	7/6/2012
Participant Consent Form – Study 1	2	7/6/2012
Participant Consent Form – Study 2	1	31/5/2012
Semi Structured Interview Questions	1	Submitted 8/6/2012
Questionnaires	1	Submitted 8/6/2012
Advertisements	1	Submitted 8/6/2012

HREC approval is valid for four (4) years from the approval date stated in this letter and is granted pending the following conditions being met:

## APPENDIX B: Approval of Ethics Modification Request from the University of Sydney

### Human Research Ethics Committee



**Research Integrity**  
Human Research Ethics Committee

Thursday, 14 March 2013

Dr Paul Rhodes  
Psychology, Faculty of Science  
Email: p.rhodes@sydney.edu.au

Dear Paul

Your request to modify the above project was considered by the Executive of the Human Research Ethics Committee.

The Committee had no ethical objections to the modification/s and has approved the project to proceed.

Details of the approval are as follows:

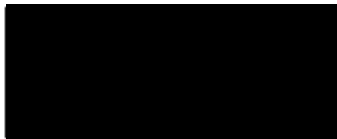
**Project No.:** 2012/1529  
**Project Title:** Investigating the lived experience of recovered voice hearers

**Approved Documents:**

Date Uploaded	Type	Document Name
15/01/2013	Organisation Approval	Letter Hearing Voices Network NSW Chairperson B. Roberts
06/02/2013	Participant Consent Form	Consent Form Study 1 - Part 2
06/02/2013	Participant Info Statement	Participant Information Sheet Study 1 - Part 2

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours sincerely



**Dr Stephen Assinder**  
Chair  
Human Research Ethics Committee

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.

## APPENDIX C: Ethics Approval from St Vincent's Hospital Human Research Ethics

### Committee

# St Vincent's Hospital

A facility of St Vincents  
& Mater Health Sydney

St Vincent's Hospital Sydney Ltd  
ABN 77 054 038 872  
390 Victoria Street  
Darlinghurst NSW 2010  
Australia

T + 61 2 8382 1111  
F + 61 2 9332 4142  
www.stvincents.com.au

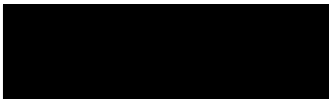
Douglas Holmes  
Level 4, O'Brien Centre  
Cnr Burton and Victoris St  
Darlinghurst, NSW, 2010

16 February 2012

To Whom It May Concern,

This letter confirms permission for Adèle de Jager, a doctoral candidate at the University of Sydney, to conduct research at the O'Brien Centre, Darlinghurst, NSW, as part of the requirements of a Masters research degree. Permission is subject to approval of the research ethics application by the University of Sydney Human Research Ethics Committee. The research process will include conducting qualitative, face-to-face interviews with participants. The full title of the research is 'Investigating the lived experience of recovered voice hearers'.

Kind regards,



Steven Bernardi  
MHA, BN, Dip HSci, MHGC, RN  
Program Manager - Inner City Health  
St Vincent's Hospital Sydney



Douglas Holmes.  
Consumer Participation Officer  
Inner City Health  
St Vincent's Hospital Sydney



**APPENDIX D: Permission from the Hearing Voices Network NSW to attend groups**



**To: Human Research Ethics Committee**

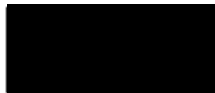
Please accept this letter as confirmation that Hearing Voices Network NSW (HVNNSW), is pleased to invite Adele de Jager to attend meetings at several of HVNNSW self-help groups for voice hearers, in order to speak with group members about her research (Investigating the lived experience of recovered voice hearers, protocol number 15033.)

This will allow potential participants to meet Adele and make an informed decision about whether or not to participate in the research. It will also allow the group members the opportunity to ask questions about the research and what it would involve.

Our group facilitators will firstly ask the members of each group whether they are happy for Adele to come to their meetings and address them, following which Adele will be invited to attend those group's who have consented to her attendance.

If you require any further information, I can be contacted on 0425 334244.

Yours Sincerely,



**Bruce Roberts**  
**Chairperson**  
**Hearing Voices Network NSW**  
**10<sup>th</sup> June 2012.**

**APPENDIX E: Participant demographics, diagnoses and quantitative measures.***Table 2: Participant demographics, diagnoses and measures of stage of recovery, quality of life and global psychological distress.*

<i>Participant</i>	<i>Age range (years)</i>	<i>DSM-IV diagnosis</i>	<i>STORI*</i>	<i>MANSA**</i>	<i>K10***</i>
1	20-30	Schizophrenia	5	Mostly satisfied	Moderate
2	50-60	Schizoaffective Disorder	4	Mixed	Moderate
3	40-50	Schizophrenia	5	Mixed	High
4	50-60	Schizophrenia	5	Mixed	Low
5	60-70	Bipolar Disorder I	5	Mostly satisfied	High
6	50-60	Schizophrenia	5	Mostly satisfied	High
7	30-40	Schizophrenia	5	Mostly satisfied	Low
8	30-40	Schizoaffective Disorder	5	Mostly satisfied	Low
9	40-50	Schizophrenia	5	Mostly satisfied	High
10	50-60	Schizophrenia	5	Mixed	Low
11	50-60	Schizoaffective Disorder	4	Mixed	High

\**STORI=Stages of Recovery Instrument*

\*\**MANSA=Manchester Short Assessment of Quality of Life*

\*\*\**K10=Kessler 10 assessment of global psychological distress.*

All participants were in stage four or five of recovery as per Andresen et al.'s (2003) Stages of Recovery Instrument (STORI; 1=least to 5=most advanced stage of recovery). They reported mixed or mostly satisfied ratings of quality of life on the Manchester Short Assessment of Quality of Life. There was a broad range of global psychological distress reported on the Kessler 10 scale, from low to high. Participant information is listed in a different order to that in other tables to ensure confidentiality.

## APPENDIX F: Information about participants' voice-hearing experiences

Table 3: Additional information about participants' voice-hearing experiences

<i>Participant</i>	<i>Brief information about voice-hearing</i>	<i>Current voice-hearing experiences</i>
1	Several different male voices, some of whom gave good advice and others who were critical and encouraged social isolation. Onset associated with health and work stressors and isolation from others.	Yes
2	One male voice, exuberant, encouraged excitement and acting impulsively. One female voice, critical. Similar characteristics to person known to the hearer. Onset after bereavement and stress associated with family difficulties. Crowd noise increasing with stress or fatigue.	Yes
3	One male voice. History of repeated interpersonal trauma including physical and sexual assault. Sparse information provided as it remains painful to discuss.	Yes
4	Two male voices, critical, talking to each other about the hearer. Historically heard music. Onset associated with chronic stress and social isolation.	Yes
5	One male and one female voice, threatening to the hearer and their family and talking about the hearer. Onset associated with job loss, increased anxiety and social isolation.	Yes
6	Three male and one female voice. Male voice dominant and threatening to hearer and other voices, also helpful and friendly at times. Other voices loving and supportive. Female voice strongest emotionally.	Yes
7	Male voices, unidentifiable. Encouraged reckless behaviour, critical, encouraged social isolation.	Yes
8	Female voice, threatening. Reported history of assault by extended family member during childhood. Onset during school years associated with withdrawal from others.	Yes
9	Male voices, gave orders, threatened to harm hearer and family.	No
10	Three female voices. The first was friendly and alleviated the hearer's sense of isolation. The second appeared later and was more interested in intellectual conversations. The third was more childlike and mostly made comments related to bodily needs, for example, encouraging the hearer to eat or go to sleep when needed. A group of male voices appeared during a time of increased stress and life transition. They increased the hearer's anxiety and were associated with a strong but vague sense of threat.	Yes
11	Male and female voices, insulting, bossy and threatening at times and agreeable at others. Amplified hearer's anxieties, for example worries about life choices such as which degree to pursue at university.	No

## APPENDIX G: Additional information regarding the development of the model of recovery over time

The preliminary model of recovery was developed by the candidate through reading, re-reading and reflecting upon narratives generated from interviews. Common threads in recovery processes were identified and included in the model. Following this, the model was reconsidered in terms of whether it accurately represented each individual narrative. The model was also discussed with primary supervisor, Dr. Paul Rhodes and associate supervisor, Dr. Mark Hayward and changes made accordingly. The resulting preliminary model is presented in Figure 3.

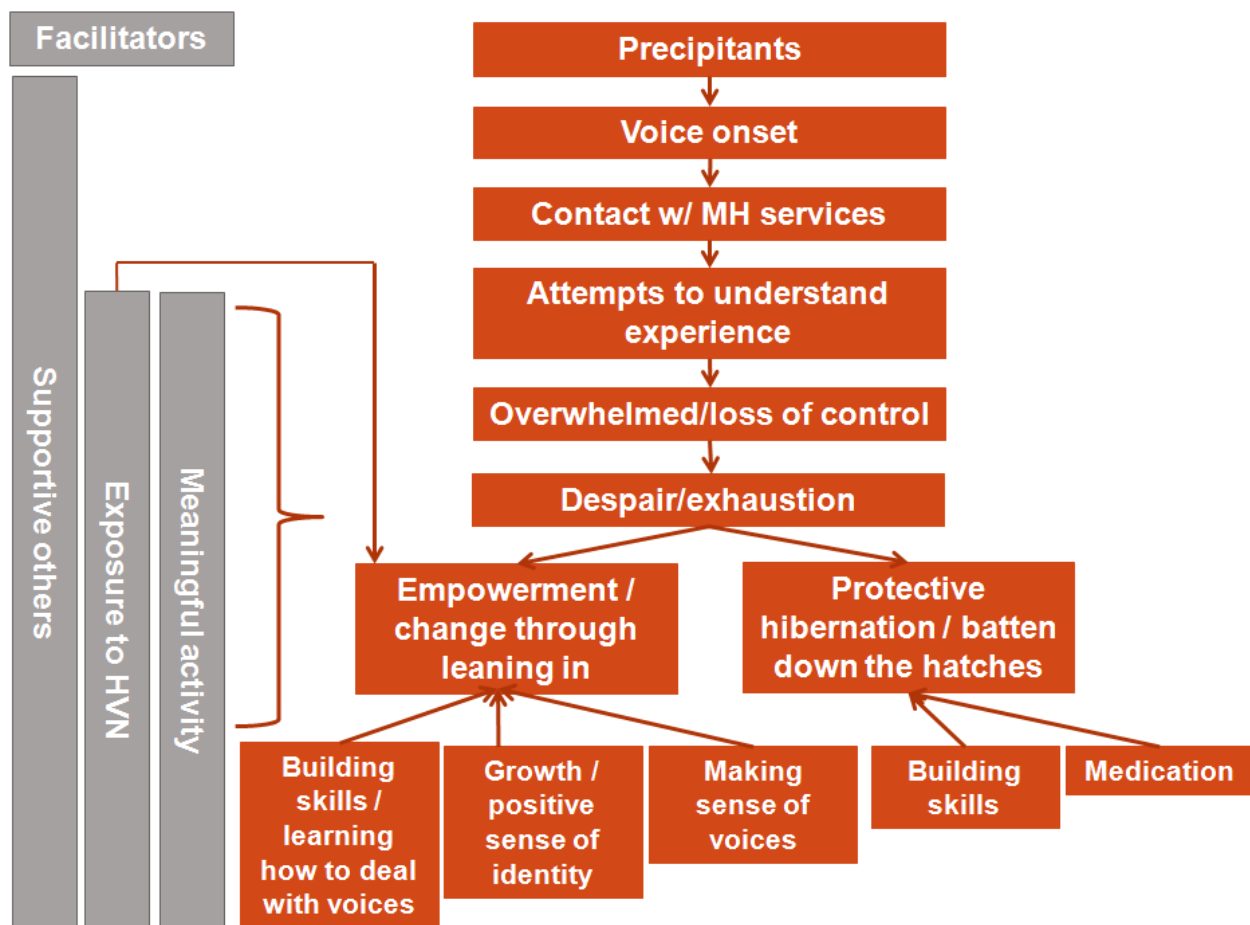


Figure 3: Preliminary model of recovery over time.

The notion of ‘protective hibernation’ was chosen after careful reflection to indicate an active withdrawal in order to survive rather than ‘giving up’. The notion of active withdrawal has been commented upon in literature by consumers and other authors (see Andresen et al., 2003). The preliminary model of recovery over time was presented at the World Hearing Voices Congress, 2013, held in Melbourne, Australia.

Once all narratives had been member-checked, they were sent to the four members of the focus group, who were all experts by profession, research, clinical experience, lived experience, or a mixture of the above. The group included Dr. Vanessa Beavan, Debra Lampshire, Dr. Simon McCarthy-Jones and Dr. Neil Thomas. They were also sent the preliminary model of recovery and asked to comment upon it in relation to the narratives. The aim was to change or refine the model to more accurately and authentically represent participants’ narratives. The candidate also met separately with Dr. Vanessa Beavan to discuss this process. This meeting resulted in a clarification of the aim of the focus group. Group members were unfamiliar with narrative method and thus there was a need to explain it and idea of typologies or types of recovery story. The notion of ‘the boxer’ and ‘the rock-climber’ as narrative typologies were briefly discussed. However, they were ultimately not adopted. Group members did not reside in the same area, being spread across Sydney, Melbourne and Auckland. Therefore, meeting face-to-face was not logistically feasible. An appointment was made with group members to discuss the model via Skype. Feedback from the meeting was very useful. The most important point made was that the model made recovery appear far too neat and linear. It did not therefore authentically represent the lived experience of participants and others with lived experience of recovery. This raised concerns that the model could be applied in a rigid manner in clinical settings, with people distressed by their voices and experiencing mental health difficulties

expected by mental health staff to follow a linear process of recovery in a prescriptive manner. Group members emphasised the messy, non-linear, cyclical nature of recovery. It was agreed that this should be emphasised when presenting the model. It was also noted that inhibitors of recovery such as stigma, isolation and fear of disclosure of voice-hearing experiences were not included in the model. Group members also noted that there were several processes implicated in recovery which were common across typologies related to meeting basic human needs. These included connection with others, coming to hold a positive sense of self and engagement in meaningful activities. It was also noted that isolation and poor general mental health formed the context in which voices appeared to commence. One group member felt that stressors preceding voice onset was not a factor which was clear in the narratives. This was checked by the candidate following the group meeting. Several other points were made. Following the meeting, changes were made to the model incorporating the main points raised by the focus group. The revised model is presented in Figure 4.

The candidate met with Dr. Beavan to discuss the revised model. The model had become almost too detailed and therefore unclear. Changes were made to simplify unnecessarily detailed aspects of the model. For example, stigma, disconnection from others and fear of disclosure were collapsed into one category, while poor general mental health was included as a contextual factor. It was also decided that proximal and distal stressors should be included in the model as this more authentically represented participants' experiences. It was also noted that the two recovery typologies should be made to stand out more in the model, as this was the main concept to be communicated.

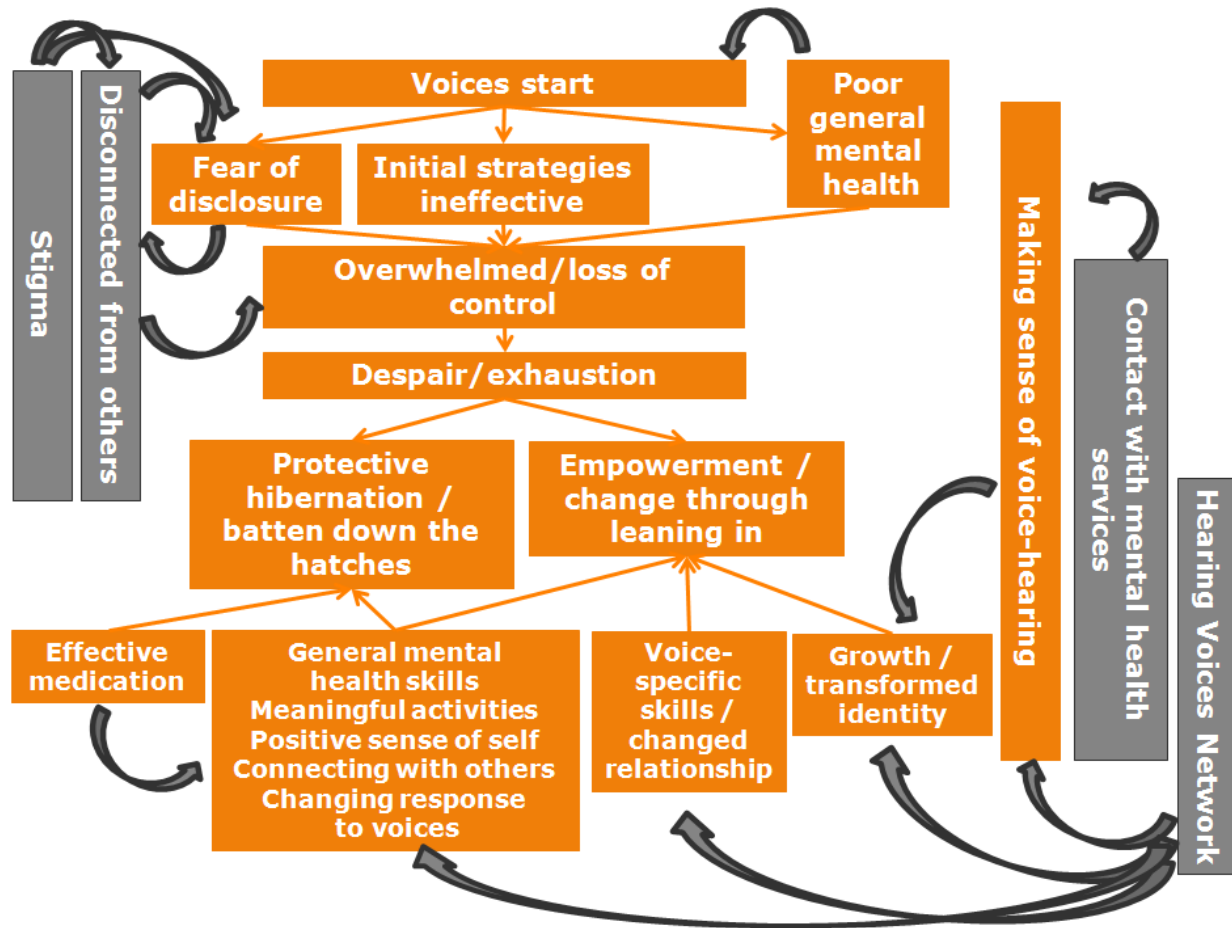


Figure 4: Revised model of recovery incorporating feedback from the focus group.

Further iterations of the model were discussed with the candidate's primary and associate supervisors. Finally, through discussions with Dr. Mark Hayward, it appeared that the concept of 'empowerment/leaning in' and 'protective hibernation/batten down the hatches' narratives was similar to the notion of 'turning toward' and 'turning away' developed in his and colleagues' research. It was agreed that in order to make the research most useful clinically it would be preferable to build some consistency in the terms used in research rather than opting for idiosyncratic terminology which may dilute the overall impact of these ideas. The tension between remaining true to one's participants and results on the one hand and making research of most benefit to clinicians and voice-hearers was noted. Ultimately, as these terms reflected very

similar if not identical concepts, it was decided that the ‘turning toward’ and ‘turning away’ terminology would be adopted. The final model of recovery developed is presented in Figure 5.

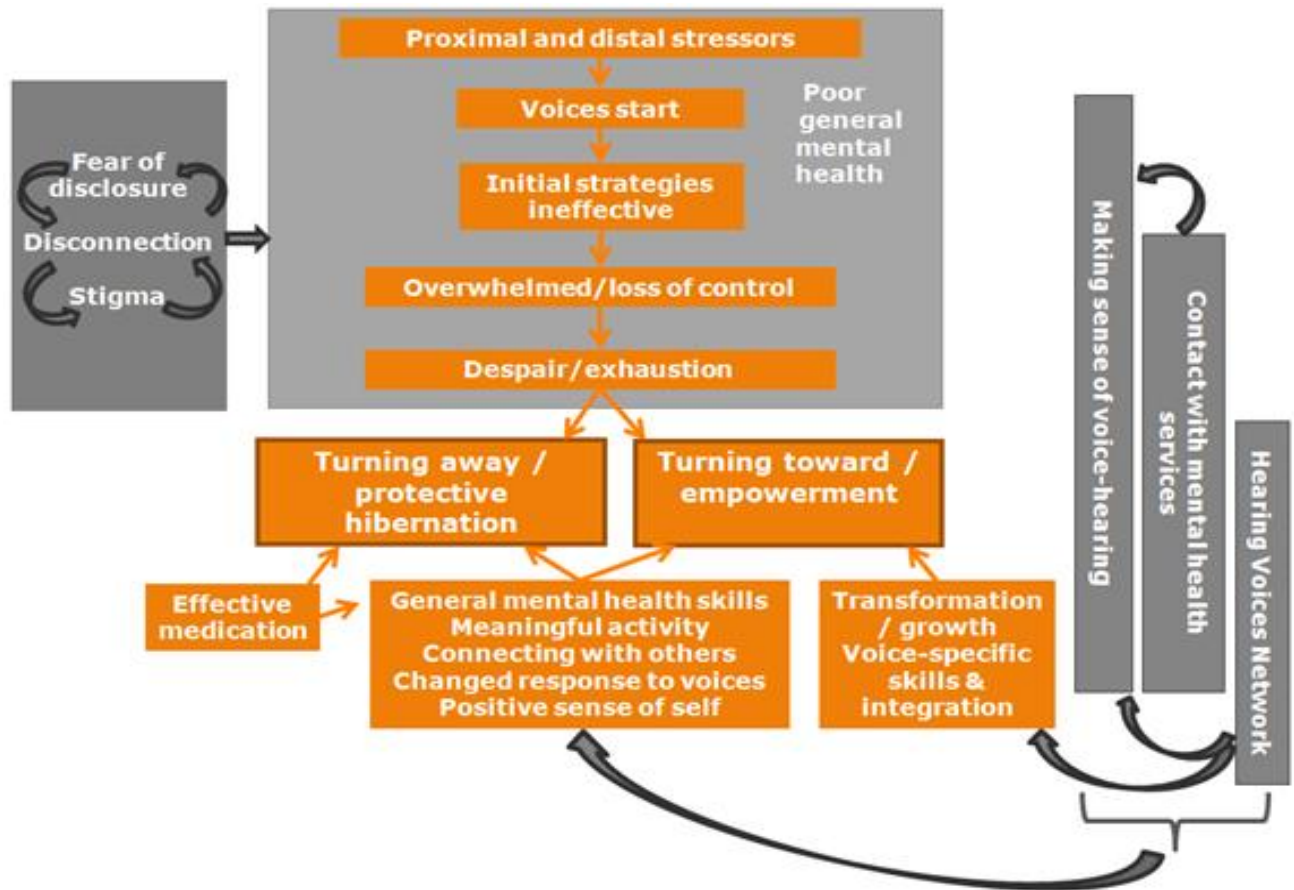


Figure 5: Final model of recovery over time.



## APENDIX H: David's narrative

### Narrative – David

David grew up in Sydney with his parents and younger brother. He had no difficulties in his home life and got along well with his parents. He was bright, did well at school and went to a selective high-school. He was always hard-working and pushed himself to do well. As a kid and teenager he was sociable and always had friends. He finished a bachelor's degree at university. He did a couple of different jobs after graduating, but things really started to change for him when he started in a role that he felt was a proper career job in his mid-20's. Work became his main focus. He was driven to succeed and enrolled in certificates through TAFE that would help him to progress at work. When he finished one certificate, he enrolled in the next one.

*“I was doing a certificate in (area), so I'd do one certificate, I think part-time it would last a year and then I'd do another one and another one so I moved up like three or four...and then I'd come home and work as well when I got home. Yeah so it was pretty stressful, I suppose I was pretty stressed at the time.”*

For three or four years, his life involved working full-time and then coming home to do more work:

*“I was always run into my work, I would work all day then I'd go off to TAFE I should say and study and then go home and do my work and then go to sleep. So I did that for about three or four years.”*

Because of the demands of his work and study routine, he had almost no time to socialise with his friends. Gradually, he lost contact with them:

*“All I did was work. I didn't have much of a social life. The only social life I had was going to work or TAFE and seeing people.”*

David didn't realise he was stressed out at the time:

*“I was wired all the time, thinking back I was on the edge the whole time. So at the time I didn't realise, but now looking back when I'm not working as hard I can see why I went a bit weird.”* Eventually, he started having black-outs:

*“For some reason I don't know why – it wasn't like I was doing any extra than normal – I started having strange things happen to me, like black-outs and outer-body experiences and stuff like that. And I was waking up in – at first in just strange places. I'd be reading a book or something and wake up in the bath-tub.”*

These experiences were very frightening. David went to his doctor, who told him he was too stressed out and he needed to cut down on his work-load. She prescribed him anti-depressants. David took three weeks off work, but continued to have strange experiences. Then, one day, something even more serious happened:

*“I was at the shopping centre and I had an out-of-body experience where I came out of my body and I was watching myself and I walked down to the rail-way line and started lying on the rail-way line – I couldn’t stop myself, I was just doing it and I was watching myself do it.”*

Fortunately, David came to and got up off the tracks before a train arrived:

*“That’s the scariest thing that’s ever happened to me by far, because if there was a train coming, I’d be dead.”*

David had had no suicidal thoughts and did not have a history of depression.

*“It was like it wasn’t me. I’ve never been depressed or anything.”*

Afterwards, he was worried that he might do something similar again and be seriously injured or killed. David had had no suicidal thoughts and no history of depression:

He went straight to the emergency department of the nearest hospital and asked to be committed for a little while. The staff agreed to admit him to hospital for a week or so. That turned into just over a month. His black-outs stopped while he was in hospital:

*“It stopped happening while I was in hospital, I wasn’t stressed out anymore, I didn’t really have anything to do so I really wasn’t too worried.”*

It was in this context that David first heard voices. At first, he thought he was just over-hearing people talking in the ward. He heard two male voices talking to each other about him, criticising him:

*“They’d say that I was lazy and that I’m worthless and things like that. They’d talk to each other, like one guy would go “isn’t he lazy, he’s just sitting there watching television.” And the other would go “yeah, that’s pathetic.” And then they’d just talk back and forth to each other.”*

At first, it was sporadic. He would hear voices positioned just behind his right shoulder and when he turned around, no one was there. Then it started happening more frequently. David didn’t tell the hospital staff because he wanted to get out of hospital and was worried that if he talked to them about his voices that he wouldn’t be allowed to go home. He was discharged. When he went back for his follow-up assessment, the voices were still there and he decided to tell medical staff about them:

*“I told them what was going on, I said there’s two guys and they talk to each other. It wasn’t happening all the time at that stage, maybe happen once every couple of days for five minutes at a time or something along those lines.”*

They did a number of tests to try to ascertain what was causing his experiences. David was assessed by a psychiatrist, who told him he was experiencing the early stages of schizophrenia, which was a degenerative brain disease. The first thing David did was read everything he could find about it. Everything he found was very negative:

*“Everything I read was like ‘ah, the drugs will take it away’ it wasn’t, like everything was pretty negative, it was a brain disease that you got and so I got pretty depressed after that. And of course I wasn’t able to do the stuff I used to be able to do. I got really depressed.”*

The explanation of his experiences provided by the psychiatrist and in text-books about schizophrenia was not helpful to David. The idea that he had a degenerative brain disease made extremely anxious about what might happen to him in the future:

*“It was really scary too because I didn’t know – the voices weren’t threatening me or anything, which was good, but it was just, this is going to get worse and worse and worse until I’m like one of those guys on the street yelling at people or something. So I was really worried about that and scared it was going to get worse and worse. Which it did get, it just kept getting worse and worse, the voices and that...(they got) louder, more frequent, louder especially. They started off just like people whispering and after say a month they were yelling and it was going pretty much all day. I would get maybe five minutes at a time if that, without them...The first month or two it got worse and worse and worse and worse.”*

David took the anti-psychotic medication he was prescribed, but it was not effective:

*And so then they gave me some medicine and told me it would get rid of it, but they only just kept getting worse and worse and worse...until a week or two later, it was virtually non-stop, these two guys talking to each other about me.”*

The medication had no effect on his voices, if anything, they became more frequent. It did two things which weren’t helpful. Firstly, David put on a lot of weight as a side-effect of the medication:

*“The doctor said the drugs would work in 4-6 weeks and all they did was like make me fat and that’s the only thing they did.”*

Secondly, apart from hearing voices, David had always heard music. This was a very normal experience for him and he didn’t realise that other people didn’t experience the same thing: he thought that is what people meant when they said ‘I have a song in my head’:

*“They did one thing though which I didn’t know at the time. When I went into the original time...I said I hear music, it’s like I’ve got an iPod on. And they said that’s not what everyone else has. Cos I started hearing music when I was about 14 or 15 and I just assumed that everyone had it and when someone said ‘I’ve got a song in my head’ I thought that’s what they meant...it had never worried me or anything like that. And the drugs did get rid of the music, which was bad, because I liked the music....and I just had the voices left.”*

He went back to the psychiatrist, who increased the dosage of his medication. He trialed the increased amount for a couple of weeks as advised by the psychiatrist, but unfortunately, it still didn’t work for him. He went through the same process with a second drug, which also didn’t work. Eventually, David put his foot down and said he would agree to take only a low dose of a third drug. This was also not effective; however, he continued to take this low dosage in case it was doing something. David put a great deal of effort into trying to make sense of what was

happening to him. He pushed himself to read information about hallucinations and schizophrenia despite finding it very difficult to concentrate:

*“I read absolutely everything I could. I couldn’t concentrate, so it was really hard, but I found if I put in ear-phones, it blocked it out, so I could read a little bit.”*

All the information he found was very negative in terms of prognosis and focussed on treatment by medication:

*“I bought every book on Amazon I could find on schizophrenia and went googling and everything and all the drugs and stuff. And it was just all, ah you’ve got a brain disease and drugs fix it.”*

David put a great deal of effort into trying to understand his experiences and wanted to be able to talk to someone about it. In his case, his need to talk about his experiences was not met through seeing his psychiatrist:

*“He didn’t talk to me much about what was going on. I say I’ve got voices, there’s two guys talking and he sort of said ah yeah, that’s early stage of schizophrenia that you’ve got and take these drugs and that’ll fix it. And that’s about all he said. He didn’t really ask what was going on with anything, just said take these drugs and they’ll fix you up.”*

David also only saw his psychiatrist for ten to fifteen minutes every two to three weeks. Overall, David found going to a psychiatrist to be unhelpful. He also questioned whether he really had schizophrenia or not, because from reading the diagnostic criteria, he felt that he only experienced auditory verbal hallucinations. He explained that while he developed paranoias, these were related to worrying that he was acting weird because of his voices, for example, talking back to them without realising, or that other people could tell he was hearing voices and judging him negatively for it.

*“When I was reading all the books, I really only had the voices. And all the other little things like the paranoias were all related to the fact that I had the voices there and I was worried that people knew and could tell that there was something wrong with me and things like that. So all the other stuff about paranoia and all that I didn’t really have, so I was like, ‘I don’t know if this is what I’ve really got, maybe it’s something else.’”*

The idea that David’s experiences were due to a degenerative brain disease – which was the explanation provided by the psychiatrist and in textbooks he read – increased his anxiety and made him feel hopeless for the future:

*“It made me really depressed and really scared ‘cos it’s like I thought, this is just the start, it’s some degenerative thing that’s going to keep getting worse and worse.”*

It was particularly difficult for David given that the medications he trialled hadn’t worked, because this is the only treatment for his voices that he had read about at that time.

David started seeing a psychologist and a social worker, both of whom he found helpful. Importantly, he was able to talk to both of them about his experiences. The social worker helped him to get back to work, which was very important to him. Through working with her, he developed a lot of diversional techniques, which helped him cope on a day-to-day basis. This was especially important during the first year after his diagnosis. He used relaxation to help him cope at work. If he noticed he was becoming tense, he would take a couple of minutes' break and breathe deeply.

*“The social worker was really good. Same thing, someone to talk to, just getting a different view-point on things. And it was good like I was saying you get the little diversion type techniques. And if your voices are getting too loud, de-stress type stuff, which was really good at the time, ‘cos it helped me get through periods at work and I’d be sitting there and they’d be yelling. I couldn’t answer my phone because I couldn’t concentrate. So I’d have to go outside and I just breathing slowly, relax, “alright, go back in now”. It definitely helped me get through the first year or so...just the day-to-day living of the first year.”*

David saw a psychologist for about a year after he became unwell. Through talking to her, he learned how to step back and evaluate whether the negative, critical things his voices were saying about him held any validity:

*“I got to talk about things that I don’t talk to anyone about and it was good, she talked me through the fact that I wasn’t lazy and – because after they keep going for a while you start thinking, ‘well maybe I am, maybe I should be doing more’. And because they’d get louder when I wasn’t doing anything, I’d think ‘maybe I am lazy, I should be back, maybe I should go back to studying or something’. And then the psychologist talked me through why I wasn’t lazy and why they weren’t right and helped me with not being so depressed and helped me with my self-esteem a little bit.”*

David was determined to get back to work. However, he had difficulty travelling in to work by train because he started to worry that he was behaving strangely and that others were noticing this and laughing at him or judging him negatively. His therapist’s feedback about him was very helpful in this regard, giving him some reassurance that he was behaving in a normal way:

*“She told me ‘you’re not acting weird, you’ve been coming here for six months and I’ve never seen you act weird. So there’s no need to worry about it, no one can tell that there’s something wrong with you and even if they could, who cares? It doesn’t matter’. And I thought OK.”*

David started pushing himself to travel by train to work. He would stay on the train for one or two stops and then get off and wait for the next one, then get on again for another couple of stops and get off again. His anxiety about people judging him negatively gradually subsided. Eventually, he was able to stay on the train for the whole journey.

David’s psychologist also recommended that he start practicing meditation, which relaxed him and helped to improve his concentration:

*“My concentration is absolutely awesome now....I just pushed myself over and over again for like over a year – pushed myself, pushed myself, pushed myself....There’s a couple I used to do – I used to stare at a candle and just concentrate on that as long as I could...and I’d do the one where you sit there and you try to think of nothing and if a thought pops in your head you push it away and start again. And the other one I did where stuff just floats around and you just go ‘well, there it is, don’t worry about it’. So I did a few, I read so many books about how to meditate and watched so many YouTube videos. Yeah, I got pretty good at it.”*

Eventually, he got used to functioning and being able to concentrate even when he was hearing voices:

*“It relaxed me and because I was focussing, say I’m doing the one where I’m focussing on a candle, and the voices are going but it’s kind of like, it doesn’t matter. I’m concentrating. And that sort of, I explained it to my mum...it’s like living under the flight path: at first you hear the planes and they’re so annoying and so loud, but after a while you just get used to it, kind of they’re just there.”*

During these initial months after he became unwell, David was working part-time. But with the increase in the frequency and volume of his voices, it became almost impossible for him to concentrate:

*“And so once it started getting to the point that it was virtually non-stop, I was incapacitated, I couldn’t concentrate or anything. It was becoming really scary and really really annoying.”*

David took a less stressful position at same workplace and cut down to part-time hours. This allowed him to maintain an income and some routine in his life. He didn’t know anyone in his new department. Some of the people he used to work with knew what was happening in his life, but his new colleagues and boss were unaware of exactly what had been going on for him, just that there was something “wrong in (his) brain.” David was worried that he was doing strange things without realising it. On top of that, because his new colleagues hadn’t known him from before, he was worried that they were judging him negatively, thinking that he was a weirdo. He felt that he had to hide things from people, which he didn’t like doing. All of these things created an immense emotional burden:

*“For the first six months or something at the new job, some of the old IT guys knew what was happening, but at my new job, no one knew I why I was sick. I felt like I was hiding things and I wasn’t sure if they were thinking I was acting strange or – because like I said I couldn’t really tell. So I thought I might be acting strange, no-one’s going to say anything, because I’ve been, probably since I’ve started with them I’ve probably been acting strange, so they probably think I’m a weirdo or something.”*

Because of David’s worries about how he was acting and how others saw him, he tended to interpret ambiguous situations which could have been benign or not related to him as potentially indicating negative judgement from others:

*“I was really worried...like I said if someone’s laughing, I thought that someone from HR had told them I had a problem and they were laughing because I had a problem.”*

He was really worried that he would lose his job because he was acting strangely and people didn’t know why:

*“I kept thinking ah they’re going to sack me, they’re going to get rid of me.”*

Despite being reassured by his psychologist that he had shown no signs of becoming violent, David still feared that he would harm someone:

*“I still at the back of my mind was thinking this could get worse, like just one day snap and do something cruel or something to someone.”*

His worries and the sense of having to hide things were a great emotional burden. David weighed up whether to tell his colleagues and boss about his mental health difficulties. After around six months back at work, David’s confidence was improving. He decided that he didn’t want to carry on having to hide things from people and be in a constant state of worry. He decided to disclose his diagnosis to people he worked with:

*“I pulled everyone at work who I deal with – like my bosses and my co-workers. I said look this is what’s happening, I’m hearing things, I’ve got schizophrenia, but I’m working on it and if you see me doing anything strange, please tell me, please pull me up and let me know. Yeah that was the first thing I did when I got more confident was tell people at work.”*

He knew before disclosing his diagnosis that they may respond negatively. But he had come to a point that he could not tolerate the sense of constantly hiding something from his colleagues and worrying about what they thought about him. He had a plan in place for what he would do if they responded negatively, which was to try to get a job through an employment agency for people with disabilities. Fortunately, his colleagues reacted very well:

*“They were really good after that. After I told them if needed leave just take it, which I did take a lot of days off. It was good to know that people cared ‘cos or that they cared enough to ask how I was and things like that....But it was good to know that people cared, really good. And that there were maybe two people out of, I told about – grabbed about 15 to 22 people – maybe two who stopped talking to me. I don’t know why they did. They were probably scared I was going to freak out or something.”*

David’s boss also responded really well:

*“But what I didn’t know was my boss who I got transferred to actually had a psychology degree, so he was really good. And my boss was a really good guy and would always ask how I am.”*

David emphasised that recovery was not just about learning skills and techniques to cope with distressing voices. Instead, it involved a significant change in his lifestyle overall:

*“They say recovery is living with the voice and being able to control them a little bit and things like that. That’s not really total recovery for me, ‘cos it’s not just go to a social worker and read all this stuff and a lot of it is diversions and things. A lot of it is changing your life. It’s no use if I’d gone ‘alright I can handle the voices, I’m able to work, let’s go mad and work all day and all night’ and then have another break-down. So it’s about changing, not only being able to live with the voices but changing aspects of my life which were pretty bad before with work...they weren’t moderate before...I was an extreme person. I was an extreme person. So yeah, it’s not just about living with voices. It’s about changing things about me which weren’t right before and probably caused it. And one of those it just being concentrated totally on what I need, and so that’s – I need money, I need a promotion, so I’d just work non-stop.”*

All of these things happened within the first year after David started hearing voices. After the first year, things evened out. Importantly, he started to be able to recognise when the voices were going to get worse:

*“Basically when I could tell what was about to happen with them, that’s when it got a little bit easier.... You can tell, when they start their volume and frequency rises a little bit. Whereas in the first year or so, they’d get loud and I’d be like, why the hell did that happen? But now they get a little bit loud and I think, alright what’s causing this, what, why are they getting louder? Am I stressed out? Am I bored? Am I doing something that’s causing this to happen?”*

Being able to recognise these minute changes was key to his recovery, because once he was able to identify when they were getting worse, he could reflect on why that might be and do something to help alleviate what was causing it:

*“So I can kind of tell now, they start raising and I start looking around, well what am I doing that’s causing them to get louder, what am I doing that’s causing them to yell. So I’m thinking well maybe I am a little bit stressed, I might duck out for a smoke or something...”*

David became exquisitely finely attuned to minute changes in their volume and frequency:

*“It’s like – have you ever tried to speak Chinese? Like they’ve got ups and downs...the words have ups and downs in them. And when they’re talking, you don’t even realise that there are ups and downs and all that. But once you learn a little bit, you can tell ah that’s gone up. Yeah, it’s like grabbing a little knob on the radio, ‘vroom, vroom’, and it changes just a little bit up there, if that makes sense...I can notice the little tiny changes. Whereas before I’d go from just ‘I’m alright’, to ‘Ah! They’re yelling’, now I notice little minute changes in them.”*

Through being attuned with his voices, David could identify when he needed to do something to stop them from escalating. For example, if his voices increased and he realised that he had too much work to do, he would ask another team member to help him. Or if he was worried about a problem that he needed to solve for someone, instead of worrying about it, he would take a break, step outside for a moment and think about how he wanted to tackle it.

Being able to manage worry better has been very important in David’s recovery. In the past, if he had a problem, he would ruminate about it and start to feel overwhelmed:



*“I used to worry about everything. I’d have like five things to do at work and I’d worry ah I’m never going to get that done, I’m not going to get any of that done. Or things that wouldn’t be going right at home, set right at home, or with friends or whatever. And I’d be worried, sitting up at night thinking about it.”*

Over time, David came to deal with worry more effectively. This was key to his recovery. It brought down his overall level of stress and meant that his voices became quieter. It seemed that in the past, being generally anxious provided material for his voices to become louder and louder:

*“Now I’m more – if there’s a problem and I can fix it, then I’ll fix it, but I won’t worry about it. And if I can’t fix it then I’m not going to worry about it either....that sort of stuff would make them loud and yelly.”*

David changed his outlook on things a great deal and stopped worrying as much. His view of what his experiences meant started to change when he starting going to the hearing voices network. He started to meet people who had heard voices for many years and did not appear to be getting any worse. In fact, some of them seemed to be getting better. This challenged the idea that he had a degenerative brain disease and would inevitably get worse over time:

*“(I) heard about people getting better or recovering as they say, or just being able to live with it. I thought well those people had it for like ten years – they’ve been hearing voices for ten years – and they haven’t gone violent or anything, they’re not yelling at people in the street or homeless guy picking through rubbish or anything like that. They got better, their lives are better than it was ten years ago. That’s probably when I stopped thinking about it, I thought well it might be degenerative, but who cares? It might be degenerative, but they seem to be doing alright. So even if it’s degenerating they seem to cope with it, so....I felt a lot better about (the future).”*

Whereas before, David thought he would have to live with his parents for the rest of his life and not be able to buy his own home. He felt that even if he managed to save enough money for a deposit, he would not feel confident enough to buy a house, in case he became unwell again. Hearing about other people who had recovered through the Hearing Voices Network meant that he had the confidence to start planning positive things for his future:

*“When I sort of saw these people and read about people who had recovered, I thought I can start planning things now. I know that if I work hard and change things that are causing it to happen and basically if I push myself and work on it, then it’s not going to get worse...the worst of it is over, I can start planning my future now.”*

David explained that previously, even though he had progressed very well, the information provided by his psychiatrist when he became unwell still held a lot of weight and he thought he may suddenly become unwell again:

*“There’s security in knowing it’s not going to get any worse. Whereas before I had no security, I just thought, any day now I could snap again.”*

Attending the Hearing Voices Network groups and conferences gave David hope that he could recover to live full life, normalised his experiences and gave him a different perspective on how debilitating hearing voices was:

*“It helped me normalise it a little bit, ‘cos I was really, I was still thinking there’s something seriously wrong with me, other people don’t have this. And I went there and I realised this is not after being there a little while, it’s not such a big deal. Everyone has something wrong with them. It’s just a matter of I have voices, some other person may have a problem with drinking or with gambling or coffee or something. Everyone has something that they’re a little strange about...Especially when I went to conferences and heard other people talking about their experiences and how they got to the point where the voices weren’t an issue for them anymore, it’s just something that happens in their life and they manage it. And I started thinking there isn’t that much wrong with me, I’m actually pretty lucky that this is all I’ve got.”*

It also meant that he slowly started shifting away from an interpretation of his voices as a meaningless phenomenon caused by neurons firing abnormally to a view that they were meaningful and potentially helpful:

*“At first I thought it was just nonsense they’re talking about, I don’t know, I just think they’re talking nonsense. At first I didn’t pay attention to what they were saying, I thought it was just a bunch of neurons in my brain firing and they’re just making them say gobbeldy-gook, just stuff that doesn’t matter. I went to the group for a little while and then they had a couple of presentations with people and they all talked about their own experiences and I read a couple of the books published on it and people were talking about having meaning in the voices and things like that.”*

As David progressed in his recovery, he came to interpret his voices as trying to communicate something potentially useful to him, but in a strange way. He first started to think this way when he started attending HVN groups. During group meetings, the possibility of voices communicating something helpful, albeit in a sometimes frightening way, was discussed:

*“When I thought about it I thought there probably is meaning there, it’s just they’re saying differently in the way that you would normally say it.... I think they’re trying to tell me things, they just tell me in a strange way.”*

David learnt to take what the voices were saying and make small changes in his life distilled from what the voices were saying. For example, when they talked incessantly about how lazy he was, he worked with his therapist to challenge what they were saying, but also kept going to work. He also made some other changes in his lifestyle, including exercising a bit more. Today, while David still tends to think he could work harder and do more exercise, his voices only occasionally comment that he is lazy. Recently, David turned his attention to saving his money to buy a unit. In order to achieve his goal, he has to be careful about how much money he spends. His voices have started talking to each other about how stingy he is with money and encouraging him to give his money away. However, instead of acting on their suggestions or becoming very upset, David has considered whether or not he is really being stingy with money and decided to sponsor a child. This means that when his voices accuse him of being tight with

money, he can think about the facts of the matter and know within himself that he is not stingy. In a tangential way, they give him material to reflect upon and then make his own decision about what to do. The voices don't control this process:

*“They don't control what I do. The voices don't have any control over what I do; they don't make me do things...They're trying to get me to give away my money, but I'm not going to do that. And I thought, well I've done my exercises, pushing myself to get to work, doing my exercises and stuff and they stopped saying I'm lazy. Maybe if I like be a little less stingy with my money, not give it all away, but maybe if I maybe give 20 bucks a month to charity maybe they'll leave. But it's the same as when they were saying I'm lazy, when they're saying I'm stingy I go well, I am pretty stingy, 'cos I've been saving to buy, since I started working, maybe a year after I started working in my current job in the (name) department, I've been saving to buy a unit. So I don't spend anything more than I need to spend. So yeah I am pretty stingy with money. But now if I see a homeless person I'll chuck in 50 cents. I do sponsor a child now, so I know it's not true, I'm not stingy with my money, I'm helping people out a little bit so...they're still talking about it, but it's not true, so it's not a worry to me.”*

David also attended an HVN conference where Marius Romme and Sandra Escher were presenting. At this time, he had read a lot of material about living with voices and stories of recovery, however, he still thought of eliminating his voices altogether as full recovery. During question time, he was able to discuss this with them. Through his discussion with them and reading stories of recovery, David define recovery as being able to manage his voices and live a full life which is different but not worse than his life before hearing voices, rather than eliminating his voices altogether. This definition of recovery was helpful because it validated the progress that David had made and changed the goal-posts for what he was aiming for. He now feels that he is recovered or close to recovered, rather than still having a long way to go:

*“Then they said that (eliminating voice hearing) is not necessarily the thing that you should be after. And I read the books again and I realised that it's kinda like, I'm doing the right thing then. I am coping, I'm able to work, I'm able to live my life not the way I lived before, I'm not as functional as I was before, but I'm able to live my life pretty well...it's is not any worse than it was, it's just different.”*

Through his experiences, David has changed something very significant about who he is and how he interacts with others. He has become more sensitive to the needs of others and more empathetic toward people who are having difficulties in their lives. He is no longer harsh in his judgement of other people, or, importantly, of himself:

*“It gives me heaps of empathy for other people too. Like I was saying, I used to think anyone who bludges off tax-payer money, anyone who's just sitting there on a pension who in my mind could work – and I didn't even know what was going on inside their head or anything – I used to think they were the scum of the earth. I just thought – and I'd see drug addicts out in the street and I'd think you're just total scum, you should be working. You're a real drain on society and things like that. Now, I see people and I rather than thinking you're just scum, I think about well I wonder what's going on in their head, I wonder why they're not at work, or I wonder why that guy is taking drugs. So I think more that way now than I used to, I used to be really harsh on*

*people....I'm a lot nicer than I used to be. I wasn't a mean person, I wasn't mean to the people I knew and liked, but I was very selfish and had very very high standards of myself. I would just be so pissed off if I didn't achieve what I wanted to achieve. Yeah I was really driven. Now I'm not so much – I still like to do well and that, but if I fail at something, it's not the end of the world, I'm not going to beat myself up about it, whereas before I would've, before I got sick I would have been really pissed off if something didn't go my way at work or at home."*

Because of these shifts, David is able to get along better with others and live in a shared house:

*"In a way it's been good that I got sick because I'm a lot less angry. And I live with my brother and one of his friends. I lived when I was young for about six months with some friends. I couldn't live with other people, like before, I'd be pissed off that they wouldn't do things the way I wanted.... So now I can live with other people and I'm fine with it."*

Overall, hearing voices and having to come to terms with dealing with them had a positive influence on his life. While David has not regained his previous functioning, he doesn't see his life currently as being 'worse' than his life before his voices started. He has gone through a transformation within himself and in his lifestyle that it seems inaccurate to compare his life before hearing voices with his life currently. Running HVN groups is only one example of the many changes he has made:

*"There's things I'm doing now that I would never have done before, like facilitate the group. I'd have never done that before, I wouldn't have even thought about helping anyone else out, I just thought about myself."*

Helping others has become an important part of his life:

*"I love it. 'Cos I'm doing something for other people, I'm helping out people, when someone new comes for the first time to the group I feel really good that I can help them out a little bit maybe and maybe give them some tips from my experiences, or just even in a lot of cases just talk to someone else, ask how they're going and what they've been up to and stuff. 'Cos a lot of the guys I don't think that happens for them, I think a lot of them live in a group home and they're sort of isolated from other people. So even just to ask how someone's week was and things like that I think is helpful. I feel real good about it, it makes me feel good."*

## APPENDIX I: Caroline's narrative

Caroline is the youngest of ten children born when her mother was 47. She was very close to her mother as a child and did not see a lot of her father, who was often at work. Caroline's mother died from cancer when she was ten years old. This had a big impact on Caroline, particularly given how close they had been. From the age of ten to fifteen she lived with her father, who she trusted and felt safe with. Sadly, her father died when she was fifteen. Caroline missed her father very much. She remembers feeling fearful after he passed away:

*“Children always feel safe with their mother and father, you know, it didn't matter that I had only my father for five years, I still believed him and trusted him....after (my father's death) I was missing my father – I just felt awful, you know, like just terrible fear and feeling unsure about the future or something...feeling unsafe or something, yeah.”*

After her father died, she went to live with an older sister, who never married. Caroline's sister was kind to her: she described her as being like a second mother. She explained though, that she did not feel that her sister was her real mother, and did not regain the sense of safety, security and trust in another person that she had with her parents:

*“After I lost (my father) I just couldn't trust anyone and I felt lonely... my sister and brother couldn't be my real father and my real mother. I could live with them and get more trust (in them), but they were just my brother and my sister, and not my real parents.”*

Apart from the loss of her parents, Caroline's childhood was very happy. After her parents passed away, she put a lot of effort into things she needed to learn, including how to live by herself, look for work, progress in her studies and make a good life. She was a good student and felt that she could be successful in life:

*“I just feel like my life was very successful, because....I'm quite good at studying and I could get a lot of successful things of life.”*

For a while, her hopes were realised. She did well academically, attended university and successfully completed a bachelor's degree. Following this, she spent eight months in a Buddhist monastery. She spent a lot of time alone, meditating. Previously, Caroline had been quite sociable, but by the time she attended the retreat she had started to avoid other people and was quite isolated. She had trouble sleeping and often climbed up the mountains surrounding the monastery at night. Once, she got lost in the mountains and did not sleep the whole night. The head of the retreat group was sent to look for her and eventually found her. She thinks that the monks knew that she had emotional problems because they noticed that she hardly spoke to other people. She spent a lot of time crying and remembers thinking *“I just feel like life is suffering, I shouldn't have been born...everything is suffering, just my thoughts, you know?”* Caroline feels that her illness started from this feeling of sadness. It was in this context, while meditating at the temple, that Caroline first heard voices. She heard the voices of monks talking, as if she were listening to them on a cassette tape. She heard four or five voices, most of them negative and *“probably telling lies”*. A lot of time the voices told her that she *“shouldn't do that, should do*

*this*” in a constant manner, which often confused or distressed her. Less frequently, Caroline heard helpful voices, which gave her advice consistent with Buddhist practice and told her to practice mindfulness, concentrate on her work, or to do her best. These voices made her feel calm. She strongly believed what they said to her, because they gave her sound advice:

*“I felt I believed them very much, because the good voices just tell me to get out of bad things, you know?”*

The voices frequently gave her instructions. For example, she heard a monk’s voice:

*“telling me to do this thing and that thing...(I started) thinking I heard what the monks said, just the monk telling me about Buddha teaching....during meditation or mindfulness or something.”*

Their instructions ranged from benign advice on how to follow Buddhist rituals, to more harmful instructions to verbally abuse members of her family. Her first response to hearing voices, the content of which was mainly centred around Buddhist spirituality, was to feel pride:

*“It made me feel pride about me learning special knowledge...I learned like the Buddha teaching...(as if I was) like the Buddha or something like that.... I felt grateful, I just..(I felt I was) over people, you know, I know the special spirituality, and I’m grateful... I was bigger... I looked down at people a bit. I felt I was over people, I just thought people were foolish.”*

However, the voices also gave her instructions to stay away from others, not contact people, not believe what others said to her, which made her feel unsure. For example, they would tell her:

*“Don’t contact that (person)”, “don’t believe that”, “don’t go there”, “get (away from) other people – don’t talk, don’t contact (them)...just stay with yourself, don’t believe anyone.”*

The voices’ comments functioned to isolate Caroline from those around her. Looking back, Caroline feels that it was at times when she felt alone that her voices told her to do *“not the right thing....to hurt people or do something to myself.”* Most frequently, they instructed her to verbally abuse family members. Caroline described a sense of losing herself:

*“When I was in trouble with hearing voices, I didn’t know myself... I lost my feeling, lost my self-knowledge.”*

When Caroline started hearing voices, she lost control of herself and behaved in a way that she would not ordinarily wish to behave:

*“With the voice telling me to do things I just lost my self-control... I behaved toward people...just aggressively.”*

While Caroline was not physically aggressive toward others, she was aggressive in the sense of holding herself above others, not speaking to them, and feeling she was special or better than them:

*“I was just thinking I learned spirituality...special knowledge, like the Buddhist teachings tell from the Buddhist book, and I was just thinking ‘I’m wise, I have good wisdom’, and I just looked down on people and just behave aggressively – I didn’t talk, I just watched and thought by myself....Just thinking people foolish...just look down them.”*

However, while one of Caroline’s main emotions was feeling like she was a special human, “like the Buddha”, who knew everything about people and didn’t need to connect with anyone, her sadness was always there. Her sense of specialness and rejecting attitude toward others overlaid constant sadness, loneliness and distress:

*“The thing is I always felt upset, I always felt sad....with my life, with my loneliness.”*

One of the worst thing about hearing voices, however, was not having any knowledge about them and how to deal with the experience. Caroline’s lack of knowledge was disempowering: it meant that she could not differentiate between “good” voices which told her to do things which were beneficial to her and those which told her to harm herself or others.

*“I couldn’t make some consideration about which ones were not good voices, (that) told me to do the wrong thing and I couldn’t control myself, I lost control... no one told me about the voices – hearing voices – and the problem voices...(they) distressed me and (said) untrue things.”*

After returning home from the monastery, Caroline went to see a psychiatrist and was prescribed a heavy dose of anti-psychotic medication, which led to side-effects, including eye-rolling, difficulty concentrating and feeling sleepy. She saw her psychiatrist fairly regularly, however, did not find the treatment helpful:

*“I think this was an unsuccessful treatment, you know, because the psychiatrist, the hospital...lacked the knowledge to promote to the people...The psychiatrist just let us talk, you know. ‘What do you feel, what happened last week, what happened last month, what are you doing with your study?’ Just normal talk.”*

Caroline explained that she did not gain any knowledge or understanding about herself through seeing her psychiatrist. She came to understand more about her voices and how to cope with mostly by herself, through trial and error. She learned by:

*“...getting lost and doing the wrong thing and learning from the wrong thing...getting back on track by myself, recovering by myself.... I learned by myself, and the bad voices and the good voices and which ones lie.”*

Caroline started to work but was self-conscious about the side-effects of the medication eye-rolling when she started work and felt that her co-workers were thinking negative things about her because of it (although now she thinks this may not really have been the case). With the support of her family, Caroline calmed down and had become less socially isolated. Subsequently, the doctor decreased the dose of her medication. Caroline found the lower dosage helpful in keeping her calm.

Once she had stabilised, Caroline got a full-time job and worked for a couple of years. During this time she continued to feel calm and had no major periods of low mood or distressing voice-hearing. Following this, however, Caroline decided to enrol in a Masters degree, which was a very demanding and stressful. During her studies, she was diagnosed with hyperthyroidism and other medical difficulties, including muscle fatigue. She says:

*“My eyes were yellow, my skin was yellow, and I think I was admitted to hospital.”*

She underwent liquid radiation treatment twice. The cumulative effect of being enrolled in a demanding course in context of medical difficulties took its toll on Caroline, who felt extremely tired:

*“I had no strength, I couldn’t hold on on the bus, I couldn’t climb up the stairs...my legs, my arms, they were just tired, you know? (I had) no strength.”*

On top of this, her family discussed her living situation and decided that she could no longer live with her brother in the city. One of Caroline’s sisters explained that her brother was too busy to look after her while she was physically unwell and that she would have to go to live with their other sister:

*“Yeah, she said I can’t stay with my brother because my brother is just too busy and can’t look after me well...and she just made decision move to stay with my sister...another one.”*

Caroline moved in with her sister in a smaller town. She started to feel down, and this had a negative impact on her studies. She did not pass all of her subjects. In contrast, most of her friends completed the course in two years’ time, and after they left university, she lost contact with them and became socially isolated. By the second or third year of her studies, her mood was very low and she had started to hear distressing voices again. She decided to stop her tablets without consulting her doctor. With the negative impact of her health problems, low mood and distress from hearing voices, Caroline considered withdrawing from her course. However, one of her lecturers supported her:

*“The teacher hadn’t had any student who couldn’t finish off the degree. She said “No no, not at all. All of my students need to get it” – the degree – and they just said to me ‘you have to come to my office every day, sit beside me...and do your work. She supported me. At that time she didn’t know I had mental health illness, she just know I had a lot of health problems...”*

With the help of her lecturer, Caroline continued to study part-time and completed her Masters degree. At this time in her life, Caroline felt bad about herself. Although she had always been a good student and felt she had the ability to succeed, she did not achieve the success she had hoped for. She tried and tried to find a way out of her situation, to change her life, but couldn’t. In the end, she felt like everything was hopeless:

*“When I got the mental illness I just felt unsuccessful, I felt like ‘I can’t work, can’t study’; I feel ‘Oh, what happened to me is very unlucky’ and that it shouldn’t have happened to me. I just feel*



*very – what you call it – useless. You know....not (helping others)...I felt hopeless - everything was hopeless.”*

She felt extremely isolated and had no friends to help her with her problems:

*“But when (people) have no friends, no support and they have a lot of problems in life, something just falls down, you know. Just fail in life and just ‘bang’, just like that.”*

Immediately after passing her Masters degree, she started a practical placement, however, was unable to pass due to her mental health problems interfering with her functioning. She was failed from the placement after six months:

*“I just felt down and felt upset...and I was just thinking I’ve lost my ability and just felt like ‘I can’t work anymore”.*

This was in stark contrast to how she felt when she finished her bachelor’s degree:

*“After I finished my bachelor’s degree I just felt ‘oh, the world is wonderful’, you know. But contrast that with when I graduate my Master degree...(I felt) life was in the bottom of the mountain, you know? Lack of support, lack of knowledge...I just felt sadness... I couldn’t work, I couldn’t have happy times; I just felt down.”*

She had negative thoughts about herself, struggled with being able to differentiate between ‘true’ and ‘untrue’ voices, and experienced significant side-effects from the medication prescribed to her by her psychiatrist:

*“At that time I still feel mixed with the true and the untrue and a lot of side-effect of medication killed my confidence.”*

She felt disappointed with her occupation because she felt she was unable to succeed after she became unwell:

*“I was very upset with my occupation because I’m lost my success after I’m got the mental illness.”*

Caroline’s psychiatrist focussed mainly on medication and did not help her to understand her experiences. As a result, she felt abnormal:

*“The psychiatrist didn’t give me more advise, you know? I still didn’t understand about my voice-hearing and I just felt like ‘I’m abnormal’ ...Sometimes I just felt like “Oh, I shouldn’t be like that, I shouldn’t be like this” and I just had negative feelings about myself – about my life – and I just felt like ‘ah, I’m unsuccessful’, like yeah, I didn’t feel good about life...and I just felt bad and unlucky or tired...I had a lot of side-effects. A lot of time I felt sleepy and couldn’t concentrate during the day.”*

It took at least one year for Caroline to find another job. Fortunately, Caroline was happy at her new workplace, and she started to feel better. Caroline explained that after she got a job that she really liked, she *“recovered, yeah, and my life it just got better.”* She continued to work at the same organisation for 4 years, only leaving when she decided to immigrate to Australia with her husband. She recovered faster from distressing voice-hearing the second time she became unwell. Caroline explained that this is due to many things. Firstly, she was living with her sister and her nephew and nieces, two of whom were studying medicine or nursing and *“knew about human problems and supported me”*. Her nephew and niece talked to her and helped her to cope with her voices:

*“I know a family member is really helpful, because I just tried to believe people around me and I tried to talk about my problem voices and about hearing voices to my sister, and my youngest niece said “ don’t think too much, don’t believe it” or something like that....Yeah, I recovered, I got better.”*

Finally, Caroline’s medication was helping her to keep calm. She was still able to seek out activity and do things to make her life good. In contrast to the first time she became unwell due to distressing voices, she felt there was hope for her future, that she could get something valuable of life, and that she was a valuable human being with a contribution to make to others around her.

*“I am valuable.... I’m a valuable human, I’m full of resources, I was born to (give some) benefit to the community and benefit others...”*

It is difficult for Caroline to explain to other people how she has come to be able to deal with her voices:

*“I have a friend... she asks me about how I can deal with the voices. I just tell her, I can’t explain my voices to other people, because they didn’t understand my voices....I can understand my voices and learn with them and deal with them all the time.”*

Similarly, she finds it difficult to identify the voices and tell others which ones are ‘good’ or ‘bad’:

*“I can’t tell people I hear this one or this one is the good one of them or this one is the bad one of them.”*

Overall, though, Caroline used trial and error to find out how to cope with her voices. As any one of her voices may sometimes say helpful things and at other times advise her to do something harmful, it was not possible to discount everything a particular voice might say. Caroline started to ask herself whether the voice’s comments were in keeping with Buddhist practice or not. For example, if it told her to be impolite to others, she would conclude that the voice was lying, as this is against Buddhist principles of not harming others. Today, if a voice is telling her something emotionally harmful, she respond to it saying “you’re lying today”. She also used mindfulness to help cope with her voices.

She also had discussions with other people in the temple she attended who had similar problems to hers. These group discussions were helpful and allowed her to increase her understanding of voice-hearing. Caroline emphasised, however, that everyone's experience of voice-hearing is different, and her understanding of voice-hearing and strategies that work for her may not apply to other people:

*“We can't tell them to stop, because for a lot of voices it is just their own experiences. We can't change anyone, you know. The only thing is we can change ourselves – we can (teach) people from other people's experiences...but we can't tell people (how) to think about things...the thing is they need to learn by doing it by themselves. We can share knowledge, we can share knowledge and give some opinion (about it), but it depends on them to decide what they believe, make their own opinion or make their own decision...to believe us or not....it is just like a child..you know? They learn by doing, they learn to consider (their experiences) and they just learn how to share their feelings and their thoughts...Yeah (this is) my story, some things that work for some do not work for others...we all have our own experience, no one can understand us same as us ourselves...I can't say (the voices) are untrue, it's not real, to other people with the voices, because...it just depends on how long they've been dealing with the voices and how much experience they have. Same as me”*

After she moved to Australia, Caroline's understanding of her past mental health difficulties increased and she started to tell more people about it:

*“At the time I didn't tell people much, but after I moved to Australia I understood myself, I understood about my mental health problems in the past... and I just know that hearing voices makes people get lost.”*

In Australia, Caroline attended group discussions through the Hearing Voices Network. These allowed her to deepen her understanding of her own experiences and contribute to helping others. She explained that in a group discussion, people can change their experience by hearing about other people's voice-hearing and learning from their experience and how they have recovered. Caroline said more workshops and dissemination of knowledge was needed to help voice-hearers who are struggling with their experiences. She sees a role for research in this area:

*“You have knowledgeable people to tell you (about it) and probably some guidelines from the study tell what happen to long treatment or right treatment or a problem with bad voices and good voices and helping them to recover right on track.”*

Looking back, Caroline thinks a lot of things would have helped her to recover better and more quickly. Firstly, she emphasised that knowledge about voice-hearing and having someone to help her discern which voices were telling her the truth and which were not, would have helped her a great deal.

Apart from family members, she also sees medical professionals as a potential source of this kind of help and would have liked to have had a discussion with her doctor or psychiatrist about her voices.

*“If I had someone guide me about my voices – that one is not true, this one is true – or, if I had a good discussion about hearing voices, or talking with the psychiatrist about make understanding about my voices, or something make me clear about this, I probably get recover faster.”*

She also felt that being prescribed the right medication – i.e. medication which would calm her down but not lead to significant side-effects – would also have helped her.

*“I just needed some knowledge, the right doctor, the right medication...to make me calm and make me recover more quickly.”*

Today, Caroline is proud of herself and what she has achieved and sees herself as a valuable human being with a contribution to make to others. What makes her achievements particularly meaningful is the amount of effort that she had to put in to get where she was going. She had to have more patience and fight harder for what she wanted for her life than people who have not faced as many challenges. Having achieved the things she has in her life, she feels not only that there is hope for her, but that there is hope for other people with similar difficulties:

*“You know something people just have more difficulty in life, (but) they can get something of success of life too....because they have more patience, they just have more effort for their life, because they just feel like they fight a lot in life....to reach to the purpose of life and they just feel like they’re wonderful, they’re excellent.”*