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

A narrative inquiry

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Acknowledgments

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Contributions of the Candidate

The research presented in this thesis represents original work undertaken by the Candidate, in conjunction with the School of Psychology at the University of Sydney and the Hearing Voices Network NSW. Ethics approval was granted by the University of Sydney Human Research Ethics Committee (see Appendix A). Approval to advertise the study and use rooms at the O’Brien Centre, St Vincent’s Hospital, Darlinghurst, was granted by St Vincent’s Hospital Human Research Ethics Committee (see Appendix B). Finally, the Hearing Voices Network NSW granted permission for the researcher to attend some groups, with the permission of group members, to discuss the research project and provide an opportunity for potential participants to ask for more information if required.

The Candidate was responsible for coordinating the research under the supervision of Dr. Paul Rhodes (Clinical Psychologist and Associate Professor, University of Sydney) and Dr. Mark Hayward (Clinical Psychologist, Director of Research at Sussex Partnership NHS Foundation Trust and Visiting Senior Lecturer at University of Sussex, Brighton, UK). The data were collected and analysed by the Candidate. The Candidate took primary responsibility for all aspects of the research presented in this thesis. The candidate wrote this thesis and maintains chief responsibility for it.
Statement of Authentication

This thesis is submitted to the University of Sydney in partial fulfilment of the requirements of the degree Doctor of Clinical Psychology/Master of Science (DCP/MSc). The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

30/04/2014

________________________________________  _______________________
Adèle de Jager                                                                 Date
Abstract

There is evidence of both clinical and personal recovery from distressing voices. However, the process of recovery over time is unclear. The overall aims of this thesis were 1) to produce a systematic review and synthesis of existing studies employing narrative inquiry to examine the process of recovery, across disorders and 2) to investigate recovery from distressing voices using narrative inquiry and to use this to critically appraise Romme et al.’s (2009) notion of recovery. Results of the systematic review indicated the following processes were implicated in recovery process across studies: rebuilding a positive sense of self and identity (including agency, self-worth), hope, occupation and activity, acceptance and support, contributing / helping others and making sense of or reframing experiences. Participants emphasised that the recovery process was not linear, and involved integrating their experiences and a transformation of self. Narrative inquiry contributed uniquely to understanding recovery processes and was subsequently employed to investigate the lived experience of recovered voice-hearers. Results revealed two divergent recovery typologies emerging after a period of despair/exhaustion: 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 and wherein participants emphasised the importance of medication in recovery. Results indicate 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.
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Chapter 1

Introduction

1.1 Background

Voice-hearing is commonly experienced in the context of schizophrenia and other psychological disorders, as well as in the general population (APA, 2000; Beavan, Read & Cartwright, 2011; Choong, Hunter & Woodruff, 2011). Hearing voices is highly stigmatised and associated with poor mental health, distress, and isolation (APA, 2000; Ruddle, Mason & Wykes, 2010; 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). 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), while the latter emphasises living a “fulfilling and satisfying life, in the presence or absence of symptoms” (personal recovery) (Carlton & Bradstreet, 2006, p16; Slade et al., 2012). While evidence to date indicates that recovery from distressing voices – both clinical and personal – is possible, there a lack of research into the recovery process over time. While many first-person accounts of recovery exist and are valuable in and of themselves, 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 study addresses this gap in the literature, employing Narrative Inquiry to examine recovery and including quantitative and diagnostic measures.
1.2 Overview of the research thesis

Although there is evidence of both clinical and personal recovery from distressing voices, the process of recovery over time is unclear. The main objective of this thesis was to investigate the lived experience of recovery from distressing voices. Specifically, the primary aims of this research were 1) to critically evaluate the research evidence regarding recovery from distressing voices and examine various definitions and approaches to treating distressing voices 2) to produce a systematic review and synthesis of existing studies employing narrative inquiry to examine the process of recovery, across disorders, 3) to investigate recovery from distressing voices using narrative inquiry and to use this to critically appraise Romme et al.’s (2009) notion of recovery and 4) to consider findings in the context of existing literature and paradigms.

To address these aims, this thesis provides a review of the relevant literature (Chapter 2), includes a systematic review of studies employing narrative inquiry to examine the process of recovery from a range of psychological disorders, trauma and abuse (Chapter 3), presents the narrative inquiry study conducted by the Candidate (Chapter 4), and concludes with an overall discussion of the research findings, theoretical and practical implications, strengths and limitations and directions for future research (Chapter 5).

1.3 Thesis presentation

This thesis is presented as a thesis by publication. This format was chosen to allow for the inclusion of a systematic review and an empirical study, both of which contain their own introduction, method, results and discussion. It begins with Chapter 2, which provides a comprehensive background and rationale for the two subsequent chapters. Chapter 3 presents a systematic review of narrative inquiry into recovery from psychological disorders, trauma and
abuse. Chapter 4 presents a narrative inquiry study into recovery from distressing voices and is a reproduction of the following manuscript:


Additional information not included in the article submitted for publication is provided in appendices. This includes further information about participants’ voice-hearing experiences and two examples of the narratives produced.

Finally, Chapter 5 provides an overall discussion of the research presented in this thesis.

**1.4 Choice of research.**

I was first introduced to a psychological approach to understanding voice-hearing by Professor John Read while at the University of Auckland. He encouraged students to consider alternative perspectives through which this experience could be understood. As part of his course on psychosis, Debra Lampshire came to share her experiences with us. She was diagnosed with schizophrenia, which in her case included hearing very distressing voices. She shared with us her story and how she recovered over time. She still occasionally heard voices, however, her relationship with them had changed. Challenging their power and making sense of what they meant in the context of her life seemed to be a significant part of what helped her to do so. She had a very significant impact on me and how I thought about what it means to hear
voices. At the time she came to speak to us, she was employed as a mental health educator and led groups for other people struggling with their voices. Her story led me to question the notion that there was always necessarily a bleak outlook for people who are distressed by their voices and acquire a diagnosis. More is written about the impact Debra Lampshire had in my and Paul Rhodes’s article in the online journal, the Conversation, entitled *Beyond Madness*. Suffice to say that she and Professor Read opened up the possibility that voice-hearing may be meaningful in the context of people’s life histories and made sense of, much as many other forms of psychological distress. It struck me that I had not thought of it in this way before, having taken on a mostly medical model perspective. I had previously understood auditory hallucinations to be a symptom of mental illness best treated by medication and beyond psychological intervention. Noticing this led me to reflect on issues of power and how it is expressed through knowledge production and language, which were very much the focus of study in post-modern literature and philosophy at the university. It is not insignificant that people who hear voices and are part of the Hearing Voices Movement tend to reject the word ‘hallucination’, for example. Regarding the current research, the subjective experience of people who hear voices was not particularly well-represented in psychological research. I felt it was important to conduct research which privileged the understanding(s) of people who hear voices and to draw upon their expertise in recovery. This research was undertaken in the context of a post-graduate science degree which emphasised a scientific, modernist view of the world emphasising objective observation – and holding that objective observation is possible. In contrast, the research conducted draws upon a post-modern approach which allows for multiple valid interpretations and calls for a critique of the process by which knowledge is produced. Both stances have influenced how I think. Conducting this research meant holding the value of both in mind. It
also required negotiating some kind of accommodation between the two approaches so as to be allowed to carry out research of this nature.

1.5 Glossary

Auditory verbal hallucinations
Percept-like experiences which occur in the absence of an appropriate stimulus, which nonetheless possesses a compelling sense of reality, and which the person experiencing it cannot control (Slade & Bentall, 1988).

Recovery
While the notion of recovery and recovery-oriented service has become common in mental health services, its definition varies across paradigms and individuals. Andreson, Oades and Caputi (2003) and Schrank and Slade (2007) provide a useful discussion of the differences between service-based versus consumer-based definitions of recovery, including recovery processes and stages. The definitions used in this thesis differentiate between clinical and personal recovery, discussed below.

Clinical recovery
Clinical recovery involves an elimination of symptoms and a return to normal functioning. This definition is considered to be professionally rather than consumer-driven and is closely aligned with a medical model conceptualisation of recovery.
Personal recovery

Personal recovery is defined as living a fulfilling life, with or without symptoms. Anthony’s oft-quoted definition of personal recovery is as follows:

‘Recovery is a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.’ (Anthony, 1993). Identified components of recovery include hope, self-determination, establishing a positive identity, empowerment, connection, purpose, overcoming the effects of stigma and symptom management (Schrank & Slade, 2007). Stages of recovery vary from model to model, for example moving from a state of moratorium to growth (Andresen et al., 2003) or a state of dependence and being unaware to interdependence and awareness (Schrank & Slade, 2007).

Narrative inquiry/analysis

Narrative analysis is the analysis of text in ‘storied’ form (Riessman, 2005). Text is broadly defined and encompasses oral speech, film, literature and writing. In this case, the text is an interview transcript. 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. Researchers must organise information generated from narrative interviews and interpret it
(Riessman, 2005). Therefore, narrative analysis involves the researcher’s interpretation of the participant’s interpretation of their experiences. While some researchers differentiate between narrative analysis and narrative inquiry, they are used interchangeably throughout the thesis, following Riessman’s (2005) definition of these terms.

*Voice-hearing*

Term preferred by some consumers for what researchers and professionals usually refer to as auditory verbal hallucinations (see above).
Chapter 2

Recovery from Distressing Auditory Verbal Hallucinations or ‘Voices’: A literature review

1. Introduction

Auditory verbal hallucinations (AVHs) or ‘voices’ are perceptions of sound – specifically, spoken words – in the absence of an appropriate stimulus (Waters, 2010; Slade & Bentall, 1988). They possess a compelling sense of reality and often elicit an accompanying emotional response (McCarthy-Jones, 2012; Waters, 2010). Voices usually occur unbidden, are not under the control of the hearer and are perceived to be separate to internal mental processes (Slade & Bentall, 1988; Waters, 2010).

Historically, voice-hearing has been interpreted variously as evidence of communication with the divine – experienced only by those of a “quieter temper and sedate mind and such as we call holy and divine men” (Plutarch, cited in McCarthy-Jones, 2012, p20) – ancestors, demons, or as the result of a disease process in the brain (Beavan & Read, 2010; Waters, 2010). Differentiating between helpful and harmful voices and to whom this task should fall, has been debated for hundreds of years (McCarthy-Jones, 2012), a topic which will be discussed more fully in the body of the review.

Given the multiplicity of theories and proponents of theories – voices, if you will – commenting on the experience of voice-hearing, it appears prudent to step back and attempt a phenomenological description, in line with the notion that, “we know not through our intellect but through our experience” (Merleau-Ponty, 1962, p45). Following this, the rationale for pursuing an investigation of voice-hearing, rather than one of the mental health diagnoses it is associated with, will be discussed. The experience of hearing voices is not homogenous: it can
be terrifying, distressing, overwhelming, distracting; alternatively, calming, helpful, supportive, or imbued with spiritual or cultural meaning (Beavan & Read, 2010). It is perhaps not surprising that the effect of hearing voices on mental health is likewise broad-ranging. The relationship between voices and mental health will be reviewed, with a brief examination of factors which may mediate the relationship between them.

Medical, neurobiological, psychological and consumer accounts of voice hearing offer divergent views of the etiology and maintenance of distressing voices. Each offers a lens through which to view voice-hearing and correspondingly, how it should be treated. The tenets of each model will be explored, with consideration of implications for voice-hearers and mental health professionals involved in their care.

Definitions of recovery from distressing voices vary greatly between medical, psychological and consumer accounts, with the former focusing on elimination of symptoms and return to premorbid functioning, while the latter does not require either of these criteria, holding that recovery can occur in the presence of ongoing symptoms and emphasizing improved functioning, quality of life, self-esteem and increased autonomy. Differences between these models and implications for treatment will be examined.

Recovery is a personal process which unfolds over time. A method with the capacity to capture these aspects of recovery is therefore required. Narrative analysis is the analysis of text in ‘storied’ form which 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 (Riessman, 2005). In social sciences, the text in question is usually a transcript from an interview. Narrative methodology is particularly suited to examining processes that unfold over time and where the temporal and individual life context of participants’ experiences is of central importance (Hall,
2011; Oke, 2008). It is thus well-suited to capturing data concerning recovery. Finally, the methodology and aims of the study will be briefly explained.

2. Auditory Verbal Hallucinations or ‘Voices’

2.1 Definition, incidence and phenomenological description

Distressing auditory hallucinations (or ‘voices’) are considered first rank symptoms of schizophrenia and are experienced by 50% to 80% of people with this diagnosis (APA, 2000; Shergill, Murray & McGuire, 1998; Waters et al., 2012). Voice-hearing is also relatively common in bipolar disorder (20% to 50%), post-traumatic stress disorder (40%) and major depressive disorder with psychotic features (6%) (Baethge et al., 2005; Choong, Hunter & Woodruff, 2007; Longden & Waterman, 2012; Waters, 2010). Finally, general population studies indicate that a substantial proportion of people who hear voices are not distressed by them and are able to function at a normal level, with 10% to 40% of the non-psychiatric population experience voice-hearing during their lives (Beavan & Read, 2010; Waters, 2010). Conservative estimates indicate that 0.45% of the population are healthy voice-hearers (McCarthy-Jones, 2012).

There is considerable variation between voice-hearers in their experience. Voice-hearers may hear one voice or many, a group of voices talking or humming; voices may comment on the person’s behaviour, talk to each other about them, or enter into dialogue with them (McCarty-Jones, 2012). Voices vary in content, duration, loudness and clarity and may speak in the first, second or third person (Beavan & Read, 2010; Jones, 2008; McCarthy-Jones, 2012). Voice-hearers are typically able to identify their voices including their gender, approximate age and whether they resemble a social other known to them (Romme et al., 2009). Voice content is
often meaningful to the voice-hearer and ranges from helpful guidance to banal comments, criticism, instructions and commands to hurt themselves or others (Beavan & Read, 2010; McCarthy-Jones, 2012).

Voices may enter into a dynamic interaction with the voice-hearer, responding to the voice-hearer’s thoughts in an ongoing, responsive manner, similar to what may be observed when debating a topic internally. They may give commands such as “kill yourself”, or “brush your hair.” Alternatively, voices may call the hearer derogatory names such as “slut”, “stupid” or “boring”, which may literally or thematically resemble past experiences. Qualitative differences in voice-hearing have lead McCarthy-Jones (2012, p186) to propose a taxonomy of voice-hearing split between Type 1 (‘dynamic’) and Type 2 (‘static’), where dynamic voices appear to be responsive to the hearer’s thoughts and behaviour, while static voices are experienced as memory-like, either in that they are verbatim recollections of things people have said to them in the past, or in that the content is unrelated to their current thoughts and actions.

The content and form of hallucinations appears to be affected by culture as well as the hearer’s immediate environment. For example, Suhail and Cochrane (2002) coded any mention of hallucination or delusions in the progress notes of Caucasian British, British Pakistani and Pakistani patients. They found a higher degree of commonality between Caucasian British and British Pakistani patients than between British Pakistani and Pakistani patients. This may indicate that the hearer’s immediate environment has a more significant impact on the content of hallucinations. Given that staff making the notes are already engaged in an interpretive act to some degree – deciding what information to note and what to leave out and what language to use to describe it – results may be influenced by differences in mental health systems, training and staff between the two countries. In addition, beliefs judged to be normative in Pakistani culture
may have been judged delusional in the UK and visa versa. These issues aside, Suhail and Cochrane’s (2002) findings remain interesting.

Voice-hearers’ emotional response to their voice(s) varies within and between people such that classification as ‘negative’, ‘positive’ and ‘neutral’ responses typically employed in research may not accurately capture voice-hearers’ experiences (Beavan & Read, 2010). This issue aside, some people may have predominantly negative emotional experiences in relation to their dominant voice and mostly positive experiences in relation to another voice. Factors contributing to emotional responses to voices will be discussed further in the body of the review.

2.2. Justification for Single Complaint Approach: Why investigate AVHs rather than mental disorders they occur within?

Over the past decade, there has been a shift toward a single-symptom approach, largely in response to concerns regarding the validity of the diagnosis of schizophrenia (e.g. Bentall, 2003; Read, Bentall & Mosher, 2004). The concept of ‘schizophrenia’, like any other mental health diagnosis, is based on clinicians’ and researchers’ observations of clusters of symptoms. They are thus not discrete, objective phenomena. Clinicians do not always agree whether a given person has a particular diagnosis. In addition, symptoms sometimes overlap between diagnoses and one person may meet criteria for multiple disorders. This brings into question whether the disorders in question are truly separate constructs. Finally, it has been pointed out that the evaluative aspects of diagnosis – which involve the clinician’s values and subjective judgment – are often obfuscated, such that the patient perceives the diagnosis to be objective and beyond doubt (Engelhardt, 1980). Harmful aspects of (correct or incorrect) diagnosis, including resulting stigma, have been debated for some time (e.g. Shackle, 1985).
However, despite these and other difficulties with diagnosis, the need for a rubric through which to understand a particular individual’s psychological difficulties remains. Likewise, an operational definition of psychological difficulties is required for research purposes. Diagnoses also provide a short-hand method for clinicians to communicate patient difficulties. Thus, rather than abandon the endeavour of providing diagnoses altogether, attempts are made to refine them so as to ensure an adequate degree of reliability and validity.

However, diagnoses are not without their theoretical and practical issues and this is particularly true of schizophrenia. As criticism of the construct of schizophrenia is one of the main reasons for pursuing a complaint-orientated approach, it deserves some mention here. The symptoms required for a diagnosis of schizophrenia have changed over time with revisions of diagnostic categories (Bruinjnzeel & Tandon, 2011). Currently, however, a diagnosis of schizophrenia requires that a person present with two of five of the following symptoms with continuous signs of disturbance for at least six months:

1. Delusions
2. Hallucinations
3. Disorganised speech
4. Grossly disorganized or catatonic behaviour
5. Negative symptoms (affective flattening, alogia or avolition) (American Psychiatric Association, 2000).

Only one symptom is required if delusions are judged to be ‘bizarre’ or auditory hallucinations in the form of a running commentary or two or more voices conversing with each other are present. These symptoms must be accompanied by social or occupational dysfunction and not be better accounted for by schizoaffective or mood disorder with psychotic features or substance abuse.
It can be argued that, of all mental health diagnoses, schizophrenia lays claim to having the most chequered history. Since the inception of the term ‘schizophrenia’ by Bleuler in (1911) it has been fraught with difficulties. The poor reliability of schizophrenia diagnoses before the introduction of the DSM-III in 1980 is well-documented (e.g. Beck et al., 1962; Ward, 1962). On average, reliability studies at this time showed inter-rater agreement of 57%, which the authors note was lower for studies with higher ecological validity (i.e. those carried out in a clinical rather than research context) (Spitzer & Fleiss, 1974). More recently, Harvey et al. (2012) note that after the introduction of structure interviews and the comprehensive ‘best estimate’ method – which draws on multiple sources of information, diagnoses of schizophrenia made by doctoral-level educated researchers using structured interviews were stable over time and between researchers. They note, however, that there has been no shift in clinical practice toward using structured interviews. Thus it appears that while methods may be available to ensure adequate reliability in the diagnosis of schizophrenia, these are not routinely employed and thus, as noted by the authors, the estimate provided by their review is not ecologically valid and reliability in clinical practice is likely to be lower. In keeping with this suggestion, Whaley et al. (2001) compared clinical diagnoses as determined by patients’ medical records with two diagnostic processes administered by the researchers, based on DSM-IV and ICD-10 respectively and found weak, non-significant correlations (0.11 and 0.13, respectively) between either diagnostic process and the patient’s actual diagnosis.

Another difficulty reflected in practice is that the presence of voice-hearing in and of itself has come to be viewed as pathological by some practitioners and therefore schizophrenia may at times be diagnosed despite no significant decline in social or occupational functioning. Perhaps the most famous example of this issue in clinical practice is Rosenhan’s (1973) whereby
8 healthy non-voice-hearing participants presented to inpatient wards claiming to hear voices and reporting no other symptoms. All were diagnosed with schizophrenia or schizophrenia (in remission). Interestingly, their experiences were noted to be extremely disempowering, with their behaviour while in admission and unremarkable personal histories interpreted by staff as being indicative of mental ill-health.

In and of itself, questionable reliability poses a threat to the validity of the diagnosis of schizophrenia. Further examination of validity requires examination of symptoms, etiology, prognosis and treatment: with higher validity corresponding to high co-occurrence of the proposed cluster of symptoms, common etiology, predictive value of the diagnosis in terms of outcome and responsiveness to treatment (Bentall, 2006). Problems with the validity of schizophrenia can be traced back to Kraeplin’s proposed classification of psychotic illnesses into three discrete types: *dementia praecox* – a form of dementia occurring in young people – *manic depression* and *paranoia* (Read et al., 2004; McCarthy-Jones, 2012). As argued by Bentall (2006), the notion, assumed in this taxonomy, that there are clear differences between sane and insane and between types of insanity, is not borne out by empirical evidence. In fact, it appears that psychotic experiences occur on a continuum within the population (Tien, 1991), hallucinations occur in individuals who are not mentally unwell and symptoms overlap a great deal between diagnoses (Bentall, 2006). For example, hallucinations are known to occur in bipolar disorder, dissociative identity disorder, dementia, stroke victims, major depressive disorder with psychotic features and post-traumatic stress disorder (Waters, 2010). There is also some difficulty in differentiating between the negative symptoms of schizophrenia, major depressive disorder and side-effects of anti-psychotic medication (Barnes & McPhillips, 1995). Given the heterogeneity of symptom clusters in schizophrenia and their overlap with symptoms
schizoaffective disorder and bipolar disorder, it is not surprising that differentiating between them can be difficult. It is also difficult to differentiate between schizophrenia and schizoaffective disorder, with evidence that in reality, patients fall on a continuum between pure schizophrenia and pure schizoaffective disorder (Kendell & Brockinton, 1980). Further, Seedat (2003) notes some overlap in psychotic symptoms between schizophrenia and post-traumatic stress disorder (PTSD) and Picken, Berry, Tarrier and Barrowclough (2010) note a high incidence of PTSD in those diagnosed with psychosis. It appears that it is difficult to differentiate between people with bipolar disorder mania and those with schizoaffective disorder (Schotte et al., 2012) or schizophrenia (Lindenmayer, Bossie, Kujawa, Zhu & Canuso, 2008).

Indeed, frustration with the somewhat bizarre, nonsensical nature of the situation is apparent in Ellason and Ross’s (1995) comment that people with dissociative identity disorder appear to have more ‘schizophrenic’ symptoms than people diagnosed with schizophrenia.

Spitzer (1975) suggested three sub-types of conditions within which voice-hearing could occur, responding differentially to electroconvulsive shock therapy, lithium and major tranquillizers. However, as noted by Bentall (2003), only one randomized controlled trial testing this hypothesis has been conducted and it found no evidence to support this claim (Johnstone et al., 1988).

Further, one of the primary difficulties with the notion of schizophrenia is to be located in the diagnostic criteria described above, namely that it is entirely possible that three people with no symptoms in common may all meet criteria for diagnosis. This poses a challenge to the very notion of ‘schizophrenia’ as a meaningful category. To complicate matters further, there appears to be inadequate inter-rater agreement (0.45 or below) between clinicians regarding which delusions are ‘bizarre’ – which is problematic particularly given that schizophrenia can be
diagnosed if this symptom alone is present (Bell et al., 2006; Cermolacce, Sass & Parnace, 2010). This situation lead Bannister (1968) to assert that “Schizophrenia is a semantic titanic, doomed before it sails, a concept so diffuse as to be unusable in scientific context.” (cited in Read et al., 2004, p46). Further, the World Health Organisation (WHO) examined the actual occurrence of symptoms and found “no single ‘schizophrenic profile’” (1973, p350). Instead, clusters of symptoms which fell broadly into positive (hallucinations, delusions and thought disorder) and negative (grossly disorganized or catatonic behaviour, affective flattening, alogia or avolition) were identified.

While criteria for schizophrenia were updated in the DSM-III (1980), the primary issue that the diagnosis did not seem to describe a meaningful category, remained. In addition, ecologically valid studies of reliability – i.e. where diagnoses were determined in the same or similar way that they are in practice – showed little improvement from pre-DSM-III days (Bentall, 2006), leading Bentall to assert that “schizophrenia is not a useful scientific category and that for all these years researchers have been pursuing a ghost within the body of psychiatry.” (Bentall, et al., 1988, p318). In keeping with this, more recent factor analytic investigations have proposed two- (positive-negative) or three- (positive-negative-disorganised) factor structure of symptoms in schizophrenia (Brugnoli,Tarsitani, Mandarelli, Fini & Pancheri, 2008). As noted by Brugnoli et al. (2008), there is still no consensus as to the ‘real’ factor structure of symptoms of schizophrenia, with their review of factor analytic studies identifying a 5-factor solution on average (positive-negative-disorganised-anxious/depressed-excitement-hostility). For this reason, many researchers have suggested that research into the individual symptoms of schizophrenia – what Bentall (2006) has termed a ‘complaint-orientated’ approach – is preferable. Interestingly, rather than abandoning the concept altogether, some psychiatrists
have argued that schizophrenia is a heterogeneous disease and is more accurately likely to reflect a number of separate diseases (e.g. Bruinjnzeel & Tandon, 2011). The majority of existing research into voice-hearing utilises a diagnostic rather than single complaint approach. As voice-hearing is more prevalent in schizophrenia than other diagnoses, much of the research reviewed below, for example, in relation to the dopamine hypothesis, relates specifically to schizophrenia. However, research into voice-hearing in the context of other diagnoses or as a single symptom is mentioned where relevant.

2.3 Effect on mental health: Healthy and unhealthy voice-hearers

For those distressed by their voices, hearing voices is often debilitating, associated with poor social and occupational functioning, poor mental health and isolation (Ruddle, Mason & Wykes, 2010; Thornicroft, 2006). As previously established, however, that not all voice-hearing is indicative of being mentally unwell. This raises the question of what determines whether voice-hearing will be healthy or unhealthy: a question which has been debated over many hundreds of years (McCarthy-Jones, 2012).

Various explanations for voice-hearing and methods of differentiating between divine and demonic voices have been suggested over the centuries. This is examined in detail by McCarthy-Jones (2012), who notes that Aristotle proposed voices could arise from dreams or from misperceptions, with the less seriously ill being able to identify that they were hallucinating, while more seriously ill may act upon them. St Augustine based his differentiation on the source and form of voices, with voices heard externally or internally more likely to be demonic, while those which presented themselves as thoughts without words were divine (McCarthy-Jones, 2012). Plutarch suggested that Socrates was able to hear his voice due to
positive personal characteristics, such as having a pure mind, sedate and quiet temper and limited enjoyment of corporeal things (McCarthy-Jones, 2012). During the Reformation, the notion that each person was able to access biblical scripture and the word of God themselves, rather than receiving interpretations of the bible from a priest, took hold (McCarthy-Jones, 2012). This meant, of course, that voice-hearers could claim to have direct access to divine intention, which posed a threat to the authority of the Church. This problem was dealt with by some leaders by declaring that voices which said things not in keeping with scriptures were not divine and alternatively by persecuting voice-hearers who posed a threat (Joan of Arc may be one of the best known examples of this) (McCarthy-Jones, 2012). The struggle for who has the power to define healthy versus unhealthy voice-hearing is also evident in modern psychiatry. In both religious and psychiatric realms, it is clear that those seeking to define the experience are not impartial observers. This is not to say that they necessarily have bad intentions toward voice-hearers and in some cases, it is clear that they are actually well-meaning. Nonetheless, an examination of who benefits from religious or psychiatric definitions of voice-hearing and what effect these definitions have on voice-hearers in practical terms is vital.

More recently, Choong, Hunter & Woodruff (2007) argued that non-threatening and positive content of voices characterize healthy voice-hearing. With regard to content, this makes intuitive sense. However, it is necessary to tread cautiously before making assumptions about the link between content and distress (or lack thereof), as content has been found to be related to distress in as little as 30% of cases (Mawson, Cohen & Berry, 2010). With regard to the degree of threat a person experiences upon hearing a voice, a similar problem emerges. It is again, intuitive that a voice saying highly critical or derogatory things to the hearer, or commanding them to hurt themselves or others, may be experienced as more threatening. However, it appears
that again, while overall, omnipotent, threatening and malevolent voices are associated with higher distress, this is not always the case. The person may also have formed an association between hearing voices and negative consequences of this in the social world, for example, involuntary admission. Similarly, if their voices were heard in a religious or spiritual context and interpreted to have a figurative rather than literal meaning, then a voice which is powerful and intimidating may be interpreted in a less threatening manner. Finally, meta-beliefs about hearing voices, discussed above, are also relevant to distress (Beavan & Read, 2010).

In addition to these factors, hearing voices is a highly stigmatised experience, which results in discrimination, social exclusion and lowered quality of life (e.g. Thornicroft, Brohan, Rose, Sartorius & Leese, 2009). A significant proportion of people diagnosed with schizophrenia reported negative discrimination in both personal (making and keeping friends, intimate relationships, family relationships) and public (finding and keeping a job) domains (Thornicroft et al., 2009). Indeed, a significant part of the disability associated with distressing voices may be socially related (e.g., stigma, decreased social status and reduced employment opportunities (Morrison, 2001; Williams & Collins, 2002).

Goffman (1963) describes stigma as a characteristic possessed by an individual which makes them different to others in an undesirable way and which negatively affects their sense of personhood, reducing them to a “tainted, discounted”, less than whole, person. Stigma occurs at social, structural or individual levels (Livingston, 2010). Internalised stigma refers to the latter level, whereby individuals come to believe negative stereotypes held by society about people with a given characteristic which the person possesses, in this case, being mentally unwell (Livingston, 2010). Livingston’s (2010) systematic review and meta-analysis of 45 papers on internalized stigma found that internalized stigma was positively associated with symptom
severity and negatively associated with hope and empowerment. The direction of causality between these variables, however, remains unclear.

Stigma and hopelessness can also be perpetuated by mental health professionals, who continue to hold low expectations for improvement (Williams & Collins, 2002). Expectations of outcome have been shown to affect emotional and behavioural responses and thereby affect outcome in severe mental illness (Lobban, Barrowclough & Jones, 2003). Indeed, personal accounts of recovery have shown that finding the ‘right’ doctor, psychiatrist or mental health professional can be pivotal to recovery (Romme et al., 2009). There is also evidence that defeatist beliefs mediate the relationship between symptoms and social and occupational outcomes (Grant & Beck, 2009).

An issue related to internalized stigma is an individual’s self-esteem and view of themselves more generally. Qualitative data indicates that a loss of sense of positive identity occurs as a result of hearing distressing voices and becoming mentally unwell and that regaining this is part of the recovery process (McCarthy-Jones, 2012; Romme et al., 2009).

Finally, depressive symptoms, adverse side-effects of antipsychotic medication and lack of empowerment have also been found to contribute to patients’ quality of life (Brenner, St-Hilaire, Liu, Laplante, & King, 2011; Kao, Liu, Chou, & Cheng, 2011; Sibitz et al., 2011). For example, Kim et al. (2011) found that change in depressive symptoms in response to medication was the only factor which significantly predicted improved subjective well-being.

3. Medical, neurobiological, psychological and consumer accounts and treatment of distressing voices

3.1 Medical and neurobiological accounts and treatment
The predominant treatment approach to treating distressing voices is defined by the medical model, which categorizes them as a result of a disease process in the brain (Read, Bentall, & Fosse, 2009). Evidence for the notion that symptoms of schizophrenia occur due to a disease process will be considered. The dopamine hypothesis of schizophrenia will be examined, with consideration of evidence from imaging and autopsy studies regarding differences between the brains of people diagnosed with schizophrenia and controls.

The dopamine hypothesis of schizophrenia developed from findings that 1) antipsychotic drugs alleviated symptoms of schizophrenia and 2) the known action of these drugs was to block dopamine receptors (Howes & Kapur, 2009). The dopamine hypothesis – the idea that schizophrenia was caused by excess activity of dopamine in the brain – was inferred from these findings. It is worth noting, however, that originally, many researchers viewed these findings as indicative of the mode of action of antipsychotic drugs and not necessarily of the etiology of schizophrenia (Moncrieff, 2009). Indeed, a review of the evidence available in the late 1970s found that the dopamine hypothesis was not the only possible interpretation of the data (Matthysse, 1973). Nevertheless, the dopamine theory of schizophrenia, gained a strong foothold as a legitimate explanation of the aetiology of schizophrenia (Moncrieff, 2009). The dopamine theory of schizophrenia was refined in the early 1990s to state that underactivity in the frontal lobes accompanied by overactive dopamine system in subcortical, mesolimbic areas, were responsible for negative and positive symptoms of schizophrenia, respectively (Davis, Kahn & Ko, 1991).

A burgeoning interest in this area is evident in the sheer number of articles published since Davis, Kahn and Ko’s (1991) paper (Howes & Kapur, 2009). Evidence argued to confirm the dopamine hypothesis includes findings that more dopamine is released in the brain by
response to amphetamine in people diagnosed with schizophrenia, increased uptake of F-dopa (an index of dopamine activity), higher D2 receptor density identified by imaging studies, that stimulants can induce psychotic states in people with no previous history (Moncrieff, 2009). However, there are a number of significant methodological issues with the studies mentioned above.

Firstly, studies which compare the density and sensitivity of D2 receptors in people with schizophrenia versus a control group are confounded by the fact that receptors change in response to medication. Indeed, studies which have employed drug-naïve participants have found no differences between these groups – either in studies of F-Dopa uptake, dopamine release in response to amphetamine. The bulk of research also shows no difference on post-mortem examination (Moncrieff, 2009). Thus there is insufficient evidence to claim an a priori difference in the dopamine systems of people diagnosed schizophrenia.

Another problem with these studies is that variance due to confounding factors likely to systematically affect dopamine activity is rarely accounted for. Indeed, as pointed out by Moncrieff (2009), dopamine is known to be implicated in motor activity, attention, executive functioning, reaction time, pleasure- and reward-seeking behaviour and is released in limbic and cortical areas in response to stress, as well as some recreational drugs – notably, nicotine. Given than people diagnosed with schizophrenia are more likely to smoke and experience higher degree of stress in their lives – particularly during an acute psychotic episode – than the control group, these are potential confounding factors in any study employing a ‘schizophrenia’ versus ‘control’ design. Any differences in arousal, anxiety and motor activity would also need to be accounted for.
Further, if the dopamine hypothesis was valid, one would expect drugs which do not work on dopamine receptors to be less or completely ineffective for treatment of schizophrenia. However, it appears that studies which have compared benzodiazepines with antipsychotics have not shown the latter to be preferable, with benzodiazepines being equally or more effective in treating positive symptoms (Moncrieff, 2009). Finally, the suggestion that antipsychotic medication alleviates symptoms by dampening emotional responsiveness is given weight by the findings that opium was as effective as the antipsychotic chlorpromazine (Abse, Dahlstrom & Tolley, 1960). The finding that Clozapine, which has a reduced effect on D2 receptors and primarily affects other neurotransmitters, was effective for treatment resistant symptoms likewise calls into question the veracity of the dopamine hypothesis (Howes & Kapur, 2009).

Thus, existing evidence does not necessarily show that neuroleptic drugs alleviate symptoms of schizophrenia by reversing a disease process. Indeed, their effect on most people who take them, whether diagnosed with schizophrenia or not, is one of tranquilization – mentally and physically – and decreased salience of emotions. It is therefore entirely possible that they work through reducing the emotional response and arousal in response to hallucinations and delusions – what Moncrieff has termed a “drug-centred” model of drug action, as opposed to a “disease-centred” model.

Interestingly, Kapur (2003), while still adhering to the notion that dopamine plays a specific role in hallucinations and delusions, suggests that it functions to increase the salience of certain internal and external phenomena. As in existing cognitive models of positive symptoms, these salient phenomena are experienced as hallucinations, with delusions developing as an attempt to explain unusual perceptual experiences (see Bentall, 2003). While there are issues with the dopamine hypothesis, as discussed above, Kapur’s (2003) suggestion that “the
antipsychotics do not erase the symptoms but provide a platform for a process of psychological resolution” (p13) may hold true.

The fact that by 2009 only one study existed comparing the effect of drugs which dampen emotional responsiveness to antipsychotics bears witness to the extent to which the dopamine hypothesis still holds sway in contemporary conceptualizations of schizophrenia. It would be naïve to suggest that vested monetary interests of pharmaceutical companies have had no effect on this situation (see for example, Mosher, in Read, Bentall & Mosher, 2004).

Despite over 100 years’ investigation into the neuropathology of schizophrenia, the pathology hypothesized to give rise to symptoms remains elusive (Harrison, 1998). In addition to dopamine system differences, a number of other structural and functional differences have been suggested to exist between people diagnosed with schizophrenia and those not. A meta-analysis of MRI research with a combined total of 1,588 patients showed that people diagnosed with schizophrenia had significantly decreased volume in the amygdala, hippocampus and parahippocampus (bilaterally) and enlarged lateral ventricles (Wright et al, 2000). Likewise, Steen, Hull, McClure, Hamer and Liberman (2006) found decreased cortical and hippocampal volume and increased ventricular volume. These differences are often taken to provide evidence of a neurodegenerative process. However, a neurodevelopmental explanation for these differences is entirely plausible and is rarely mentioned in the discussion of such articles (with the exception of the Steen et al. (2006) mentioned above).

Further, a review which included research articles with employed a broad range of methods (CT, MRI, post-mortem and imaging studies) found that the only reliable difference was enlarged lateral ventricles and that this feature overlapped considerably with controls (Chua & McKenna, 1995).
Another issue is that many patients reviewed are not medication naïve and the observed differences may therefore be an effect of antipsychotic medication. Contrary to this notion, ventricular enlargement and decreased cortical and hippocampal volume have been identified in first-episode, medication-naïve patients (Harrison 1998). However, decreased gray matter volume has been found in the frontal lobes of people who are depressed and in the prefrontal and limbic regions of people who report a high degree of adverse, stressful life events (Ansell, Rando, Tuit, Guarnaccia & Sinha, 2012; Kang et al., 2012). Given the high rate of stress and depression in people diagnosed with schizophrenia, it is possible that these factors account for or contribute to the differences observed. Further, it is unclear how cortical shrinkage is functionally linked to symptoms experienced, such as verbal hallucinations.

Finally, Read, Perry, Moskowitz and Connolly (2009) showed that most of these differences are also found in the brains of people who have experienced traumatic events during childhood. Thus, trauma may change the developing brain in such a way that predisposes people to developing distressing voices. This interpretation of the evidence is in keeping with research showing a higher rate of childhood abuse in people who go on to develop distressing voices than the general population (Read, Agar, Argyle & Aderhold, 2003; Romme & Escher, 2006).

3.1.1 Effectiveness of antipsychotic medication

Regardless of whether the theoretical basis of the medical model is sound or not, if the treatment following from it is helpful, then one could argue it does not matter in practical terms. Thus, an examination of the therapeutic effect of antipsychotic medication, the mainstay of treatment for distressing voices (Lieberman et al., 2005) is required. The general consensus in psychiatric literature is that antipsychotic medication significantly improves positive symptoms
in 75% of cases (McCarthy-Jones, 2012). However, as noted by McCarthy-Jones (2012), evidence to support this claim is lacking. This is further complicated by the finding that papers funded by pharmaceutical companies are 4.9 times more likely to find that antipsychotic medication is effective in diminishing psychotic symptoms (Perlis et al., 2005 cited in Bentall, 2009). In addition, side-effects of antipsychotic medication remain a significant concern. Typical or first-generation antipsychotics are commonly associated with fatigue, apathy and extrapyramidal symptoms, including tardive dyskinesia and dystonia (Miyamoto, Duncan, Marx & Lieberman, 2005). Drowsiness, lethargy, inability to concentrate, lack of emotional responsiveness and motivation form a common cluster of side-effects of conventional antipsychotics collectively referred to as Neuroleptic Induced Deficit Syndrome (NIDS), which is difficult to differentiate from depression and negative symptoms of schizophrenia (Barnes & McPhillips, 1995; Lader, 1993). Atypical antipsychotics were initially marketed as having improved side-effect profiles compared to typical antipsychotics, with some researchers supporting this notion (e.g. Citrome & Volavka, 2004). However, while atypical appear to cause fewer pyramidal and ‘negative’ symptoms, they are associated with a host of significant health issues including increased risk of heart disease, significant weight gain, altered glucose and lipid metabolism and diabetes (Lieberman et al., 2005). Overall, there appears to be insufficient evidence to support the notion that atypical antipsychotics are superior to typical antipsychotics (Kendall, 2011; Turner & Horton, 2008). In addition, conceptualizing all atypical antipsychotics under one label may lead to a misperception that they have more in common with each other than they actually do, when in fact they are a heterogenous group of drugs with different side-effect profiles and efficacy (Turner & Horton, 2008). Understandably, side-effects remain a significant consideration in terms of compliance with prescribed medication. Buchanan (1992)
found that 50% to 75% of patients followed up over a two-year period had discontinued their medication, contrary to medical advice. Similarly, Lieberman et al. (2005) found that the majority of patients (64% to 82%) prescribed a variety of atypical antipsychotics followed up in the short term had discontinued their medication.

Importantly, research shows that after a certain point, increasing the dosage of antipsychotic medication does not result in any difference in symptoms (Which, 2004). This has implications for clinical practice in that one would expect medical professionals to be less likely to prescribe increasingly large doses in an attempt to control patients’ symptoms.

Treatment based on the medical model approach, aimed at eliminating symptoms such as auditory hallucinations or ‘voices’, focuses primarily on administration of antipsychotic medication (Drake, Bond, & Essock, 2009). Although such medication is a useful tool in treatment approaches (Frese, Stanley, Kress, & Vogel-Scibilia, 2001), there are significant negative side-effects associated with its use (Lieberman et al., 2005). Further, it is estimated that despite medication, up to 60% of patients diagnosed with schizophrenia continue to experience positive symptoms (Lindenmayer, 2000).

Treatment based on the medical model has been criticised for an overly simple, reductionistic emphasis on the biological basis of schizophrenia while giving little attention to the social context through which underlying genetic predispositions might be triggered (Read, Bentall, & Fosse, 2009). Excessive focus on biological processes and narrow definitions of recovery, at the expense of examining psychosocial factors and broader goals, can be harmful to patients (Fleming & Martin, 2011; Romme, Escher, Dillon, Corstens, & Morris, 2009). Harmful aspects include neglecting psychological treatment needs, providing a model of auditory hallucinations over which patients have little control and suggesting an inevitably poor prognosis (Deegan,
1997; Harding, Brooks, Ashikaga, Strauss, & Breier, 1987; Harrison et al., 2001; Morris, 2009; Romme, Escher, Dillon, Corstens, & Read, Bentall, & Fosse, 2009). For example, voice-hearer Eleanor Longdon describes the expectations set by her psychiatrist, “(My family) were told that I had a degenerative brain disease and they should prepare themselves for the worst as I might end up in a care home. I was told there was no hope, that there was nothing I could do apart from take medication.” (Longden, cited in Lakhani, 2009).

Importantly, various attitudes toward and beliefs about people with schizophrenia are affected by the causal explanation given for schizophrenia. However, there is some debate regarding which explanations (especially biogenetic versus psychosocial) produce more favourable outcomes in terms of decreasing stigma. Importantly, the view that psychotic experiences occur on a continuum in the general population, rather than in a dichotomous fashion, is associated with lower stigma (Wiesjahn, Brabban, Jung, Gebauer & Lincoln, 2012). In some cases, biogenetic explanations have been found to actually increase stigma (Wiesjahn et al., 2012). It appears that the biogenetic explanation is consistently associated with a decrease in attribution of blame. However, it appears that biogenetic explanations of mental disorder can also lead to more punitive behaviour toward the person affected (Mehta & Farina, 1997).

Interestingly, Lincoln, Arger, Berger and Rief (2008) found that biogenetic explanations decreased the attribution of blame by both medical and psychology students groups, however, decreased unpredictability/incompetence beliefs and social distance in the medical student group and increased perception of poor prognosis for psychology students. In contrast, medical students’ ratings of dangerousness and social distance were decreased following the psychosocial explanation for schizophrenia. This suggests that explanations for schizophrenia need to be tailored according to research on the intended audience.
3.2 Neuropsychological and psychological accounts and treatment

3.2.1 Inner speech / source-monitoring model

First proposed by Frith (1987), the inner speech model of voice-hearing posits that auditory verbal hallucinations are experienced when internal speech or auditory imagery is misattributed to an external source (Allen, Aleman & McGuire, 2007). Thus, in voice-hearing, inner speech may occur with a diminished or absent sense of agency which usually accompany it, leading to the thought being experienced as “not me” – originating from elsewhere (Lakeman, 2001; Morrison, 2001). Research which showed that particular regions of the brain are implicated in predicting the outcome of self-generated motor movements is also relevant to understanding voice-hearing (Sugimori, Assai & Tanno, 2011). Deeper consideration of these findings to voice-hearing blurred the line between functions, as speech involves motor action, thought is typically regarded as involving language (although thought without language is also recognized) and inner speech or thought can be regarded as an action (Sugimori et al., 2011). A developmental model of inner speech posits that talking out loud to oneself is a normal phase which is eventually suppressed, taking the form of inner speech (Vygotskian, 1966). Indeed, in Frith’s application of forward modeling or corollary discharge models by which human beings are proposed to predict the outcomes of motor actions, it is assumed that language and thoughts are a type of motor action (Allen, Aleman & McGuire, 2007). Behavioural and neurobiological evidence for this model have shed some light on the veracity of the inner speech model of voice-hearing.

Behavioural investigations into this paradigm have produced mixed results (Allen et al., 2007). Typically, people with a diagnosis of schizophrenia who experience hallucinations are compared to those with no hallucinations and a control group, to whom a distorted version of
their own voice is played back. There is some evidence that people who hear voices are more likely to misidentify their own (distorted) voice as belonging to another person (Allen et al., 2004; Johns et al., 2001). However, other studies have found no significant differences in speech attribution between these groups (Versmissen et al., 2007). Further, Johns, Gregg, Allen, Vythelingum & McGuire (2006) found that people with delusions, as well as hallucinations, tended to misattribute their distorted voice as someone else’s. This suggests that the tendency to misattribute ambiguous stimuli is not specific to voice-hearers. More generally, a tendency for voice-hearers to misattribute the origin of stimuli during ongoing and memory tasks has been noted (Sumigori et al., 2011; Waters, 2012). For example, Brebion, Amador, David, Malaspinar, Sharif & Gorman (2000) presented a list of 24 items to people diagnosed with schizophrenia, then asked them to identify those items on a list of target and distractor items, as well as the source (whether read by the researcher, the participant or presented visually). They found that higher hallucination scores were positively associated with incorrectly identifying items as being presented on an original list and to attributing self-produced items to the researcher.

Similarly, Sugimori et al. (2011) presented undergraduate students with a list of words semantically associated to an unnamed word (for example, ‘hill’, ‘climb’, ‘valley’, ‘summit’, ‘top’, ‘climber’, ‘steep’ are semantically associated with ‘mountain’). Participants were then asked to identify which words had been read out on a recognition trial. A higher degree of proneness to auditory hallucinations was associated with the tendency to incorrectly name the semantically primed but unnamed word as having been included on the original list.

However, while some researchers have found a specific link with auditory verbal hallucinations (Franck et al., 2000) others have found that this is a characteristic of people
diagnosed with schizophrenia more generally (Henquet, Krabbendam, Dauzenberg, Jolles & Merckelbach, 2005; Keefe, 1999).

Neurobiological investigations into the inner speech model of voice-hearing generally employ Positron Emission Topography (PET) or Functional Magnetic Resonance Imaging (fMRI) scans to measure activity in the brain during periods of voice-hearing compared to no voice-hearing within the same person. More recently, there has been some investigation of white matter tracts, with special attention given to the arcuate fasciculus (Abdul-Rahman, Qui, Woon, Kuswanto, Collinson & Sim, 2012).

Unfortunately, fMRI studies have been hampered by small sample sizes (below the n=20 which is the standard minimum) (Sommer et al., 2008). In this context, varied, sometimes unreplicated results identifying activation in Broca’s area, the anterior cingulate cortex, the temporal cortex (bilaterally), the primary auditory cortex and parahippocampul gyrus, have been identified (Allen et al., 2007; Copolov et al., 2003; McGuire, Shah & Murray, 1993; Shergill et al., 2000). Interestingly, these regions are known to be active during speech production, perception of auditory stimuli and memory processes. The activation of speech production areas during voice-hearing provides evidence for the role of inner speech or auditory verbal imagery, while activation of sensory regions is consistent with phenomenological descriptions of voice-hearing (Allen, Aleman & McGuire, 2007). Further, McCarthy-Jones and Fernyhough (2011) found that 26 percent of a student sample reported the voices of others in their inner speech.

In one of the few fMRI studies with an adequate sample size, Sommer et al.’s (2008) found there was bilateral activation in the insula and supramarginal gyri, as well as the right superior temporal gyrus in people with diagnoses of schizophrenia, schizoaffective disorder or psychosis (not-otherwise-specified) while hearing voices. Interestingly, lateralization of
activation was related to whether or not voice content had a positive or negative emotional connotation for the hearer. While some differences in activation in a word generation (inner speech) condition compared to hearing voices, the authors note that the main difference appears to be in lateralization, with activation of right inferior frontal regions activated during auditory verbal hallucinations.

Fractional anisotropy (FA) is a method of investigating the integrity of white matter tracts, with higher FA values corresponding to thicker white matter, indicating better connectivity between regions (Abdul-Rahman et al., 2012). FA studies of voice-hearing have given particular attention to the arcuate fasciculus, which usually functions to connect the frontal cortex with the posterior tempo-parietal junction (Abdul-Rahman et al., 2012). It was once thought to connect the speech comprehension (Wernicke’s) and production (Broca’s) areas of the brain, however, more recently, it has been suggested that it actually connects posterior receptive areas to Broca’s areas via the premotor or motor areas (Bernal & Ardila, 2009).

Further, hypoconnectivity of the arcuate fasciculus, a fronto-temporal-parietal white matter tract which usually functions to help identify the origin of speech as internally or externally generated, has been identified in people diagnosed with schizophrenia (Abdul-Rahman et al., 2012). Diminished integrity of the arcuate fasciculus may also contribute to the experience of hallucinations through diminished top-down inhibitory control (Hugdahl, 2009). Similarly, Braver, Cohen & Barch (2002) proposed that the anterior cingulated cortex, which is involved in cognitive control processes, may contribute to this failure of top-down inhibition of perceptual phenomena originating in the temporal lobe. In keeping with this notion, studies of cognition indicate source-monitoring deficits in people diagnosed with schizophrenia (Waters, 2012).
Phenomenologically, the types of intrusive thoughts observed in obsessive compulsive disorder have been noted to be similar in content and emotional resonance to some descriptions of voice-hearing. This fits with an inner speech model of voice-hearing: potentially, the main difference between the two may be that intrusive thoughts occur in people who do not have neuropsychological deficits in source monitoring (McCarthy-Jones, 2012). As noted by McCarthy-Jones (2012), it is not yet clear what differentiates which parts of inner speech are misattributed to external sources. The strong emotions elicited by many voices may suggest that inner speech which is too distressing or too intense (even if positive) are more likely to be experienced as a voice. However, this is not compatible with accounts of voice-hearing which involve banal commentary (“brush your hair”). Again, this is consistent with the notion that different underlying neural networks may underlie different types of auditory verbal hallucinations (McCarthy-Jones, 2012). It is to the mechanism suggested to underlie ‘static’ voices that we now turn.

3.2.2 Hypervigilance / trauma model

There is evidence that voice-hearing may result from misattribution of traumatic memories. While the relationship between trauma and schizophrenia was initially less well-researched – the “bio-bio-bio” explanation (Read, Bentall & Fosse, 2009, p299) rendering psychosocial factors of minimal interest, it is now well-established not only that trauma is associated with distressing auditory hallucinations, but that there is a dose-response relationship: the more trauma experienced, the more likely a given individual is to develop symptoms of schizophrenia, especially distressing voices (Read, Bentall & Fosse, 2009). There is a relationship between stressors including sexual, physical, or emotional abuse, bullying and
witnessing violence and voice content (Read, Agar, Argyle & Aderhold, 2003; Romme & Escher, 2006). While not all people who experience trauma develop distressing voices and not all people with distressing voices have experienced trauma, it appears that trauma plays a role in the development of distressing voices for a substantial proportion of people who suffer from them.

Waters et al. (2006) have suggested that hallucinations may occur due to an unintentional activation of memories, or failure to inhibit recall of memories. Indeed, it appears that the severity of auditory verbal hallucinations is correlated with the degree of difficulty people have in suppressing material they had previously been exposed to on a recognition task (Waters et al., 2003). People diagnosed with schizophrenia who experience auditory verbal hallucinations are also worse at identifying who performed a task in the past (themselves or the experimenter) compared to those who do not experience hallucinations (Waters et al., 2006). These two deficits, in combination, may give rise to the experience of voice-hearing.

Alternatively, or in addition to Waters et al’s (2006) hypothesis, the mechanism by which trauma may lead to hallucinations in some people may be similar to that by which intrusive memories occur in PTSD. PTSD is characterized by intrusive recollections of traumatic experiences - including being involved in combat during war, being attacked, raped, robbed, or one’s life threatened (Herman, 1992). It is well-established that people respond differentially when exposed to traumatic experiences and that in some cases, traumatic events are not processed in the same way as other experiences are. Emotional detachment or dissociation during the traumatic event may have an adaptive function at the time, allowing the individual to survive. However, dissociation is known to place the individual at higher risk for developing PTSD (Kumpala, Orcutt, Bardeen & Varkovitsky, 2011). Experiential avoidance, whereby the
person avoids thinking about or recollecting the experience, even when they are no longer under threat, interferes with extinction of the associated fear response (Kumpala et al., 2011). Fragments of memory are recalled unbidden, but without the usual temporal and episodic markers which allow the person to identify this phenomenon as a memory. They may therefore be experienced as distressing, intrusive phenomena.

The hypervigilance model has long been applied to PTSD. However, it may also be applicable to voice-hearing. Indeed, differentiating between intrusive recollections in PTSD and hallucinations diagnosed in context of schizophrenia appears to be a difficult task at times, particularly given the vivid sensory qualities of flashbacks, which lend a sense of reality and ‘re-experiencing’ to recollections. In both cases, the phenomenon elicits strong emotions and the person also perceives sound (and in the case of flash-backs, visual content) to be originating from outside themselves in the absence of an appropriate stimulus. Finally, it is of note that many mental health professionals do not ask people presenting with distressing voices if they have experienced childhood trauma (Read, Hammersley & Rudegeair, 2007). This may contribute to symptoms being diagnosed in context of schizophrenia rather than PTSD.

Differentiation between schizophrenia and PTSD is complicated by overlapping symptomatology and a high incidence of PTSD in those diagnosed with psychosis (Picken, Berry, Tarrier & Barrowclough, 2010; Seedat, 2003). Indeed, patients diagnosed with PTSD or schizophrenia may share a predisposition to psychotic symptoms due to changes in the brain as a result of trauma (Seedat, 2003). Finally, as previously mentioned, the high rate of trauma in people who go on to develop psychotic symptoms, in combination with the direct, thematic or figurative relationship between traumatic events and voice content or form, suggests that this model is accurate and appropriate for some types of voice-hearing (Read, Agar, Argyle, &
Aderhold, 2003; Romme et al., 2009). Overall, memory-based accounts of voice-hearing appear, as do inner speech models, to provide a plausible explanation for at least a sub-set of voice-hearing experiences (McCarthy-Jones, 2012).

3.2.3 Psychological treatment approaches

Psychological approaches to distressing voices have evolved over time, from psychoanalytic treatment, through which voices were conceptualised as symbolic expressions of the unconscious, to the medical era, when it was believed that people suffering from distressing voices were beyond psychological intervention, to current models such as cognitive behavioural therapy, relating therapies, compassionate mind training and acceptance and commitment therapy and trauma-focussed therapy (Thomas et al., 2014). It is to a consideration of current models that we now turn.

3.2.4 Cognitive Behavioural Therapy

CBT operates on the assumption that interpretations of experience – accessed by eliciting the person’s thoughts – directly affect a person’s emotional response and behaviour (Beck, 1976). It appears that people suffering from particular difficulties – such as persistent low mood or anxiety – have developed a particular interpretive lens, based on previous and current experiences (Beck, 1976). Common styles of thinking have been identified as commonly associated with depression, anxiety disorders and eating disorders (Beck, 1995; Barlow, 2008).

For many years, CBT was not applied to schizophrenia or distressing voices generally, as psychological therapies were thought to be ineffective for these problems. Dissatisfaction with the medical model and behaviourist approaches, however, led to CBT gaining support as a
treatment model for auditory hallucinations, with the earliest trials dating back to the early 1990s (Wykes, Steel, Everitt & Tarrier, 2009). CBT for distressed voice-hearers focuses on altering maladaptive appraisals and behavioural responses to voices which lead to and maintain distress (Morrison, 2001; Tai & Turkington, 2009; Zimmermann, Favrod, Trieu & Pomini, 2005). The goal of CBT is thus not to eliminate voice-hearing, instead targeting the distress sometimes associated with it. Maladaptive appraisals are targeted through therapeutic techniques including cognitive challenging, considering alternative explanations, weighing up the evidence for and against a particular interpretation of the voice and behavioural experiments. Behaviourally, the function that voices play in a person’s life may also be a maintaining factor. For example, voices may be adaptive in the sense of allowing the person to define their identity in a manner preferable to reality, or by providing social contact (Hayward et al., 2008; Morrison, cited in Read, Mosher and Bentall, 2004). In terms of a behavioural analysis of voice-hearing, the importance of building relationships with social others is clear.

It seems logical that a voice which the hearer perceives to be malevolent, powerful and omnipotent would be more distressing that a benevolent, supportive, non-threatening voice. This is indeed what has been confirmed empirically (Birchwood & Chadwick, 1997; Birchwood, Meaden, Trower, Gilbert & Plaistow, 2000). For example, Birchwood and Chadwick (1997) found that beliefs about voices and what the voice-hearing experience meant was related to emotional responses and coping strategies in a sample of 62 voice-hearers diagnosed with schizophrenia or schizoaffective disorder. A recent review (Mawson et al., 2010) found that appraisals of voices as malevolent, dominant or powerful and attitudes of rejection toward voices by the hearer were associated with higher distress. Similarly, qualitative data indicates that
diminishing fear and gaining control were associated with developing a positive relationship to voices (Jackson, Hayward & Cooke, 2001).

Further, it appears that interpretations of voices as threatening leads to physiological arousal and low mood, hypervigilance and safety behaviours, which in turn reinforce beliefs about the hallucination (Chadwick, Birchwood & Trower, 1996; Morrison, 2001). Selective attention to information which confirms the threatening nature of the voice and biased information processing likewise reinforce fear of the voice(s) (Morrison, 2001). As in anxiety and mood disorders, behavioural responses such as avoidance of the feared situation and safety behaviours serve to maintain this cycle (Morrison, 2001).

There is evidence that CBT can be effective for treating distressing voices. Trower et al. (2004) found that cognitive therapy for command hallucinations resulted in decreased distress, depression and strength of belief in the power of the voices and need to comply. However, while treatment based on challenging the accuracy of cognitions about voices and increasing patient assertiveness, has had some success (Trower et al., 2004), results are mixed. Mawson et al.’s (2010) review of treatment trials returned mixed results, with only two out of four CBT trials showing improvement in distress (Mawson et al., 2010). Therefore, current research seeks to improve treatment for distressing voices.

Interestingly, negative voice content has been found to be related to perceived voice malevolence in as low as 30% of cases (Mawson et al., 2010). Given mixed results for therapeutic interventions targeting perceived malevolence, the link between voice content, perceived malevolence and distress requires further illumination. Determining what makes voices distressing is complicated by findings that neutral observers rated voice content as directly related to beliefs about voices in only around a quarter of cases reviewed (Birchwood &
Chadwick, 1997). Further, while Beavan and Read (2010) found that content of voices was the only significant predictor of emotional distress in a sample of 154 voice-hearers, others have found voice content to be related to distress in only 30% of cases (Mawson et al., 2010). Hence other variables are implicated in determining distress.

Meta-beliefs in the form of explanatory models about the experience of voice-hearing itself are related to the voice-hearer’s emotional response (Beavan & Read, 2010). Overall, participants in sample of 154 voice-hearers who explained their voices in a spiritual context had a more positive emotional response and were less likely to have come into contact with mental health services, while the opposite trend was observed in those who gave psychological or biological accounts of voice-hearing (Beavan & Read, 2010). Similarly, Morrison (2001) suggested that voice-hearing leads to distress and disability when cultural interpretations of the phenomenon are negative. However, it is unclear whether existing beliefs about voices shape the manner in which first voices present, or whether voice characteristics shape beliefs about voices. Examining the circumstances and existing beliefs at the time of an individual’s first voice experience and subsequent development of their explanatory model over time, would help to illuminate this issue. Examining explanatory models may also contribute to the understanding of inconsistencies in voice content and perceived malevolence. For example, if an individual believes that hearing voices is a sign of “going mad”, this may influence them to interpret positive or neutral voices as negative, which may in turn increase their distress (Beavan & Read, 2011).

In addition, Beavan and Read (2010) note that categories of ‘negative’, ‘neutral’ and ‘positive’ regarding voice content and ‘known’ or ‘not known’ regarding voice identity, do not capture the variability in experience described by voice-hearers in their population sample.
Thus, utilising the categories developed in their study may assist in delineating the relationship between voice content, beliefs about voices, relational variables and distress.

Indeed, while many voice-hearers hear more than one voice, most studies focus on the dominant voice. This may overlook the effect of secondary voices on distress and associated variation in beliefs about voices. For example, an individual with three voices of mostly negative content is likely to experience more distress than an individual whose negative voice is counter-balanced by a voice with mostly positive content. The effect of multiple voices requires further clarification. Further, while the identity of the voice generally corresponds to voice content, this is not always the case, with some voice-hearers reporting negative content from voices whose real-world counterparts are generally pleasant toward them (Mawson et al., 2011). This emphasises the variation between individuals regarding factors which may influence their distress.

3.2.5 Relating theories

A number of researchers have explored the nature of voices, patients’ style of relating – both interpersonally and to voices – coping strategies and sense of self. They have revealed a similarity between an individual’s style of relating to others, perceived social rank and the way they relate to and appraise voices (Hayward et al., 2011). For example, Birchwood et al. (2000; 2004) found that relationships to voices characterised by subordination were related to subordination and marginalisation in the social realm, with low social rank leading to appraisal of voices as being powerful and increased distress and depression. Fox et al. (2004) found that people who complied with self-harm voice-commands were more likely to rate themselves as inferior to others, while those who complied with commands to harm others tended to rate
themselves as superior. Voice-hearers who relate to their voices with suspicion and little communication and whose voices are insulting and domineering, experience higher levels of distress (Vaughn and Fowler, 2004). Distant relating on the hearer’s part has also been found to be significantly correlated with higher distress (Hayward, Denner, Vaughan, & Fowler, 2008). The importance of the nature of the person’s relationship to their voices has thus emerged as an important factor that needs to be considered (Ashton, Berry, Murray, & Hayward, 2011; Mawson et al., 2010). Indeed, a person’s style of relating to voices may moderate or mediate the relationship between beliefs about voices and distress.

Qualitative research has shown, however, that the notion of ‘relating’ to voices as one would to social others holds valid for most voice-hearers, although not all (Chin & Hayward, 2009). Further, incorporating this relational aspect of voice-hearing, treatment based on challenging the accuracy of cognitions about voices and increasing patient assertiveness, has had some success (Trower, 2004). However, results are mixed, with other studies reporting no significant differences in distress or assertiveness post-treatment (Hayward, Berry & Ashton, 2011). Thus, further investigation into factors contributing to distress is required.

3.2.6 Attachment style and social schemas

Investigation of relating theories has generated increased interest in the role of attachment. The relational history of voice-hearers and potential impact of this on their style of relating to their voices has not been examined. Attachment has been posited to play a role in the development and maintenance of distressing voice-hearing (Read & Gumley, 2010). Attachment style has been shown to be predictive of interpersonal difficulties and symptoms in patients with psychosis (Berry, Barrowclough & Wearden, 2008) and insecure attachment has been associated
with schizotypy and associated sub-clinical auditory hallucinations (Berry, Wearden, Barrowclough & Liversidge, 2006; MacBeth, Schwanneaer & Humley, 2008). However, associations between attachment and style of relating to voices in general populations has not been examined (Hayward et al., 2011). The potential moderating or mediating influence of attachment and relating variables on the relationship between beliefs about voices and distress has not been adequately clarified.

Finally, Paulik (2011) has proposed a pivotal role of social schemas in determining voice-hearers beliefs about and responses to their voices. This proposition is in keeping with research into parallels between voice-hearers relationships with social others and their style of relating to their voices, as well as evidence relating to trauma and voice-hearing.

3.2.7 Trauma-based treatment

Despite the evidence for the role of trauma in causing at least a sub-set of distressing voices (McCarthy-Jones, 2012), adaptation of established trauma-based therapies for people with distressing voices, particularly with psychotic-spectrum diagnoses, is in its infancy (Thomas et al., 2014). For example, van den Berg and van der Gaag (2014) have recently evaluated a pilot study of Eye Movement Desensitisation and Reprocessing (EMDR) for treating trauma in psychosis.

3.3 Consumer accounts and the Maastricht approach

Many voice-hearers report being dissatisfied with the treatment they receive. There is a strong sense of unmet need, which is fuelled by vastly different accounts of the essence of the problem in distressing voice-hearing. This is clearly expressed by recovered voice-hearer
Eleanor Longden: "My original psychiatrist told me I would have been better off with cancer because it was easier to cure. She still says that to people. What happened to me was catastrophic and I survived only because of luck. If I had lived one street to the right, I wouldn't have been referred to (psychiatrist). That can't be how people's lives are determined. I'm not anti-medication; I'm pro-choice. Hearing voices is like left-handedness; it's a human variation, not open to cure, just coping." (Longden, 2009).

Distressed voice-hearers are often actively engaged in attempts to understand their voice-hearing experiences and typically give complex and detailed explanations for them, blending biological, psychological and spiritual explanations (Geekie, 2004). Voice-hearers often wish to discuss this with their psychiatrist or doctor. Unfortunately, as noted by Romme et al. (2009), many psychiatrists remain reluctant to talk to patients about their voices, for fear of ‘reinforcing’ their hallucinations.

User-run services for voice-hearers developed out of a shared recognition of unmet need (Chamberlain, 2004). While critical of psychiatry and the invalidating manner in which voice-hearers are often treated, there is a wide variety of attitudes toward the medical model and treatment within user-led organisations. Some voice-hearers report, for example, finding antipsychotic medication to be helpful.

Marius Romme, Sandra Escher and colleagues have been passionate advocates of consumer rights. Their work with voice-hearers, especially Patsy Klein, developed into the Hearing Voices Network (HVN) and later INTERVOICE. First developing in Holland and then the UK, there are currently over 200 HVN groups worldwide, including the UK, Holland, New Zealand and Australia. Their approach aligns with patient definitions of recovery and with patients’ needs for
a more holistic treatment model, which normalises voices and takes into account contextual factors (Beavan & Read, 2010; Fischer, 2003).

The HVN philosophy, based on empirical investigation as well as personal values, states that voice-hearing is simply a human characteristic possessed by a minority rather than majority of people and is not pathological in and of itself. Secondly, distressing voices are viewed as expressing an emotional problem or providing a temporary solution to one. Interestingly, this strongly echoes Bleuler’s assertion that “in part (possibly entirely) the overt symptomatology certainly represent the expression of a more or less unsuccessful attempt to find a way out of an intolerable situation.” (p460, cited in McCarthy-Jones, 2012, p74). Recovery is believed to be possible. Voice-hearers are viewed as being in need of emancipation, much as homosexual people were when homosexuality was still considered a mental disorder. Finally, treatment involves making sense of voices, examining their relationship to life history, reinstating the individual’s participation in the community, developing a positive self-identity and connecting with the voice-hearing community (Romme et al., 2009; Fischer, 2003).

Specific therapeutic tools have been developed to help achieve the goal of making sense of one’s voices and diminishing distress. Firstly, the Maastricht interview has been created to facilitate the therapist and voice-hearer in developing a literal and figurative meaning of their voices. For example, a voice saying “I’m going to kill you” may be interpreted metaphorically to mean that the person needs to make a significant change in their life. Similarly, the appearance of a highly critical voice may be interpreted as a sign that the hearer is over-tired and needs to rest (Romme et al., 2009). Through this work, voice-hearers report coming to interpret their voices in a less threatening manner and subsequently feeling less distressed.
The voice-dialogue technique (Moskowitz & Corstens, 2007; Romme & Escher, 1993) involves asking the voices directly for what purpose they have come to the hearer and can be helpful (Moskowitz & Corstens, 2007). Interestingly, their response is often that they are there to protect the hearer. Of course, in order for this approach to be viable, the voices must be of the type that it is possible to enter into a dialogue with, which is true of many, but not all voices (McCarthy-Jones, 2012). While promising and clearly in line with voice-hearers’ needs, no randomized controlled trial of the Maastricht approach has been conducted and is thus urgently required.

4. Recovery

4.1 Definitions of and evidence for recovery

An underlying assumption of the medical model is that symptoms cause impairment and therefore elimination of, or a significant decrease in, symptoms will lead to a concomitant increase in functionality. Being ‘cured’ thus entails an absence of symptoms and return to a previous state (Whitwell, 1999). In contrast, broader notions of recovery hold that recovery can occur without resolution of symptoms or disability (Anthony, 1993). Indeed, the relationship between experiencing symptoms and quality of life appears not to be as strong as previously assumed. Surveys using general population samples indicate that there is a large proportion of voice hearers who are overall not negatively affected by hearing voices and have no contact with mental health services (Beavan & Read, 2010; Van Os et al., 2001). A significant proportion of voice-hearers have positive experiences and describe their voice(s) as a good guide, spiritual contact (gods, spirits or angels), or communicating with ancestors (Beavan & Read, 2010; Romme & Escher, 1989). In addition, Juckel and Morosini (2008) found that reductions in
psychopathology in people with schizophrenia were only weakly associated with increased quality of life. A number of other factors, including depressive symptoms, hopelessness, lack of social support, stigma, lack of empowerment, adverse side-effects of antipsychotic medication, coping style and personality, have also been found to be important (Brenner, St-Hilaire, Liu, Laplante & King, 2011; Kao, Liu, Chou, & Cheng, 2011; Sibitz et al., 2011).

Influenced by consumer/survivor groups, interest in recovery-orientated mental health services and treatment has grown over the past 20 years (Anthony, 2000). The impact of consumer groups on government policy and mental health services is apparent in an increased focus on recovery in Australia and overseas (Brown, 2008; Patterson, 2009). Importantly, the definition of recovery varies between dominant medical model discourse versus consumer/survivor discourse, with the former focusing on symptom resolution and a return to a former state of functioning, while the latter emphasises living a “fulfilling and satisfying life, in the presence or absence of symptoms” (Carlton & Bradstreet, 2006, p16). Recovery in this broader sense involves developing or regaining a sense of agency, hope and positive sense of self, accepting the limitations associated with the illness and creating a satisfying life within those limitations and improved quality of life (Anthony, 1993; Pape & Galipeault, 2002).

Distressing voices are defined as a sign of severe emotional distress in the face of overwhelming stressors that results in a person becoming displaced in the community (White, 2005). Recovery is believed to be possible and is based on the idea that, with assistance, the person can resume their previous social role and avoid a label of mental illness.

Similarly, others have defined recovery as moving toward independence, illness self-management and having the same work and living opportunities as other community members (Kirkpatrick, 2009). Recovery is a deeply personal process and definitions of recovery vary
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; Carlton & Bradstreet, 2006). A pivotal tenet of recovery-orientated approaches is that recovery is possible (Anthony, 1993; Anthony, 2000).

General population surveys indicate that a large proportion of people who hear voices are not negatively affected by them and have no contact with mental health services (Beavan & Read, 2010; Johns & van Os, 2001; Tien, 1991). McCarthy-Jones (2012) estimated that 0.45 of the population are healthy voice-hearers. Thus, hearing voices in and of itself does not necessarily cause distress. Long-term studies indicate that a large proportion of people who experience distressing voices recover to a degree which would be considered ‘normal’ by most people (Harding et al., 1987; Harrison et al., 2001). Finally, Bota and Preda (2011) reviewed longitudinal outcomes for people diagnosed with schizophrenia and found a stable or favourable outcome in 30% to 50% of patients.

4.2 Recovery processes in other psychological disorders or traumatic experiences

The process of recovery from other mental disorders, drug abuse or childhood trauma may hold relevance for recovery from distressing voices. A systematic review of studies examining recovery using narrative inquiry (Anderson & Hiersteiner, 2007; Carlton & Bradstreet, 2006; Hall et al., 2009; Kelly, Lamount, & Brunero, 2010, Kirkpatrick & Byrne, 2009; Paris & Bradley, 2001; Thornhill, Claire & May, 2010; van Niekerk, 2009) was conducted and is presented in Chapter 3. In summary, the following were identified as important to recovery across studies: rebuilding a positive sense of self and identity (including agency, self-
worth), hope, occupation and activity, acceptance and support, contributing/helping others and making sense of or reframing experiences.

Participants emphasised that their progress had not been a linear progression toward recovery or ‘return to normal’ outcome, that set-backs and disappointments were part of their experience. The formation of a positive identity was vital across narratives of recovery. An increased sense of their ability to contribute to their own care and hope for a better, more fulfilling life, enabled participants to shift away from a ‘chronic patient’ identity. Participants described the development of a more positive sense of self including increased self-efficacy. Participants described the importance of hope, or belief in the possibility of developing a more satisfying, fulfilling life, to their recovery. Mental health professionals who encouraged hopefulness despite participants’ experienced were considered helpful. Engagement in occupation or other activities was a pivotal theme across many narratives. What people did was also an important factor in how social others evaluated them and therefore affected their sense of personal worth and acceptance by others. Acceptance by others was an important theme in recovery, lessening feelings of shame and stigma and normalising difficulties. Participants described contributing to something bigger than or outside of themselves through caring for children or pets, doing volunteer work, developing spiritual connections, or being part of survivor groups. Finally, participants described a process of making sense of and re-interpreting their experiences of abuse or psychosis. This was specific to narratives of recovery from abuse or psychosis and was less apparent in recovery from mental illness generally. A full account of the systematic review and discussion of findings is included in Chapter 3.
5. **Narrative Inquiry**

5.1 *Suitability for current research*

Examination of the experience of recovery is best conducted employing a method that captures the temporal and life context within which recovery occurs. Narrative analysis is well-suited to this requirement. Narrative analysis is the analysis of text in ‘storied’ form (Riessman, 2005). Text is broadly defined and encompasses oral speech, film, literature and writing. In social sciences, the text in question is usually a transcript from an interview. 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. Narrative analysis represents ‘a storied way of knowing and communicating’ (Riessman, 2005, p.1). 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. Thus, by its nature, narrative analysis 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). Given that avoiding the researcher’s impact on this process is not considered possible, good practice involves elucidating the manner in which the researcher and general social context may have shaped the research question, method and interpretation of results (Braun & Clarke, 2008; Clarke, 2003). Narrative methodology is particularly suited to examining processes that unfold over time and where the temporal and individual life context of participants’ experiences is of
central importance (Hall, 2011; Oke, 2008). Narrative methods by nature privilege participants’ knowledge and acknowledge them as experts of their own experience. As such, narrative methods, particularly when applied using a participatory research action approach and reflexive awareness of the researcher’s subject position, have the capacity to minimise the imposition of dominant meanings upon participants’ interpretations (Andresen, 2007). While some researchers differentiate between narrative analysis and narrative inquiry, these are used interchangeably in the present thesis, in keeping with Riessman’s (2005) approach.

6. The Present Study

6.1 Aims

There is a lack of systematic inquiry into the process of recovery from distressing voices. The ‘startling’, ‘organisation’ and ‘stabilization’ phases suggested by Romme and Escher (1989) were based on personal accounts of recovery of voice-hearers who attended the first World Hearing Voices Congress. No empirical investigation of these phases has been conducted to date. The aim of this research is to critically appraise these phases in a systematic fashion, using rigorous qualitative methods. Results will provide insight into recovery processes. It is hoped that this will provide information which will help to inform clinical interventions.

6.2 Method

Participants will be voice-hearers who identify themselves as being recovered and whose responses on Andresen et al.’s (2006) Stages of Recovery Instrument (STORI) indicate they fall in stages 3-5 (out of 5) of recovery. They will also be asked to complete quality of life and distress questionnaires. They will be recruited from the Hearing Voices Network and the
Australian Schizophrenia Research Bank Research Register (ASRBRR). Non-ASRBRR participants will be asked to complete a diagnostic interview. All participants will be invited to describe the onset of their voice-hearing, when it became distressing for them, what their lives are like now that they have recovered and, importantly, how they recovered. Participants will also be invited to take part in a second study, which involves recording instances of voice-hearing over a fortnight and being interviewed regarding voice content, emotional, cognitive and behavioural responses to voice-hearing and coping methods.
Chapter 3

A systematic review and narrative synthesis of studies using narrative analysis of the process of recovery from psychological disorders, emotional traumas, abuse or addiction.


Abstract

Narrative analysis is a qualitative method well-suited to investigating processes implicated in recovery. A systematic review of studies using narrative analysis to examine recovery from mental illness, emotional trauma, abuse and addiction was conducted. Thematic analysis was employed to identify themes across studies reviewed. The following were identified as important to the recovery process across studies: rebuilding a positive sense of self and identity (including agency, self-worth), hope, occupation and activity, acceptance and support, contributing / helping others and making sense of or reframing experiences. Participants emphasised that the recovery process was not linear, and involved integrating their experiences and a transformation of self. Narrative analysis contributes uniquely to understanding the recovery process and findings have the potential to inform mental health services.
Influenced by consumer/survivor groups, interest in recovery-orientated mental health services and treatment has grown over the past 20 years (Anthony, 2000; Tomes, 2006). The impact of consumer groups on government policy and mental health services is apparent in an increased focus on recovery in Australia and overseas (Brown, 2008; Patterson, 2009). Importantly, 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, while the latter emphasises living a “fulfilling and satisfying life, in the presence or absence of symptoms” (Carlton & Bradstreet, 2006, p16). Recovery in this broader sense involves developing or regaining a sense of agency, hope and positive sense of self, accepting the limitations associated with the illness and creating a satisfying life within those limitations, and improved quality of life (Anthony, 1993; Pape & Galipeault, 2002). Similarly, others have defined recovery as moving toward independence, illness self-management, and having the same work and living opportunities as other community members (Kirkpatrick, 2009). Recovery is a deeply personal process and definitions of recovery vary from person to person (Brown, 2008). It is possible, however, to identify common threads in recovery processes and identify factors which support well-being (Brown, 2008; Carlton & Bradstreet, 2006). A pivotal tenet of recovery-orientated approaches is that recovery is possible (Anthony, 1993; Anthony, 2000). Examination of the experience of recovery is best conducted employing a method which captures the temporal and life context within which recovery occurs. Narrative analysis is well-suited to this requirement.

Narrative analysis is the analysis of text in ‘storied’ form (Riessman, 2005). Text is broadly defined and encompasses oral speech, film, literature and writing. In social sciences, the text in question is usually a transcript from an interview. 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 (Reisman, 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. Narrative analysis represents ‘a storied way of knowing and communicating’ (Reisman, 2005, p.1). 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. Thus, by its nature, narrative analysis acknowledges the role of the researcher in the process of meaning-making. Researchers must organise information generated from narrative interviews and interpret it (Reismann, 2005). Given that avoiding the researcher’s impact on this process is not considered possible, good practice involves elucidating the manner in which the researcher and general social context may have shaped the research question, method and interpretation of results (Braun & Clarke, 2008; Clarke, 2003). Narrative methodology is particularly suited to examining processes which unfold over time, and where the temporal and individual life context of participants’ experiences is of central importance (Hall, 2011; Oke, 2008). Narrative methods by nature privilege participants’ knowledge and acknowledge them as experts of their own experience. As such, narrative methods, particularly when applied using a participatory research action approach and reflexive awareness of the researcher’s subject position, have the capacity to minimise the imposition of dominant meanings upon participants’ interpretations (Andresen, 2007).

As the number of qualitative studies has increased, and qualitative research has gained recognition as a valuable source of knowledge, the impetus to synthesise qualitative findings has
grown (Dixon-Woods & Fitzpatrick, 2001; Noyes, Popay, Pearson, Hannes & Booth, 2008). This systematic review will synthesize information gleaned through narrative analysis regarding recovery from mental illness, emotional trauma, addiction, or abuse. Results were synthesised using thematic analysis and are presented with illustrative quotes. The purpose of this review is to shed light on the processes implicated in recovery.

Method

A search of five databases: PsycINFO, CINAHL, MEDLINE, Web of Knowledge and ScienceDirect, was conducted. Where possible, search terms were mapped to subject headings to ensure all potentially relevant papers were captured by the search. On databases where this option was not available, or returned results irrelevant to the topic, keyword searches were used instead. The type of search employed and search results were recorded by database for auditing. Search terms included recovery and narrative combined with psychological disorder or emotional trauma or addiction. The numbers of articles returned by each database are as follows: PsycINFO: 283; CINAHL: 96; MEDLINE: 58; Web of Knowledge: 159; and ScienceDirect: 7. Deleting duplicate results returned a total of 597 papers. A summary diagram of the review process undertaken on these papers is provided in Figure 1, below. First, the titles and abstracts of these papers were scanned for relevance, with narrative analysis or inquiry methodology used to investigate recovery from psychological disorder, emotional trauma or addiction being included. In many instances, the method was not adequately described in the abstract, and full texts were located in order to determine whether they met criteria for inclusion. After this initial refinement 103 articles remained. Articles were included in the review if 1) they involved collection of original research data, 2) data were collected through face-to-face
interviews, 3) data collected were in narrative format, 4) they were about the process of recovery from psychological disorder, trauma or addiction, 5) data were analysed in a manner which maintained the integrity of individual participants’ narratives in some form, for example, by creating individual biographies or narrative summaries, 6) they involved more than one participant (i.e., were not case studies), 7) a full text copy was available, 8) they were published in an academic journal. Papers which 1) examined characteristics of survivors or recovered people rather than the recovery process per se, 2) collected data in narrative format but analysed this data using content or thematic analysis only, and did not also maintain the integrity of each individual participant’s narrative, 3) had a vague description of methodology, such that it was not possible to identify what had been done, were excluded. Where the same data were presented separately in two articles, these were considered in combination. A random selection of 30 of the 103 articles was separately evaluated for inclusion by another researcher. Inter-rater reliability was 90%, and the remaining 10% were resolved by discussion.

Figure 1: Diagrammatic representation of the article exclusion process resulting in 11 articles being included in the review.
Quality Ratings

Cochrane guidelines indicate that despite the need to evaluate the quality of qualitative research, a consensus regarding a standardised manner of achieving this goal has not been met (Noyes, Popay, Pearson, Hannes and Booth, 2008). The quality rating system employed was therefore adapted from the recommendations of Popay, Rogers and Williams (1998) and Chiovotti and Piran (2003). This provides some indication of the methodological rigour employed in each study, and accordingly, the amount of weight given to the findings. Papers were awarded points on an eight-point scale according to the following criteria, with the exception of triangulation, for which up to three points could be awarded.

1) Privileging lay knowledge and subjective experience, as opposed to professional knowledge and objective observations.

2) Participant- or member-checking of researcher interpretations of data (codes, narrative summaries, typologies).

3) Collaborative coding of data with at least two members of the research team.

4) Evidence of triangulation in order to understand the structures and processes under research.

5) Reflexivity: data quality is evaluated by consideration of the various factors influencing research results, including the situation in which it is conducted, and the interplay between the researcher’s pre-existing beliefs, and the effect this has on the questions they chose to ask and lens applied to data analysis.

6) Acknowledge limits of generalisability and make clear what types of claims are made regarding typicality.
Privileging lay knowledge was apparent in a variety of research characteristics, including using participants own words, allowing them to redefine or challenge the interview questions, and recognising them as experts of their own experience. Triangulation was assessed according to whether the research involved obtaining data from different sources or over time to examine validity of findings, including collecting data at different points in time or from different people, involving more than one researcher in the investigation, considering more than one theoretical framework when interpreting results and collecting data using different methods (Denzin, 1978).

**Thematic Analysis**

Evidence identified in the studies was categorized and combined using thematic analysis to created synthesized results (Popay, 2005). Thematic analysis is a method used to identity and analyse patterns in qualitative data and enables organisation of results while maintaining the richness and complexity of qualitative data (Braun & Clarke, 2008). Thematic analysis was selected because it is data-driven rather than fitting data to a pre-existing theory, and is not bound to a particular epistemological position (Braun & Clarke, 2008). The analysis was conducted by the candidate and discussed with the primary supervisor.

**Reflexivity**

Reflection upon the candidate’s biases allowed unexpected themes to be identified. For example, based on exposure to literature on voice-hearing, it was the candidate’s bias to expect that reframing and making sense of experiences would be implicated in recovery across mental health difficulties. This was not the case. In fact, this process was only implicated in recovery from psychosis and abuse. The importance of engagement in meaningful activities in recovery was likewise unexpected, however, supported by existing research.
Results

Summarised findings of the eleven articles selected for review are presented in Table 1. Results of thematic analysis across articles are discussed by theme with illustrative quotes and the number of the study indicated in brackets according to the list provided in Table 1.

Recovery is not a neat or linear journey

Participants in several studies emphasised that their progress had not been a linear progression toward recovery or ‘return to normal’ outcome, and that set-backs and disappointments were part of their experience. While not categorised as a theme in some articles, this theme was apparent.

“…well certainly in my experience, the route to recovery is not a linear process and that may mean going off in directions that might not look all that productive.”(5, p43)

“The healing journey is not sort of a straight path. There are plateaus. You need to sort of stay on a plateau for a while and digest what you’ve learned and how you’ve changed. Then life sometimes sort of throws you a challenge. It’s complicated.”(1, p640)

Participants sometimes questioned the use of the word ‘healed’ to describe their experience:

“I don’t think you can ever be healed. If you were in an accident and your right arm was cut off, you’re never going to get that arm back, but you will learn to go on and manage. It doesn’t mean that you can’t have a good life. It’s just that it’s always going to be there.”(1, p640)

“I don’t think I will ever actually be healed because it’s like a part of me. It’s part of my history. You think when you start in on therapy and try to get help, everything is going to fall together like a story book. Six months from now and I am going to be fixed! Give
me a happy pill, do a little bit of talking, and everything will be fixed. It doesn’t happen like that.”(1, p640)

In addition, some participants described an ongoing daily struggle:

“I deal every day. I deal with just keeping my mind straight.”(6, p259)

“I’ll say this is not a magic pill, this is every day living.”(9, p131).

Participants indicated, however, that while the recovery journey was not neat, linear or a return to what life would have been (had they not experienced mental illness, emotional trauma, abuse or addiction), their progress in a positive direction was still recognised by and valuable to them:

“I think of a map of the United States. When you begin treatment, you start in California and the goal is Massachussetts. It’s a long journey…but even if you drive just a few miles, you’ll never be in California again.”(1, p640)

“It’s the sum of your gains and losses that counts, not the individual losses. Not to get bogged down, not to get stuck there…I’m feeling better and better all the time, and then one day I feel worse again. It’s nothing to get all hot and bothered about. You have to accept that—in the big picture.”(6, p266)

Participants indicated that mental health professionals who set hopeful but realistic expectations for progress were helpful:

“(A doctor) has said that recovery does not move forward in a straight line. Sometimes it goes backwards—but you have to accept that.”(6, p266)

They also indicated that more flexible mental health services which allowed participants to pace their recovery were important to their recovery.
Identity

The formation of a positive identity was vital across narratives of recovery. Changes in identity including increased self-efficacy, agency and self-esteem were associated with recovery.

Turning points involving a decision to participate actively in becoming well were evident:

“Why don’t I die, I’d rather die’ and something says ‘Well? Well, that’s not really what you’re here for.” So… I woke up…and said, ‘wait a minute…if you’re going to be happy, it’s up to you.” And that’s part of the live or die decision…and that’s a very liberating feeling.”(4, p661)

“You have to decide mentally, in capital letters: I’M NOT GOING TO GET SICK AGAIN.”(6, p266)

An increased sense of their ability to contribute to their own care, and hope for a better, more fulfilling life, enabled participants to shift away from a ‘chronic patient’ identity.

Participants described the development of a more positive sense of self including increased self-efficacy:

“I am doing lots of things now that I never would have done…I think ‘well God, You know, I would never have done that before’…and it now comes quite naturally…I mean, a kind of real sense of being…having an identity and…being happy with myself.”(5).

“So I got this job and learned insurance adjusting. I worked with two men, and they treated me nice. If I did a good job, they told me I did a good job,… Up until that time I didn’t feel like I had a right to be on this earth…but all of a sudden, I felt like I had a right , I had every right to be on this earth, to be breathing this air.”(2, p379)

“If you’re not actually actively taking choices, you’re not taking responsibility, and then you create into a sort of, you walk into the victim’s role.”(5, p44)
A sense of identity eroded or the absence of a positive sense of self ever having developed was common in narratives of abuse and addiction:

“\textquote{I would go any way the wind flowed to be accepted.\textquote{}} (4, p653)

“I was unable to make decisions, for example…I would deny myself what I wanted and not be able to listen to my feelings when I felt I shouldn’t do something…In my heart I felt very hurt and very heavy and very, very stressed; but in my mind I was thinking that I have to be sorry, I have to be OK with him.”(3, p421)

Recovery involved re-establishing or building a positive sense of self, and acknowledging personal qualities of strength or courage evident in their life experiences:

“I feel in a way I’ve been reborn… and it’s finally…dawned on me who I am….and what I can do, and it’s been rather gratifying.”(4, p655)

“I think of myself as a very strong person…I’ve done the best I could with what I started with.”(4, p661)

“I’ll never let anyone take away my identity again…I am me, I will do the things I want to do, I will be the kind of person I want to be and no man or nobody will ever take that away from me again.”(3, p152)

Participants reflected that their experiences of mental illness or abuse and recovering from these had made them stronger:

“I now believe that I’m only myself responsible for myself…I have to decide my life…having to experience all these things has made me strong.”(3, p422)

Finally, for those with mental illness who had been homeless, having secure accommodation provided increased agency and control, for example, being able to decide who to allow into their lives:
“I don’t know if you noticed it, but on my door, on the others side of my door I got – do not come in, do not call, do not knock on my door or I’ll call the Police – and stuff like that.”(11, p72)

Secure accommodation also provided the stability required to re-connect with family and re-assume an identity associated with a family role (mother, daughter):

“They came back and said they had an apartment for me. And it was like, is there really a God?...And I didn’t care where this place was, I didn’t care. All I know was I had a key – to my own apartment and it really gave me the, just that gave me enough will to keep fighting for my children, cause I tell you, you get so far.”(11, p71)

Hope

Participants described the importance of hope, or belief in the possibility of developing a more satisfying, fulfilling life, to their recovery:

“I always give myself a chance even when facing the most helpless and hopeless situation. I always see hope in my life, the never-ending hope. That is why I recover again and again….Yeah, I would fight for it until the last breath.”(7, p354)

Mental health professionals who encouraged hopefulness despite participants’ experienced were considered helpful:

“You need positive people in your profession. You don’t need people who say, ‘She’ll never recovery. She’s for the scrapheap, she’ll never work again, she’s on medication for the rest of her life.’”(8, p191)

Participants indicated the role of professionals in fostering a sense of hope (or hopelessness):
“Strictly speaking, until now many medical professional have not really emphasised recovery. I think that we should let them see the importance of this approach. Many professional do not truly believe that there is always hope for us….Each individual of us has different needs, and giving more choices is good for us….For us, the ultimate goal is to recover.”(7, p356)

Hope for an improved life provided the impetus for participants to orientate toward active participation in becoming well. As active participation is related to self-efficacy and agency, hope appeared to affect participant’s sense of self. Notably, for those who had experienced abuse, the effect of mental health services on hope for a better life was less apparent, with acceptance by others and reframing experiences being more important.

**Occupation and activity:**

Engagement in occupation or other activities was a pivotal theme across many narratives. What people did was also an important factor in how social others evaluated them, and therefore affected their sense of personal worth and acceptance by others.

“You find yourself…you avoid social gatherings because people always ask what you do for a living.”(5, p44)

Being engaged in an occupation and/or becoming more involved in various activities (education, sport, hobbies) contributed to self-worth, identity and a sense of doing ‘ordinary’ things.

“I suppose doing the voluntary work three times a week gives me a sense of belonging and all that mixing with the public, having interaction with your colleagues and I suppose it makes you feel good about yourself doing voluntary work.”(5, p45)
“I have a few honorary tasks at the bowling hall and that give me a certain value as a person.”(6, p266)

“So by going to Clubhouse, it gives me a structured day…but I feel, eh, valuable to Clubhouse. That makes me, that helps in my recovery. I feel worthwhile to people.”(5, p45)

Participants also valued the routine and structure provided by work:

“The whole object of the exercise with GROW is to reintroduce back into your life the things you have let go of as a result of being ill…and the only thing that really makes us will in my opinion is when you become active.”(9, p132).

“But now, like I’m getting into routine, because I can see…when I was ill I’d lie in bed all day, and just cry and scream, and drink 16 cups of tea, and you know, I was a basket case. So I’m trying actually to re-structure my life. As my mind is becoming restructured through…routine and discipline at work – everything has to be filed consecutively and numerically – so it’s a very good exercise for the mind…”(10, p460)

Engaging in work and other activities increased participants’ sense of self-worth and agency:

“My job gave me so much more space and self-esteem and I had my own money…I felt much more in control, so I didn’t want to stay at home all the time without working.”(3, p422)

“Only two people finished the class with excellence, and one of them was me…I understood I’m not so bad looking, I’m not so stupid, I’m not so untalented….I was really empowered by having this French class…”(3, p422)

“So when I’m playing a (bowling) match, I’m worth just as much as anyone else….maybe even more.”(6, p269)
“I dread having to go to work in the morning, but when I get there and working with people, interacting with people, and working together with other people, it’s enjoyable to feel that sense of self.” (10, p460)

Engagement in activities was seen by some participant as essential to recovery.

“If you see the connection—that recovery can be a bi-product of everything I do?” (6, p269)

Finally, access to secure accommodation enabled people to participate in more activities:

“I have been able to collect things which I haven’t in 25 years. I have a nice stereo, I have a nice bicycle. I have camping gear, you know, which I have used.” (11, p71)

Acceptance and Support

Acceptance by others was an important theme in recovery narratives. Many participants indicated that accepting others increased their sense of personal worth:

“I would get up early and go help my neighbours do dishes, wash windows, whatever, just to be with somebody who was safe and who appreciated that fact that I was helping them. When I was in high school, I helped the teachers after school….and their encouragement helped a lot just being there. They seemed to think I was worth something.” (1, p642)

Acceptance lessened feelings of shame and stigma, and normalised difficulties.

“Friendship is a major thing, and being honest, and not to be ashamed of who you are and to accept.” (9, p132)

“I have a friend, a best friend…she knew when I was going to relapse and sent me to the emergency room… she did not despise me one bit.” (7, p355)
“These ladies sitting in this room tonight don’t judge me. They accept me for who I am.”(1, p643)

“We’re all sitting in the same boat, we understand one another, we accept one another, we should be able to be the persons we are.”(6, p265)

“The people I work with are the people that I know. When I am amongst them I don’t have the feeling that I am sick although I know I am. So that is why I like being there.”(10, p460)

Participants also recognised strengths and positive characteristics in others who had experienced similar difficulties:

“You absolutely have something in common with every human being…and there’s no one from whom you can’t learn something.”(4, p661)

Importantly, acceptance also contributed to reframing experiences. Validation of the person’s experience by accepting others allowed them to reframe what it meant to be mentally ill, normalise this and allow for the possibility of a more positive identity.

Support from friends and family was also recognised as important to recovery:

“My recovery mainly depends on my mother’s perseverance in taking care of me. She never gave up on me. Whenever I straggled or stumbled along the way of recovery, my mother would pull me up and encourage me to move on.”(7, p354)

**Contributing / helping others**

Participants described contributing to something bigger than or outside of themselves through caring for children or pets, doing volunteer work, developing spiritual connections, or being part of survivor groups.
“My attachment to me dog caused me to think outside of myself for the first time of my life. I honestly believe the God put a dog in my life because He needed me to connect to something outside of myself….I was like a step-ladder to connecting better with people.”(1, p642)

For some, opportunities to contribute were provided in the form of group meetings with others who had experienced similar difficulties:

“...the biggest part of GROW for me was listening to other people…and trying to help them.”(9, p132).

“We can also help each other-give and take-and by helping others you’ve not totally worthless. It’s a natural human characteristic-to feel needed.”(6, p268)

Being able to help others (or planning to do so) affected participants’ self-concept:

“It’s just the fact that I-I myself didn’t realise that I had as much to give....”(4, p655)

“Giving something to someone else makes you worth something to yourself.”(6, p265)

Some participants described wanting to support their children in a way which they themselves had not been supported, while others wished to help others with difficulties similar to their own.

“What I hope I can give her (daughter) now, the support, and the understanding, I will have accomplished and will have made up for my anger of what I felt my parents never gave me...the one thing I can portray to her, that you can find honesty in yourself...”(4, p655).

“I would like to help other persons with psychiatric disabilities to recovery and live a better life. I hope that I could help others solve their problems instead of being a troublemaker.”(7, p352)
“I’d certainly like to help women in some way with this domestic violence business.” (3, p422)

**Making sense of / reframing experiences**

Participants described a process of making sense of and re-interpreting their experiences of abuse or psychosis. This was specific to narratives of recovery from abuse or psychosis, and was less apparent in recovery from mental illness generally.

Participants recovering from abuse described moments where they defined their own experience and resisted the meanings provided by abusers or accomplices:

> “we were little kids in a car….and she would pretend we were lost…she’d get us all crying and scared…That was downright damn mean…why would you wanna scare your kids?....We were scared enough for chrissake…I later figured out, so what if you get lost? You just find your way home.” (2, p379)

> “I’m learning to know that what happened to me when I was little wasn’t my fault. That’s a big lesson because I was always told it was my fault.” (1, p643)

This involved renaming and reinterpreting relationships with abusive others and accomplices. This was evident in renaming abusers, removing their relational title and replacing it with their first name:

> “She is not a mother, and never was, so I just call her Rita…” (2, p379)

Participants indicated that supportive others, including mental health professionals, assisted in reinterpreting experiences of abuse. For example, therapists were regarded as:

> “helping you look at things properly.” (1, p642)
While this clearly describes a supportive relationship, the mechanism of change in this instance appears to be reframing or challenging the meaning of abuse provided by abusers. Participants also described narrative as a means of reframing experiences:

“Talking about my story is like taking back my own power each time. It gives me more and more strength.”(1, p419)

Recovery from domestic violence involved rejecting patriarchal beliefs and interpretations:

“When you love somebody and trust what they’re saying in some ways is true and right…Any man I hear being the slightest little bit chauvinist, I back right off. Women are not the property of men, some men need a damn good lesson in how to treat women.”(3, p422)

Recovery from psychosis involved reinterpreting and normalising the nature of their experiences. For example, participants indicated that they rejected the biomedical model of illness and corresponding treatment approach with their own interpretations. For those in recovery from psychosis, realising that voices were meaningful was described as a crucial step to recovery:

“‘You are now schizophrenic and we treat you with medication’….whereas I had a very passionate feeling that I needed help with a great many human problems.”(8, p188)

“I feel like I’ve got the control back…and possibly the psychosis helped me to get that control back. I think it was the psychosis that really sort of made me look at things. And having looked at them I feel a lot more….calmer about myself.”(8, p190)

“I was experiencing being raped and being sexually abused, but there wasn’t anybody there to say…they just said, ‘paranoid schizophrenia’ which means, I was imagining it. But there wasn’t anybody there who said to me ‘well, have you in your childhood ever experienced these things?’”(8, p190)
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| 1  | Anderson et al., 2007 | U.S.A. | Child sexual abuse | 27 adults (25 female) who had been sexually abused as children | 1) Creating a coherent life narrative: making sense of their experience  
2) Defining their own experience: resisting the meanings provided by abusers or accomplices  
3) Developing supportive connections: receiving and providing care; contributing to something outside oneself (volunteer work, spiritual connections, survivor groups) |
| 2  | Hall et al., 2009 / 2011 | U.S.A. | Child maltreatment | 44 women with a history of childhood maltreatment who defined themselves as in recovery. | 1) Determined decisiveness: A sustained repeated inner effort to surmount difficulties  
2) Counter-framing perceptions: challenging the meaning of the abuse provided by abusers or accomplices as being normal or trivial  
3) Redefinition of abuse: renaming and redrawing boundaries and disempowering abusers  
4) Facing down death: Participants faced existential death in the form of denial of their personhood and physical death from the abuser or from themselves in the form of self-harm or dangerous activities  
5) Quest for learning: This involved searching for ethically clarifying or inspiring stories  
6) Moving beyond: differentiating between past and present: ‘that was then, this is now’ |
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| 3  | Oke et al., 2008 | Australia / Mongolia | Domestic violence      | 22 female participants: 11 Mongolian and 11 Australian | 1) Remaking of self  
2) Developing autonomy  
3) Connecting with and helping others  
4) Rejecting patriarchal beliefs  
5) Gaining life purpose through their experiences |
| 4  | Paris et al., 2001 | U.S.A.    | Alcohol abuse          | 3 female participants who had achieved sobriety | 1) Development of new, sober identities.  
2) Disentanglement from using alcohol as a way of avoiding painful realities.  
3) Spiritual awakening.  
4) Achieving psychosocial development tasks of identity, intimacy and generativity. |
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| 5  | Carlton et al., 2006    | Scotland  | Long-term mental health | 64 adults who self-identified as recovered from a long-term mental health problem | 1) Identity: adjusting personal attitudes and beliefs; building hope and knowledge about themselves and their wellbeing  
2) Meaning and purpose: Engagement in activities (work-related, creative, contributing to society) decreased isolation and increased self-worth and life satisfaction  
3) Hopeful relationships: Supportive others helped them to take responsibility for their recovery. Stories of other people who had struggled with mental health difficulties and recovered meant that participants began to think that recovery was possible for them as well. |
| 6  | Sells et al., 2004       | Holland   | Severe mental illness | 2 participants (1 female) | 1) Developing agency and self-determination: a conscious and effortful decision to change patterns of thinking and behaving  
2) Feeling needed by others and contributing socially  
3) Engaging in activities and work (increased personal worth)  
5) Connecting to and being accepted by others  
6) Doing ordinary things. |
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| 7  | Song et al., 2009              | Taiwan  | Psychiatric disability | 15 | Participants described an incremental process of progress which involved regaining social roles and symptom remission  
1) Identity: sense of self and internal control, mental strength  
2) Relationships: giving and receiving support  
3) Agency: management of disability, being able to perform basic life functions  
4) Informal support: religious networks, neighbourhood support and friends,  
5) Formal support: welfare support, recovery-orientated mental health treatment model |
| 8  | Thornhill et al., 2004         | UK.     | Psychosis     | 15 | 1) Identity: shifting away from a ‘psychiatric patient’ identity  
2) Reframing experiences: acknowledging voices as meaningful  
3) The importance of being listened to and validated  
4) Benefit-finding: being forced to confront issues  
5) Recovery-orientated mental health services |
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| 9  | Kelly et al., 2010 | Ireland | Mental illness, focus: occupation in recovery from a mental illness | 5 participants | 1) Taking responsibility to commence their recovery, making active choices, and re-engaging in activities  
2) Engaging in occupation and activities; doing ‘what ordinary people do’: education, work, holidays and relationships with family and friends. The development of routine and skills supported health and resulted in increased self-esteem and purpose  
3) Positive self-concept developed through community participation and unconditional acceptance of other group members  
4) Barriers to occupation and recovery were internal (e.g. symptoms) and external (discrimination) |
| 10 | van Niekerk et al., 2009 | South Africa | Psychiatric disability, focus: occupation with psychiatric disability | 17 participants | 1) Identity: Participation in work had a strong positive impact on identity (confidence and self-worth)  
2) Re-integration and contribution to society: the importance of being accepted by co-workers (both protected and competitive labour)  
3) Establishing and maintaining a ‘worker identity’. Some participants experienced significant challenges in terms of the continuity of work. Those who were able to adapt were more likely to incorporate being a worker into their identity in the long-term |
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| 11 | Kirk-patrick et al., 2009      | Canada  | Mental illness, focus: housing | 12 participants (6 female) | Accommodation allowed:  
1) Reconnecting with others  
2) Identity: re-establishing an identity in relation to others (mother, daughter)  
3) Place to store possessions, and activities associated with possessions (bike, camping gear)  
4) Privacy, control, opportunities for work  
5) Focussing on goals beyond securing basic needs |
Discussion

Thematic analysis of recovery narratives revealed that participants described the following factors as important to the recovery process: rebuilding a positive sense of self and identity (including agency, self-worth), hope, occupation and activity, acceptance and support, contributing / helping others, and making sense of and reframing experiences. Participants emphasised that the recovery process was not linear, and involved integrating their experiences into their lives and a transformation of self. They also indicated that recovery-orientated mental health services and mental health professionals who set hopeful but realistic expectations were helpful to their recovery.

Identity

Developing a positive sense of self and identity was a core theme across recovery narratives. This included improving self-esteem, perception of personal worth, and developing a sense of agency. Agency included active involvement in becoming well and managing difficulties. The finding that developing a positive identity, self-esteem and self-efficacy are involved in recovery is in keeping with existing research literature indicating that negative self-concept, self-esteem and self-efficacy are associated with poorer mental health (Cabanach, Arias, Rodriguez and Canedo, 2012; Fan & Fu, 2001; Shapiro, Schwartz & Astin, 1996; Whitney, Sullivan & Herman, 2010). Conversely, higher perceived self-efficacy and internal locus of control are associated with better mental health (Roddenberry & Renk, 2010). Higher self-efficacy is also associated with self-acceptance and positive relationships with others (Cabanach et al., 2012) and predicts recovery and adaptation in those exposed to collective trauma (Luszczynska, Benight & Cieslak, 2009). Further, it has been shown that improvements in
beliefs about the self mediated improvements in functional outcome in people with psychosis (Hodgekins & Fowler, 2010). Finally, Mawson, Berry, Murray & Hayward and (2011) identified that developing a positive sense of self may be essential to lowering distress associated with hearing voices.

**Hope**

Participants indicated that the belief that recovery is possible, or hope for a more satisfying life, contributed to their recovery. They described orientation toward active engagement in treatment when they appraised their situations as more hopeful. In keeping with this, hope has been found to be a stronger predictor of mental health than the absence or presence of mental illness (Venning, Kettler, Zajac, Wilson & Eliott, 2011). Further, there is evidence that increased hope is associated with better functional outcome in people with psychosis (Hodgekins & Fowler, 2010). Finally, a review of qualitative research on consumer definitions of recovery from schizophrenia revealed that hope was central to consumers’ definition of recovery (Andresen, Oades & Caputi, 2003).

**Occupation and Activity**

Engaging in activities, including but not limited to paid work, was a strong theme across narratives. Participants indicated that becoming active contributed to their self-worth and sense of agency. Engagement in activities was perceived to be a step toward regaining an ordinary life, as many participants had ceased engagement in activities due to their mental health or other difficulties. Participants also valued the routine and structure provided by work, and some
referred to it as a ‘habit’ which promoted their well-being. Engaging in work and other activities increased participants’ sense of acceptance and positive regard from others, as others tended to evaluate them based on their engagement in an occupation.

The importance of occupation and activity in recovery is supported by research indicating that being employed is associated with better physical and mental quality of life in people living with HIV (Rueda et al., 2011). Participants across studies reviewed commented positively upon the requirement of employment for regular, structured activity, and the impact on identity and social status, which is consistent with existing research (Ezzy, 1993; Rueda, 2011). The positive effect of engaging in occupation on quality of life and self-efficacy is further supported by findings that participants with severe mental illness who were employed had greater life satisfaction, overall self-efficacy, and domain-specific self-efficacy for social engagement (Suzuki, 2011).

Importantly, ‘occupation’ in the narrative studies reviewed was often broadly conceptualized and included paid and voluntary work, hobbies, and socializing (Kelly, 2010). Participants reported similar benefits from these activities to those reported for paid labour. This is consistent with the argument by Ezzy (1993) that employment provides a source of positive identity, and that, consequently, unemployment contributes to poor mental health and low self-esteem only if an alternative positive identity based on other activities is not developed. In addition, engagement in activities has been shown to be associated with recovery from mental illness (Hendryx, Green & Perrin, 2008). Interestingly, despite the material benefits (i.e. income, health insurance) conferred by engagement in employment, not many participants commented on this.
Acceptance and Support

Acceptance by others was a vital theme in recovery narratives. Acceptance impacted positively on self-worth, decreased feelings of shame and stigma, and normalised difficulties. The finding that acceptance by others was important to recovery is in keeping with existing research showing that social acceptance and belonging is a basic human need (Baumesiter & Leary, 1995). The stigma associated with having a psychological disorder or history of abuse or drug addiction is well-documented, and results in discrimination, including social exclusion (Angermeyer & Matschinger, 2005; Crisp & Gelder, Rix, Meltzer & Rowlands, 2000; Stromwell, Holley & Bashor, 2011). Acceptance by social others therefore meets a basic psychological need which is less likely to have been met historically in those with a psychological disorder or abuse history. Similarly, a positive effect of social support on recovery from mental illness has been observed (Hendryx, Green & Perrin, 2009). Social support was also regarded as important to recovery. This is consistent with findings that people who expect that family or friends would provide help during times of stress have lower rates of depression, global distress, post-traumatic symptoms, and negative affect, and higher positive affect (Lakey & Orehek, 2011).

Contributing / Helping Others

The finding that helping others or contributing to something bigger than, or outside of, oneself was implicated in recovery is supported by existing research. Helping others has been shown to be associated with better mental health, less hopelessness and increased sense of meaning in life (Schwartz, Meisenhelder, Yunsheng & Reed, 2003). In addition, being able to help others situates the helper in a role opposite to that of a chronic patient, thus strengthening a
positive and competent self-concept. Thus, helping others may contribute to recovery not only by increasing the helper’s sense of purpose, but by fostering a positive sense of self. Indeed, in examining the effect of authenticity, responsibility, activities of interest and purpose in life, the latter was the strongest predictor of self-efficacy in people diagnosed with a major mental health disorder (Scott, 2007). Moving into a social role which involves helping others is likely to represent the most advanced stage of recovery, as participants are not only able to care for and manage their own lives, but have developed sufficient skills and resources to enable them to help others.

Making Sense of / Reframing Experiences

Findings indicated that making sense of or reframing experiences was important in recovery from child sexual abuse, child maltreatment, domestic abuse and psychosis. The theme of making sense of and reframing experiences, however, was not apparent in narratives of recovery from alcohol addiction or mental illness more generally. Both abuse and psychosis involve an experience or experiences which are confusing, and, particularly in the case of abuse, traumatic. The manner in which these experiences are interpreted by the person affects the impact of these experiences on mental health (Beavan & Read, 2010; Feiring, Taska & Lewis, 2000).

In the case of abuse, reframing experiences appears to be related to revising the meaning of the experience, with implications for identity, self-esteem and shame. People who have experienced abuse frequently blame themselves for the abuse occurring, which, as well as trivialisation of the abuse, is often encouraged by abusers (Hall, 2009). Re-interpreting the experience of abuse such that it is no longer interpreted as being their fault may therefore be
particularly important in recovery. Consistent with this, Feiring, Taska & Lewis (2000) found that decreased shame over time and positive attributional style was associated with improved self-esteem and better adjustment in children who had experienced sexual abuse.

In the case of psychosis, reframing experiences may be more important than in other mental illnesses because of the prevalence of a biomedical explanation and treatment approach, which many people who hear voices perceive to be reductionistic and experience as disempowering (Read, Bentall & Fosse, 2009). Thus, reframing the experience of psychosis as having personal meaning, and taking into account psychosocial factors, may contribute to recovery via increasing hope, empowerment and self-concept (Romme, Escher, Dillon, Corstens & Morris, 2009). In keeping with this, a robust relationship has been found between the degree of internalized stigma and lower self-esteem, hope and empowerment in people with schizophrenia (Livingston & Boyd, 2010).

**Implications for Mental Health Policy**

Results show that mental health services which incorporate and address the factors identified above may be beneficial to people recovering from mental illness, emotional trauma, abuse or addiction. In addition, results suggest that the expectations for improvement held by mental health professionals is of vital importance and impacts critically on recovery, and this is supported by existing research (Song, 2009; Turner-Crowson and Wallcraft, 2002). Mental health professionals’ communication of hopeful but realistic expectations for improvement appears to assists in patients’ recovery. In addition, recovery-orientated services which allow patients greater degree of autonomy as they recovery would contribute to their sense of self-efficacy and personal worth (Frese, Stanley, Kress & Vogel-Scibilia, 2001).
Limitations and Suggestions for Further Research

The involvement of service-users in improving mental health services with a view to creating a more recovery-orientated service culture for people with psychosis has already been undertaken by Pitt et al. (2007). Further research making use of narrative methods, in collaboration with service users, would further contribute to revising current treatment and services. In addition, quantitative investigation of the effect of a recovery-orientated service culture on recovery outcomes would strengthen evidence for change in mental health service orientation. Limitations of this review include the relatively small number of papers reviews and findings being limited to the specific characteristics of participants involved. In addition, the quality of the method employed by some of the papers reviewed was poor, putting into question the validity of their results.

Contribution of Qualitative Research and Narrative Analysis

It is increasingly being acknowledged that the perspective and experiences of persons receiving health interventions is an important factor to consider in developing treatments and policies (Noyes et al., 2008). Qualitative research, in setting out to gather in-depth information about people’s perceptions and experiences, contributes uniquely to this goal (Noyes et al., 2008). The results synthesised using thematic analysis presented in this review demonstrate the unique contribution of narrative analysis to investigating the process of recovery. The preservation of temporal and life context elucidates contextual factors over time (Jones, 2004). Participants across a number of studies challenged researchers’ expectations and framing of questions. This is enabled by the constructivist and collaborative nature of the narrative method (Hall, 2011; Oke, 2008), making it particularly useful in investigating topics which are sensitive
and where there is little existing information. Recognising participants as experts of their own experience ensures a research ethic which aims to empower participants. The utility of this approach is that participants feel comfortable correcting or editing researcher’s interpretations. Other qualitative research has been successfully employed toward this end. For example, Chin, Hayward and Drinnan (2009) found that the concept of ‘relating’ to voices in recent theoretical explorations of voice-hearing was not relevant to all voice-hearers interviewed, and tentative use of this language to discuss voice-hearing experiences in treatment is recommended. Similarly, in the narrative analysis studies reviewed, the way in which research questions were phrased, as well as interpretations of results, was critiqued by participants, resulting in research which more accurately reflected their experience. Narrative analysis provides information not only how a participant feels about a given topic, but why they feel this way, and maintains the richness and complexity of the processes being investigated (Popay, 2005). Narrative analysis therefore contributes uniquely to current understandings of recovery and improving treatment for people who have experienced mental illness, emotional trauma, abuse or addiction.