HEARING VOICES: COPING, RESILIENCE AND RECOVERY

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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ABSTRACT

Introduction: The aim of this study was to explore the experience of people who hear voices and how the support offered to them affects coping, resilience and recovery. Individual factors such as coping, resilience, belief systems and current service provisions are discussed within the developing context of the mental health system and wider society.

Method: Seven people who hear voices were recruited from a local hearing voices group and interviewed using a semi-structured interview. Interpretative Phenomenological Analysis was used to analyse the transcripts.

Results: Six key themes emerged from the participants' accounts. These included: Psychiatry: social control; Psychiatry: a clinical model; Trauma, trauma and re-trauma; Voice awareness; Dancing with voices; and Relationships: lack of understanding.

Discussion: The participants highlighted the support provided by the Hearing Voices Group and help provided by family and friends. This was considered in contrast with psychiatry which was viewed unfavourably. The primary difference in the experience of support, perceived as either helpful or unhelpful, was linked to the emphasis on specific factors that the interviewees considered to influence their process of recovery. These included being in a safe and non-judgemental environment, being offered hope and validation of their experiences, as well as having a means to socially connect and empower their position so that they can be more active in their own recovery. The research suggests that more training in the conceptual frameworks and models of recovery, a greater focus on working with the family and wider support, enhanced collaborative working, and more tailored outcome measures would help services to better meet these individuals' needs during the recovery process.

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ABBREVIATIONS

American Psychiatric Association (APA)

Cognitive Behavioural Therapy (CBT)

Care Quality Commission (CQC)

Department of Health (DoH)

Guidance Development Group (GDG)

Hearing Voices Group (HVG)

Hearing Voices Network (HVN)

Interpretative Phenomenological Analysis (IPA)

National Health Service (NHS)

National Institute for Health and Clinical Excellence (NICE)

Randomised Control Trial (RCT)

Service User (SU): An individual who is in receipt of services from health or social care

LITERATURE REVIEW AND INTRODUCTION

Hearing voices

The experience

When a person hears a voice in the absence of external stimuli, the experience is termed an auditory hallucination (Ruddle, Mason, & Wykes, 2011). Psychosis is an umbrella term for psychiatric disorders that are considered to reflect a loss of reality, where people may experience hallucinations or delusional beliefs, and exhibit personality changes and thought disorder. Depending on its severity, this may be accompanied by unusual or bizarre behaviour, as well as difficulty with social interaction and impairment in carrying out the activities of daily life. The most common psychiatric diagnoses include schizophrenia and bipolar disorder, although psychosis is also associated with severe stress, sleep deprivation, severe clinical depression and substance misuse (American Psychiatric Association (APA), 2000). Most strongly associated with hearing voices, and relevant to this research, is the diagnosis of schizophrenia. Voice-hearing is classified as a 'first rank' symptom of schizophrenia and 60% of people who are diagnosed with this condition hear voices (Shergill, Murray, & McGuire, 1998). The voices often represent either a commentary about the person's actions or present as more commanding and persecutory (APA, 2000).

The symptoms of schizophrenia are frequently separated into positive and negative categories. The term 'positive symptoms' refers to those that are viewed as an excess or distortion of the individual's normal functioning. Delusions are false beliefs that result from a misinterpretation of perceptions and experiences (e.g. paranoia and telepathy); hallucinations refer to the perception of visual, auditory, tactile, olfactory or gustatory experiences without an external stimulus and with a compelling sense of their reality; thought disorder refers to thoughts or conversations that are deemed irrational or prone to sudden change; grossly disorganised behaviour refers to unusual behaviours that that can range from agitation to catatonic motor behaviours and can seriously impede personal safety (APA, 2000). Negative symptoms refer to the loss or absence of normal traits or abilities and include features such as flat or blunted affect, poor self-care and emotion, poverty of speech (alogia), inability to experience pleasure (anhedonia) and lack of motivation (avolition) (APA, 2000). According to these criteria, approximately one person in every hundred will receive a diagnosis of schizophrenia in their lifetime (British Psychological Society, 2000).

Conversely, there are many people who hear voices who never experience mental health services and live perfectly functional lives (Romme & Escher, 1989). Hearing voices is simply not distressing for some people, possibly because the voices are functional in that they may be grounding, pleasant, comforting or manageable (Romme & Escher, 1989). Of the many explanations people hold for why they hear voices, hearing voices as an illness is just one. Such explanations are powerful and have systemic effects ranging from the individual to society.

Research exploring the positive symptoms of psychosis, such as auditory hallucinations, has shown that the distress linked to voice activity can be understood in terms of the individual's perceived relationship with the voices, the omnipotence and power of the voice, the personification, and the appraisal of the meaning of the voices (Birchwood, Meaden, Trower, Gilbert, & Plaistow, 2000). Such theorising typically points to the disappearance of voices when underlying problems are resolved or integrated as evidence of the importance of this relationship (Escher, Romme, & Buiks, 1998).

There are many labels attached to the experience of hearing voices and, as the present research is focused on this experience, literature will be drawn from a number of areas and disorders in which the experience of hearing voices is a central theme. The names of the disorders may be used interchangeably with voice-hearing, reflecting that experience.

Causes

Psychosis is considered to be the result of a complex interaction of multiple causes (National Institute for Clinical Excellence (NICE), 2010). Research continues to attempt to elucidate the causal role of biological, psychological and social contributors but these causes are still not well understood.

Much of the research evidence on the aetiology of schizophrenia is consistent with the Vulnerability Stress Model (Nuechterlein & Dawson, 1984; Zubin & Spring, 1977). This model extends the original biological model of illness by attributing mental illness to an interaction between biological and psychosocial factors. The premise holds that individuals inherit or experience a very early trauma that creates a vulnerability or predisposition to develop psychosis which is then hatched under stressful conditions (Smith, Schwebel, Dunn, & McIver, 1993). It is proposed that when an individual possesses great vulnerability then relatively low levels of stress are sufficient to cause

problems. However, in those who inherit a low predisposition, problems may only develop under high stress conditions (Nuechterlein & Dawson, 1984).

The research trying to elucidate the biological vulnerability and the psychosocial stressors is extensive. Biological research has explored, for example, possible biochemical transmission (e.g. Kapur, 2003), gene susceptibility (e.g. Craddock, Donovan, & Owen, 2005) and brain pathology; Broome, Woolley, Tabraham, Johs, Bramon, Murray, Pariante, McGuire and Murray (2005) postulate that genes involved in neurodevelopment and/or environmental insults in early life lead to aberrant brain development. Additional biological, psychological and social factors which can predispose the individual to later onset of psychoses have also been explored (Broome, et al., 2005). For example, we now know that certain environmental factors increase the risk of schizophrenia; these include social adversity and trauma, cannabis use, migration and stressful life events (NICE, 2010). Attention has also been given to the mediating effects of cognition in this process (e.g. Cannon, Caspi, Moffitt, Harrington, Taylor, Murray, & Poulton, 2002; Fuller, Nopoulos, Arndt, O'Leary, & Andreasen, 2002).

Chadwick and Birchwood (1994) proposed that traumatic life events could represent a mediating or contributory factor in the development of beliefs about voices. Cohort and retrospective studies reveal that first-episode psychosis is often preceded by social and emotional difficulties from early adolescence (e.g. Poulton, Caspi, Moffitt, Cannon, Murray, & Harrington, 2000). These childhood antecedents of a developing psychosis will gradually develop in a social environment and such social factors influence morbidity and outcome of psychosis, such as deprivation and marginalisation (Birchwood, 2003). These factors will undoubtedly also affect 'normal' social and psychological development leading to low self-esteem, difficulty in establishing relationships and susceptibility to stress (Chadwick, & Birchwood, 1994).

Research has shown that there is a high rate of traumatic histories in people who hear voices. Escher et al. (1998), for example, found that the onset of voice-hearing amongst a patient group was preceded by either a traumatic event or an event that activated the memory of an earlier trauma; seventy-percent of voice-hearers, for example, reported that their voices had begun after a severe traumatic or intensely emotional event, such as an accident, divorce or bereavement, sexual or physical abuse, love affairs, or pregnancy. Studies exploring this link between traumatic life events and voice activation show that it is not the occurrence of voices that causes the distress but rather the beliefs about the

voices that elicit the emotional and behavioural consequences (e.g. Chadwick & Birchwood, 1994). It is further suggested that the content and beliefs about the voices reflect an individual's life history and the way they feel about themselves (May & Longden, 2007). Many studies have, for instance, highlighted the correlation with childhood abuse, including sexual abuse, and the experience of hearing voices (e.g. Killcommons & Morrison, 2005). Other traumatic life incidents have also been implicated, such as the death or murder of a close relative, witnessing a disaster, or being involved in an accident (Mueser, Goodman, Trumbetta, Rosenberg, & Osher, 1998).

Voice-hearing in a historical and political context

The way mental health professionals understand and support the experience of hearing voices and recovery is grounded within a controversial political context, namely the tension between traditional models of psychiatry and the Post Psychiatric Movement (PPM).

Within the traditional model of psychiatry, psychiatrists took responsibility for treatment; a somatic cure was sought, and people, up until times of deinstitutionalisation, were segregated and confined away from society (DoH, 2001). People were not expected to recover and were instead committed to a downward spiral of increasing, all-consuming symptoms (DoH, 2001). The conceptualisation of the disorder by Emil Kraepelin, a leading psychiatrist in the early twentieth century, originally named the disorder, 'Dementia Praecox', meaning premature dementia, representing the personal deterioration and dismal outcome of the suffering individual (Harding, Zubin, & Strauss, 1992). This negative conception of severe mental illness pervaded systemically, creating a pessimistic outlook characterised by low expectation and hopelessness (Harding, et al., 1992). The outlook, however, was challenged by published first-hand accounts detailing individuals' recovery from mental distress (e.g. Deegan, 1988) and became the foundation for the PPM which brought about social movements arguing against the dominant medical model (e.g. Hearing Voices Network (HVN)), and fronted the production and circulation of deinstitutionalisation policy and continued legislation adopted by the NHS and wider service provisions (e.g. DoH, 1999; 2001). This led to a splitting of opinion about the experience of hearing voices and recovery. The PPM advocates that voices are meaningful experiences caused by disadvantage and trauma that need validation, understanding and deconstruction. More traditional services, however, adopt a bio-psychosocial understanding of hearing voices and approach recovery through support and rehabilitation in the community and hospital settings. Deinstitutionalisation policy and continued legislation has, for example, pioneered the development of a community

stepped care model which includes more specialist teams such as the Crisis Resolution and Home Treatment teams, Assertive Community Treatment (ACT) and Early Intervention in Psychosis Services (EIPS) (NICE, 2010). In addition, the NHS plan (DoH, 2000) saw reform of the Mental Health Act advocating the use of the least restrictive treatment options, highlighting the importance of quality care, civil liberty and promotion of recovery, even to the point of compulsory detainment. Inpatient care is now typically used as a last resort when individual risk cannot be managed within the community and detainment under the Mental Health Act (HMSO, 2007) is required.

Service Provision

NICE guidance

The NICE aims to provide guidance and set quality standards to improve people's health and prevent and treat illness. As part of this, they develop clinical practice guidance; 'systematically developed statements that assist clinicians and patients in making decisions about appropriate treatment for specific conditions' (pg 11-12, NICE, 2009).

NICE (2010) recommends antipsychotic medication as a first line treatment for schizophrenia. There is strong evidence for the efficacy of medication in both the treatment of acute psychotic episodes and relapse prevention over time (e.g. Csernansky & Schuchart, 2001; NICE, 2010). However, significant problems remain. Firstly, people demonstrate an impoverished response; Pantellis and Barnes (1996), for example, found that 25-50% of people continue to hear voices on medication. Secondly, these medications are associated with a high incidence of side effects including lethargy, sedation, weight gain and sexual dysfunction; these are often considered worse than the original symptoms so many people discontinue use (McCabe, Saidi, & Priebe, 2007). A number of psychological therapies are also recommended by NICE for the treatment of schizophrenia. Cognitive Behavioural Therapy (CBT), for example, is recommended as a routine adjunct to medication (NICE, 2010). CBT, through a collaborative relationship, helps individuals to understand and normalise a psychotic experience. It also demonstrates efficacy in a number of other mental health conditions. In the management of schizophrenia, CBT has shown positive outcomes in symptom management (e.g. Rector, Seeman, & Segal, 2003), relapse reduction (e.g. Garety, Freeman, Fowler, Bebbington, Dunn, & Kuipers, 2008), social functioning (Startup, Jackson, & Bandix, 2004) and insight (Turkington, Kingdon, & Turner, 2002).

New developments in cognitive therapies have produced fruitful alternatives to treatment, all of which have a growing evidence base showing effectiveness. These include mindfulness-based approaches, which involve training the mind to disengage from an automated pattern of thinking (Tai & Turkington, 2009). Acceptance and Commitment Therapy (ACT) encourages people to find personal meaning and value in their lives and teaches people to 'just notice', accept and encompass internal events. Compassionate Mind Training (CMT) is delivered in conjunction with CBT but with an added focus on increasing awareness of shame and self-criticism. Meta Cognitive Therapy (MCT) aims to change the way people experience and regulate their thoughts by teaching people techniques such as attention training and altering meta-cognitions (Tai & Turkington, 2009).

NICE (2010) also recommends family therapy, which has accumulated evidence showing efficacy in the treatment of schizophrenia (e.g. Pilling, Bebbington, Kuipers, Garety, Geddes, Orbach, & Morgan, 2002). Family-based interventions derived from behavioural and systemic ideas were adapted for those with psychosis following research that found that family environments altered the course of schizophrenia (Vaughn & Leff, 1976). Further developments specifically showed that the level of expressed emotion within a family environment could predict relapse (e.g. Brown, Birley & Wing, 1972). Family interventions are used to help families cope; they provide support, education and problem solving skills, reduce levels of distress and improve the ways in which the family communicates and negotiates problems in order to reduce or prevent relapse (NICE, 2010). Family therapy is long and complex (NICE, 2010) and for this reason it may be inconsistently applied and unavailable for many.

Art therapies are also recommended; these include art therapy or art psychotherapy, dance movement therapy, body psychotherapy, dramatherapy and music therapy. These therapies facilitate meaning and insight through the medium of art and help people build and develop social relationships (NICE, 2010). The guidance further recommends the use of psychoeducation to support consent, good quality of care and engagement (NICE, 2010).

Hearing Voices Groups

Self-help groups are an important resource for many people as a form of support that either complements or substitutes formal mental health treatment (Spaniol, 2001). The Hearing Voices Network (HVN) is the longest standing voluntary provider of support

groups for people who hear voices (Romme & Escher, 1989). The HVN is a philosophy and social movement founded within the realms of critical psychiatry. The HVN's philosophy of accepting voices redefines the experience of hearing voices as a normal human experience, widely prevalent in the general population (e.g. Romme & Escher, 1989). The HVN challenges the medical model which emphasises an organic pathology that can be treated by pharmaceutical intervention; instead, it highlights the significance of the voices to the individual's emotional distress, and the expertise of individuals in helping themselves. The HVN accepts a full range of explanations for voice-hearing and supports the individual to find empowering ways to work with their understanding to discover what it means (May & Longden, 2007).

HVN support groups are typically run by a voice-hearer together with a clinician from a local mental health service. The group aim is to encourage acceptance that voice-hearing is a valid experience, and to seek to understand the experience from a holistic perspective. The format tends to be unstructured and open-ended (Ruddle, et al., 2011), designed to focus on the provision of support and resources in order to aid understanding and capacity to cope (May & Longden, 2007). Statutory services also provide hearing voices groups which are typically offered in the form of social skills training, CBT and mindfulness.

Problem solving and skills based groups are based on the theoretical assumption that attentional capacity is limited and the learning of certain skills can help control the voices. CBT groups for voices focus on normalising the experience to alleviate isolation and self-stigma. In line with cognitive models of psychosis (e.g. Garety, Kuipers, Fowler, Freeman & Bebbington, 2001) focus is placed on exploring held beliefs and explanations to increase the person's sense of power and control. These groups may also focus on coping strategies, self-esteem, and relapse prevention. Common to all of these group formats is the focus on coping strategies and self- determination (Ruddle, et al., 2011). Although there is good theoretical rationale regarding the provision of these groups there is limited evidence detailing their effectiveness.

Ruddle, et al. (2011) reviewed the evidence exploring the mechanisms for change in the Hearing Voices Groups (HVGs). The HVGs discussed in the literature clustered into four categories: unstructured, open-ended support groups (e.g. user-led hearing voices network group), skills training groups, CBT and mindfulness. The review found no reliable evidence to show the effectiveness of the HVN group. The skills training group showed

some effectiveness but a control group is required. Some positive outcomes have been found for the CBT groups. The only controlled evaluation of a mindfulness group failed to show a positive outcome. From these results, Ruddle, et al. (2011) emphasised the need for a Randomised Control Trial (RCT) to demonstrate any usefulness. In addition, they highlighted the importance of exploring the predictors and mechanisms of change in these groups. Five potential mechanisms were sought from the quantitative data; beliefs about voices (e.g. Wykes, Parr & Landau, 1999; Newton, Landau, Smith, Monks, Shergill & Wykes, 2005), relationships with the voices (e.g. Sayer, Ritter & Gournay, 2000; Sorrell, Hayward & Meddings, 2010), coping strategy enhancement (e.g. Wykes, Hayward, Thomas, Green, Surguladze, Fannon & Landau, 2005), level of social activity (e.g. Wykes, et al., 2005), and self-esteem (e.g. Barrowclough, Haddock, Lobban, Jones, Siddle, Roberts & Gregg, 2006). The evidence suggests that the changes in beliefs surrounding the perceived power of the voice may mediate distress reduction. This relationship may be further influenced by changes in other variables such as the personal coping strategies, self-esteem and social activities. Evidence from qualitative studies illustrates the value given to the provision of a non-threatening space, reduced isolation and normalisation (Meddings, Wally, Collings, Tullett, McEwen & Owen, 2004). More rigorous studies have further demonstrated the importance of safety, normalisation, sharing, and mutual support (e.g. Newton, Larkin, Melhuish & Wykes, 2007, c.f. Ruddle, et al., 2010). Despite Service User (SU) reports highlighting the value of these groups, Ruddle et al. (2011) notes that in the current climate resources are limited and any justification of use requires knowledge about their contribution to individual recovery.

Barriers to treatment

Despite the useful application of the NICE guidance, it has been argued that the implementation of these guidelines is reducing the choice of services that are being recommended by professionals and offered within the mental health service (Guy, Thomas, Stephenson & Loewenthall, 2010). As such, this could be undermining the government's aim of giving patients more choice and control in their treatment (DoH, 2010).

The guidelines are embedded within a medical or biomedical model which assumes that patient experiences (symptoms) are indicative of underlying conditions that need to be diagnosed in order for an appropriate treatment to be prescribed (Guy, et al., 2010). Mental health is classified by disorder, and the assessment of treatment tends to be based on the diagnosis given. NICE (2010) highlights the problems that surround

diagnosis. Firstly, receiving a diagnosis of schizophrenia can be a daunting prospect given the associated stigma coupled with the diagnostic uncertainties; secondly, there is reluctance from clinicians to diagnose, which can prevent access and delay treatment; thirdly, SUs may reject the diagnostic label, dismissing the experience as an illness in need of treatment; and finally, accepting the diagnosis often means receiving compelling treatment which is often contested given the uncertainty surrounding the classification (NICE, 2009). The likening of psychological therapies to drug-like interventions implies that the therapist provides active ingredients to reduce patient symptomatology (Guy, et al., 2010). Contrary to the evidence underpinning the NICE guidance, research shows that it is the common factors across therapy that are pivotal, such as the therapeutic alliance (Wampold, 2001). DuRubies, Brotman and Gibbons (2005) state that there is no significant difference between different psychotherapies.

Rather they assert that there is a statistical relationship between the therapeutic alliance, as a common factor in therapy and outcome, which is largely underrepresented. Recovery research has illustrated that people in recovery judge their psychiatric care according to the therapeutic relationship and the helper's contribution in terms of presence and actions rather than the treatment provided (e.g. Johansson & Elkund, 2003; Topor, Borg, Girolamo & Davidson, 2011). Interestingly, people's narratives are divided; some discuss the obstructive nature of their clinician, whereas others discuss their aid. This reflects the clinicians' approach; whether they are seeing a 'patient', a 'schizophrenic' or a 'person' (Topor, et al., 2011). Topor, et al. (2011) note that the recurrent theme in the narratives is reciprocity; they describe situations where the 'professional went that extra mile' to do something greater, or different to what was expected. However, this loosening of boundaries has the potential to be harmful or misconstrued and for this reason is often associated with a lack of professionalism.

The evidence base underpinning this guidance comprises large scale RCTs. RCTs follow a rigorous method designed to determine a causal effect between a treatment and the outcome whilst minimising spurious causality and bias. However, these studies may be reductionist and display questionable external validity. External validity refers to whether you can generalise the findings from the experiment to a definable group in the wider population (Rothwell, 2006). The discrepancy between the experimental condition and the naturalistic setting is often illustrated in the difference in selection criteria and treatment protocol. Rothwell (2006), for example, reports that some trials are 'enriched' through the active recruitment of patients who are likely to respond well to treatment.

Thus, patients who have shown a good response to antipsychotic medication have been specifically selected for trials of antipsychotic drugs (Rothwell, 2006). RCTs function within a positivist framework and some therapies (e.g. CBT) may be more suited to this type of systematic inquiry. As such, therapies, experiences or concepts that prove difficult to operationalise and measure are often neglected and therefore are excluded as a viable treatment option. Whilst NICE do recognise that there are problems with RCTs, particularly for psychological therapies, Guy et al. (2010) argue that the Guidance Development Group (GDG) acts as though this is the only way to make recommendations for treatment. They further assert that the GDG attract the professionals with a vested interest in the process. Mollon (2008) has argued that it is the clinical psychologists committed to the research and development of CBT, who involve themselves in the development of NICE guidelines. It follows that, it is important to contextualise the guidance in the political arena and recognise any possible allegiance effects. For these reasons, one should be keen to question, and open to ideas, theories and practices that may not have an established evidence base. To date, there is no reliable evidence demonstrating the efficacy of the HVGs (Ruddle, et al., 2011) despite the fact that the groups have a large and committed membership nationally and internationally.

Finally, despite the representation of SUs on the GDG, Guy et al. (2010) suggest that their viewpoints are relatively neglected in the development of guidelines in favour of the findings from RCTs. An example they cite comes in the development of the guidance for depression, where the SUs were arguing for the need for long term therapy (NICE, 2009).

Assessment of outcomes

Developing a care plan is essential to treatment in the mental health system, yet studies show that needs for care are often assessed quite differently by patients and mental health professionals (Hansson, et al., 2001). Kovess-Masféty, Weirsma and Xavier (2006) found that on average one in four patients had needs that were not adequately met by their mental health service. Issues that patients felt were not being addressed included; clinical needs (e.g. psychotic symptoms, slowness and under-activity, side effects of medication), occupational skills (e.g. managing own affairs, managing money and problems in carrying out household chores) and social needs (use of drugs or alcohol).

A new movement embracing SU expertise, which looks beyond symptom reduction, has been a major driver in the assessment of outcomes (McCabe, et al., 2007). A patient-

reported outcome is any outcome based on a patient's perception of a disease and its treatment, without any interpretation by a clinician or researcher (McCabe, et al., 2007). Self-reported outcome measures are useful for obtaining unobservable symptoms, such as paranoid thinking, to offer a personal account of treatment effectiveness. Feedback provided by the patients is considered to enhance the rapport between the SU and provider and, further, reflect the patient as a consumer of care (McCabe, et al., 2007).

The DoH (1999, 2001) has been central in developing a SU-centred NHS, and the involvement of SUs and carers in key decisions permeates through all levels of NHS structures; this is both recommended in policy and remains publicly accountable (DoH, 2001). Service User (SU) in this context refers to an individual who is in or has been in receipt of services from health or social care. The DoH has recently published a report 'Helping the NHS put Patients at the Heart of Care' which focuses on 'Public and Patient Engagement'. This document details what the public wants from the NHS and Social Services, that is: 'services to get the basics right; fit services around their lives; treat them as individuals and not as a set of symptoms; and work with them as equal partners' (Pg 4, DoH, 2009-10). The document further summarises the DoH's vision for the future:

> 'Our vision is for patients and the public to drive the design and delivery of high-quality services. To achieve this, every day, everyone working in the NHS needs to engage patients and the public in making decisions' (Pg 3, DoH, 2009-2010).

The Care Quality Commission (CQC), formerly known as the Healthcare Commission, defines Patient and Public Engagement as 'a process through which patients, users of services and communities, share their views and experiences with trusts, and work together to plan and improve services' (Pg 3, Healthcare Commission, 2009). According to the CQC it covers how health services consult with users, involving, engaging and responding to people's views (Healthcare Commission, 2009).

The DoH (2009-2010) recognises that meeting these expectations will require a change in the relationships between the SU and the staff throughout the NHS structures. The objective for Patient and Public Engagement is to instill a norm for services to listen, understand and respond to patients (DoH, 2009-2010). Strategies cited in the report include empowering people, putting patient experience centre-stage, and helping services to become more accountable (DoH, 2009-2010). According to the report 'Listening,

Learning and Working Together' (Healthcare Commission, 2009), whilst there are some examples of excellent practice across the health and social care system, there is evidence to the contrary suggesting that improvement is required (Healthcare Commission, 2009). A large national study of over 20 trusts across the UK by the Healthcare Commission (2009) found that:

> *'The people [we] involved in this study generally did not feel that they had enough say in the health services that are provided in their area, or the way they are delivered. Those in the poorest health, in vulnerable circumstances or experiencing discrimination, often found it more difficult than others to engage with health services. Many groups of patients and users and community groups still needed to be convinced that health services wanted their views or would act on them'* (Pg 5, Healthcare Commission, 2009).

The traditional role of psychiatry often prevents medical practitioners from working jointly with the individual to incorporate their values and points of view when determining treatment (Topor, et al., 2011). Thus, self-rated symptom measures have been largely unused with people diagnosed with schizophrenia primarily because the measures are characterised as having poor insight and questionable validity (McCabe, et al., 2007). Shared decision making may also be hampered by the patients' inability to rationally evaluate the treatment and, further, particularly at an acute paranoid stage, by limited attentional capacity (Hassan, McCabe & Priebe, 2007). In addition, the history of treatment in society of people with severe mental distress may mean that they do not trust the system enough to feel that their opinions will make a genuine contribution to the service. Growing research, however, suggests that SUs are in fact individuals with a wealth of knowledge and experience about their condition and not simply a collection of symptoms and failings (e.g. Topor, et al., 2011; Pitt, et al, 2007; May & Longden, 2007).

The growth of SU expertise is beginning to challenge the traditionally strict conceptual boundaries between reason and madness, and rational and irrational behaviour, where people are deemed unreasonable (Topor, et al., 2011). Furthermore, it is fuelling the demand for greater recovery-orientated services that are person-centred, strength-based, community-focused and offered in the context of a collaborative relationship in which power is shared between the person and the practitioner (Topor, et al., 2011).

Social Exclusion and Stigma

The experience of hearing voices or auditory hallucinations is highly feared and stigmatised in society. People who hear voices suffer adverse social consequences and stigma; they experience long-term problems with social functioning and isolation to the extent that 80% remain unemployed (Ruddle, et al., 2011).

Stigma in society has been shown to be a major barrier to recovery for those who experience mental health difficulties. Stigma is defined as a sign of disgrace or discredit which sets a person apart from others (Byrne, 2000). It is psychologically driven and refers to the tendency of the majority to alienate and restrict the rights of those within a devalued group. This then has the potential to be internalised by individuals in an already disadvantaged group (Hinshaw & Stier, 2008). Social anxiety in the recovery period may be as a result of internalised shame, disadvantage and stigma. Birchwood (2003) proposed that it is the perceived loss of standing, shame, adverse social identity, fear of stigma and the consequent rejection that contributes to social anxiety. Birchwood, Trower, Brunet, Gilbert, Iqbal & Jackson (2006) further found that individuals with social anxiety tend to experience greater shame attached to their diagnosis and felt that the label placed them apart from others through marginalisation and low social status.

Research has shown that stigma is a marker to adverse experiences (Birchwood, et al., 2006). In two public opinion surveys within the UK, 80% of those taking part endorsed the statement that '*most people are embarrassed by mentally ill people'* (Huxley, 1993). Psychiatric disorders are viewed as more blameworthy than physical health conditions such as cancer and heart disease and, as such, common stereotypes about people with mental illness seem to parallel those about drug dependence to include dangerousness and blame (Angermeyer, Matsinger & Corrigan, 2004). Despite an increased awareness and understanding of mental health problems, public attitude surveys have found an increase in the level of stigmatisation towards serious mental health problems (Hinshaw & Stier, 2008). This may be as a direct result of the media portrayal of those with psychosis to be dangerous and unpredictable often only discussed in relation to a serious crime. In addition, large scale studies (e.g. Oestman & Kjellin, 2002) have shown that between a quarter and a half of family members believe that their relationship with a person with mental illness should be kept hidden, or is otherwise a source of shame in the family. For some, it contributes to strained and distant family

relationships. The shame seems to be linked to blaming the family for the individual's psychiatric disorder.

Corrigan, Watson and Miller (2006) found that families report not only being blamed for the onset of their relative's disorder, but also that they are held responsible for relapse and viewed as an incompetent family member, leading to feelings of shame and contamination. Interestingly, the survey revealed that sample members of the public were more likely to stigmatise the individuals who directly experienced the health condition than their family members. It also found that members of the public blamed, and thus viewed more harshly, those family members who have drug dependent relations compared with those who had a relative with schizophrenia or emphysema. They did find, however, that those with family members who had a sibling with schizophrenia were viewed with more pity than those with emphysema. This survey further explored whether family stigma varies with role. They found that adults, be they a parent or spouse, with an immediate relative with a health condition, were more likely to be viewed as responsible for the health condition, while children were more likely to be viewed as 'contaminated' by all three of the disorders. However, it should be noted that the role of the family members in terms of stigma was significantly higher for those who had a drug dependent relative.

This finding is consistent with a central tenet of Heider's attribution theory; when the negative behaviour of an individual is ascribed to violation or personal control then blame and harsh responses are expected from the observers. Conversely, when such problematic actions are attributed to non-controllable causal factors such as a medical condition then observers will show less blame and more empathy towards the individual (Weiner, Perry & Magnusson, 1988).

Another common reaction among people with mental illness is to anticipate rejection and discrimination, and thus impose upon themselves a form of self-stigma. The reaction is frequently connected to feelings of shame, resulting partly from actual discrimination from others. Knight, Wykes and Hayward (2003) conducted a study exploring individuals' personal accounts of events and situations, as well as the issue of stigma and discrimination, with a view to providing an account of the inherent experience of living with a diagnosis of schizophrenia. A total of six participants were interviewed on four main areas; the individual's life history, personal experience and understanding of their mental health issues, their social understanding of the issue,

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and finally the impact the issue has had on their life. The final question asked whether the term stigma held any personal relevance for the interviewee. The data were analysed using Interpretative Phenomenological Analysis (IPA).

Three themes emerged from the analysis; judgement, comparison and personal understanding of the issue. The theme of judgement emerged from the anticipated or experienced encounters of stereotypical attitudes, prejudice and discrimination from friends, family, and authority figures, including health professionals as well as society in general. The ramifications of this were extensive; feeling labelled had a detrimental impact on the individual's self-concept and daily living.

The theme of comparisons surfaced as the individuals discussed intra- and interpersonal dilemmas which included reflections on the effects and cause of their illness across their lives; issues of normality, ability and happiness were contrasted with different life situations. Within this theme also came a desire to be part of 'normal' society along with a struggle between wanting to belong to a group and wanting to keep oneself separate from a group that doesn't have a positive social identity, such as HVGs and day services.

Finally, within the theme of personal understanding of issues, the participants provided insights into their conceptualisations of their life situation, including whether they viewed themselves as 'ill' and, further, how they coped with stigma such as avoidance-withdrawal, education and secrecy. The findings of this study demonstrate the potency of the burden that labelling and shame from stigma imposes on the individual and the recovery process. The research further highlights some of the insurmountable barriers and issues that the individual faces during the process of recovery.

Recovery

Recovery as a concept

Recovery is a concept introduced in the 1980's through the personal narratives of people coping with, and recovering from, the experience of voice-hearing (e.g. Deegan, 1988; Leete, 1989). This has been encouraged by longitudinal research illustrating positive outcomes for a number of people who experience severe mental illness, albeit with variability (Harding, et al., 1992), and policy supporting the optimism in the notion of recovery (e.g. National Institute for Mental Health in England (NIMHE), 2005).

Recovery has been conceptualised as an individual process of change (e.g. Topor, et al., 2011). Although there is no concrete and shared definition, they do all share the notion of commitment to personal growth. Anthony (1993), for example, defined recovery as a;

> *'deeply personal, unique process of changing one's own attitudes, values, feelings, goals and/or roles'*, and further asserts that "*a person with mental illness can recover even though the illness is not "cured" . . . . [Recovery] is a way of living a satisfying, hopeful, and contributing life even with 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'* (Pg 19).

Similarly, Spaniol, Koehler and Hutchinson (Pg 1, 1994) defined recovery as;

> *'the process by which people with psychiatric disabilities rebuild and further develop their important personal, social, environmental and spiritual connections, and, confront the devastating effects of stigma through personal empowerment. Recovery is a process of adjusting one's attitudes, feelings, perceptions, beliefs, roles and goals in life. It is a process of self-discovery, self-renewal, and transformation'*.

The literature on the concept of recovery highlights three distinct meanings; medical, rehabilitative and empowering (Andressen, Oades, & Caputi, 2003).

The medical model assumes that mental illness is a physical disease which requires a cure; that is the person returning to their former state (Whitwell, c.f. Andressen, et al., 2003). Outcome measures tend to include symptomatology, hospitalisation, medication and functioning and are typically used in outcome studies of schizophrenia and other serious mental illnesses (Andressen, et al., 2003). The authors note that some people who appear to have recovered from serious mental illness to the outside observer do not consider themselves as recovered. This may be because the individual no longer feels like themselves, they continue to use prescribed medication and coping strategies, or they simply do not believe that people with mental illness can get better (Andressen, et al., 2003). The authors further add that clinicians and researchers need to be clear in their own meaning of recovery.

The rehabilitative model asserts that, although mental illness is incurable, rehabilitative efforts can enable the individual to return to a semblance of their former life (Anthony & Liberman, 1992, c.f. Andressen, et al., 2003). The model is primarily based on the medical model and assumes that the person can learn to live within the limits of their disability (Andressen, et al., 2003). In comparison, the empowerment model holds that mental illness is indicative of severe emotional distress in the context of overwhelming stressors (Ahern & Fisher, 2001, c.f. Andressen, et al. 2003). The extreme versions of this model deny the need for medical intervention at all (Andressen, et al., 2003).

Andressen et al. (2003), from their extensive literature review, found that the beliefs of individuals diagnosed with serious mental illness were compatible with psychological recovery; this referring to the establishment of a meaningful life, and a positive sense of identity founded on self-determination and hopefulness (Andressen, et al., 2003). Psychological recovery is not grounded within any causal theory and positions itself between the rehabilitative and empowerment models of recovery (Andressen, et al., 2003).

Researchers often provide an operational definition of recovery; Harrow, Grossman, Jobe and Herbener (2005) defined recovery from schizophrenia as the absence of major symptoms, adequate social functioning including instrumental or paid work, the absence of poor social activity, and no hospital readmission, measured using the Lavenstein-Klein-Pollock Scale and the Strauss Carpenter Scales (Harrow, et al., 2005). This definition, albeit functional for the research, is suggestive of more middle class ideals and expectations for recovery, focusing only on the end product rather than a journey. Andressen et al., (2003) reviewed SU accounts of recovery finding further difficulties with used operational recovery criteria. The recovery criterion, 'the return to former self' was found meaningless to SUs, given that they feel qualitatively different. Similarly, 'the return to expected roles' was discounted given the SU onus on moving on and dreaming a new dream. Finally, 'the absence of symptoms' received mixed reviews from the SU accounts. Some SUs felt that their treatment was worse than the illness and therefore prevented their recovery, some considered the stopping of medication as a mark of progress and others saw medication as part of their recovery (Andressen, et al., 2003).

Psychological recovery as a concept is helpful as it does not limit the possibilities and is grounded in SU accounts and recovery literature. These concepts are considered to lie

on a continuum. Fischer, Shumway and Owen (2002) identified six goals of treatment from a focus group with patients; increasing energy and interest, improving social relationships, reducing disturbing or unusual experiences (hallucinations and delusions), reducing confusion and concentration difficulties, reducing medication side- effects and increasing productive activities such as having a job. In a follow-on study of the outcome priorities of people with schizophrenia Rosenheck, Stroupe, Keefe, McEvoy, Swartz, Perkins, Hsiao, Shumway and Leiberman (2005) similarly found that participants prioritised reducing confusion and increasing energy over improving their social life and reducing side-effects; these preferences, however, depended on patients' well-being and clinical status. Those further into their recovery showed more interest in recovery-orientated goals such as social relationships, employment and personal energy, whereas those who had progressed less were more concerned with symptoms, confusion or side-effects (Rosenheck, et al., 2005). Interestingly, patient- reported outcomes focusing on psychological well-being emphasise resilience, aspects of which include empowerment, self-esteem, sense of coherence and recovery, in the journey of recovery rather than symptom management (McCabe, et al., 2007).

Coping

There are many ways of coping with mental health problems; Roe, Yanos and Lysaker (2006) extended Schwarzer's (2001) proactive coping theory and applied it to severe mental illness to look at how people cope and influence their own recovery. The model describes four types of coping; reactive, anticipatory, preventative, and proactive. Reactive coping describes the way in which someone copes with a stressor. This type of coping can be separated into emotion-focused and problem-focused coping, looking at both the emotional response to a stressor as well as the way someone actively manages that stressor. Problem-focused efforts include attempts to directly cope with symptoms with strategies like self-instruction. Anticipatory coping relates to a person using their own resources to prepare for an unknown upcoming risk that may cause harm or loss (Roe, et al., 2006). Preventative coping refers to the process by which a person builds up resources and resistance as preparation for any potential stressors in the distant future (Schwarzer, 2001). It refers to a lengthier timeline than anticipatory coping and is more about developing ways to maintain emotional well-being (Roe, et al., 2006). Proactive coping was originally referred to in Schwarzer's model (2001) and involves efforts to actively strive, seek new challenges, create new opportunities, and negotiate appraisals of these situations so that they are experienced positively.

The way someone copes with the negative effects of mental illness can significantly influence their recovery. Research shows that less adaptive coping predicts greater distress, symptom exacerbation and less community participation (Bak, Myin-Germeys, Hanssen, Bijl, Vollebergh, Delespaul, & van Os, 2003, c.f. Roe, et al., 2006). People who hear voices develop naturalistic coping strategies to help them manage their voices (e.g. Romme & Escher, 1989; McNally & Goldberg, 1997). Frequent coping techniques cited include distraction, ignoring, selective listening and setting limits (Romme, Honig, Noorthoorn, & Escher, 1992).

Research has shown that people with a diagnosis of schizophrenia often use avoidance coping strategies such as 'sealing-over' rather than approach strategies (Thompson, McGorry, & Harrigan, 2003). Sealing-over is a process often encountered in those who hear voices; this involves denial of the existence, or severity, of the problem, high expectations for immediate return to normal functioning, and an impaired ability to recall or describe the period of acute psychosis (Pg 246, Greenfeld, Strauss, Bowers, & Mandelkern, 1989). This contrasts with those who hear voices and wish to understand and contextualise the experience (Greenfeld, et al., 1989). Such coping mechanisms have been directly linked to adjustment to psychosis. Sealing-over, for example, tends to be associated with poorer social functioning and quality of life and higher levels of depression (Thompson, et al., 2003). Tait, Birchwood and Trower (2004) found that sealing-over recovery styles are associated with negative early childhood experience, insecure adult attachment, negative self-evaluated beliefs and insecure identity. Those who have an insecure adult attachment are less likely to engage with services. These results suggest that individuals who seal-over have less resilience as a result of previous adversities such as abusive parenting. The authors suggest a number of possible clinical implications; a focus on attachment concerns may help reduce barriers to collaboration and enhance engagement with services, while intrusive, stigmatising and coercive services are likely to exacerbate sealing-over, thus reducing service engagement.

The HVN advocates a number of coping strategies that voice-hearers can adopt to set limits, challenge their voices and take control. These include a number of distraction activities such as singing, cooking, exercise and reading; relaxation strategies such as meditation, prayer and focused breathing; self-care and comfort such as positive self- talk and self-forgiveness, eating healthily and doing something enjoyable; making sense of the experience by, for example, talking to someone you trust about the voices, acknowledging the association between a trauma or stressful life event and the voice- hearing

experience, keeping a record about what the voices are saying; challenging the voices by, for example, time sharing, setting boundaries and asking the voices to justify their comments (May & Longden, 2007). They also advocate a number of mindfulness exercises to help anchor people in the here and now, such as mindful breathing and mindful walking (May & Longden, 2007).

Personal belief systems and the influence on coping

The capacity to cope has been found to link to people's beliefs about the voice-hearing experience. Bentall, Kaney and Dewey (1991) demonstrated that people who are paranoid or delusional tend to attribute bad events to an external cause with great confidence. Chadwick and Birchwood (1994) further found that such causal links to external circumstances created fear of and compliance with the voices. Studies found, for example, in a sample of in- and out-patients with schizophrenia and auditory hallucinations, a strong correlation between types of belief systems and coping strategies used to manage the voices (e.g. Sayer, et al., 2000; Soppitt & Birchwood, 1997). These studies show that people who hear benevolent voices attempt to engage with them whilst people who hear malevolent voices try to employ resistant strategies. The data, however, held a few anomalies in those participants who held conflicting beliefs about their voices, illustrating how their coping strategies altered accordingly. This suggests that the relationship between attribution and coping is relatively complex and, as such, interventions have to be tailored to enable treatment and coping strategies to be responsive to the belief system held (Sayer, et al., 2000). Knudson and Coyle (2002) conducted a phenomenological study of voice-hearers, exploring the meaning that the participants attribute to their voices and how this influences their coping efforts. Consistent with previous research, the study highlights the need to understand the individual's subjective explanation and experience of hearing voices in order to understand and work therapeutically with their coping efforts.

Religion and spiritual belief can significantly influence the lives of many. For those diagnosed with schizophrenia it can be both a source of strength and liability (e.g. Koenig, 2000). However, any of these belief systems are largely understudied, minimised and ignored by mental health professionals (Gearing, Alonzo, Smolak, McHugh, Harmon, & Baldwin, 2011). In a systematic review on the relationship between schizophrenia and religion and spirituality, Gearing, et al. (2011) found that religious beliefs and affiliations were related to better prognosis, higher quality of life, increased psychosocial adaptation, greater social integration and fewer positive symptoms, and were thus considered a general aid to recovery. In contrast, a notable number of other studies highlight the

negative associations between religion and schizophrenia symptomatology. Risk factors have been associated with the religious content of the hallucinations, high levels of mental distress, spiritual and psychotic despair, as well as increased social isolation. Research has also shown associations between religious belief and suicide, delay in treatment and substance abuse. This review demonstrates that religion can be either a strength or a liability for individuals with schizophrenia, and highlights the importance of exploring this further. The research does, however, rely mainly on comparative methodology, and despite the differences shown in the findings, little differentiation is evident between religions (Gearing, et al., 2011).

Resilience

Resilience refers to 'the capacity of people who are faced with adversity, to adapt, cope, rebound, withstand, grow, survive and define a new sense of self through situations of adversity, including psychiatric disability' (Pg 1, Deegan, 2005).

Deegan (2005) conducted a qualitative study exploring how people with psychiatric disorders demonstrate the capacity for resilience in their daily lives. The study found that when the participants were asked about psychiatric medication they turned their attention to discussing their own 'personal medicine'. Personal medication was found to comprise those activities that gave life meaning and purpose, and self-care strategies that served to raise self-esteem, decrease symptoms and avoid hospitalisations. Activities that gave life meaning were individual for each person, but involved connecting to others in society, for example singing in a choir or going to university. Self-care strategies included keeping busy, exercising and being involved in advocacy; all of these activities were emphasised as being helpful in alleviating various types of distress.

This supports the work of Spaniol (2001) who looked specifically at values that support recovery. He discusses the pivotal role of strength-focused rehabilitation as both an enabling and hopeful process, as well as developing empowerment and personal involvement. He considers empowerment to be a critical component; working collaboratively with the person can be empowering and create a sense of equality. The traditional medical model has often undermined this, leaving people with a sense of impotence. This collaborative approach requires professionals to relinquish power and appreciate the collaboration between SU and professional expertise (Topor, et al., 2011).

Personal involvement is seen as a vital adjunct to formal treatment; people are encouraged to get actively involved in their treatment and be a part of the decision making process. Sadly, service contact may have taught SUs that expressing an opinion can be unsafe, and evoke retaliation. As a result, people may require validation and support to participate due to their diminished confidence and trust in the process (Spaniol, 2001).

Finally, focusing on community activity, people are encouraged to regain a sense of identity through participation in the community, this reconnection to society being shown to promote recovery (e.g. Pitt, et al., 2007). This, however, can be thwarted by societal stigma and the consequential social anxiety this generates. Any prospect of recovery needs to be supported by stable conditions such as housing, finance, and meaningful occupations, accountable through appropriate legislation (Mezzina, Davidson, Borg, Marin, Topor, & Sells, 2006). This is often compromised by individuals' poor social functioning which renders them vulnerable to unemployment, poor housing and poverty (Fox, 1990). This in turn narrows their opportunities to reconnect socially in society.

People's identities can be diminished when friends are replaced by professionals in a psychiatric context (Topor, et al., 2011). From this perspective, connecting with others is essential in recovery, to reduce self-alienation and hopelessness. Family support is pivotal; they are able to reflect the individual's identity and personhood, reminding them of who they were before they became a 'psychiatric patient' and, furthermore, inspire a sense of continued hope (Topor, et al., 2011). In addition, SU friendships have been cited as a meaningful form of support and a positive reconnection to others (e.g. Longden & May, 2007; Topor, et al., 2011). HVGs seek to support this through providing a forum that allows people to meet who share the same experiences and thus feel accepted (Longden & May, 2007). Further, these groups enable people to experience a dynamic relationship where they can help others as well as receive support (Topor, et al., 2011).

The values that support change in recovery have also been shown to overcome the debilitating effects of shame. Shame is often avoided and rarely talked about in society; in fact it is often considered shameful to feel shame and, as a result, is rarely acknowledged (Byrne, 2000). The adaptive response to private and public shame is secrecy; secrecy, however, acts as a barrier to the presentation and treatment of mental illness (Byrne, 2000). Wang, Berglund, Kessler, Olfson, Pincus and Wells (2005) have shown that many people with mental health problems delay seeking and accessing treatment for periods of time because of ignorance, shame and other by-products of stigma. Van Vliet (2008)

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conducted a grounded theory study which explored the processes through which adults rebound from significant shame experiences. The purpose of the study was to develop a theory of recovery on the basis of the perspectives of individuals who recalled events or situations that elicited intense feelings of shame. Participants were recruited through a local newspaper advertisement and university postings in a large Western Canadian city. Volunteers were over 18-years old, had a significant shame experience that occurred in their adulthood, believed that they had made significant progress in overcoming or recovering from the situation or event, and a willingness and ability to articulate the shame experience and recovery processes. The participants disclosed a broad range of events and situations that elicited shame. These were grouped into one of four categories; social, moral or personal transgression; personal failure; ostracism or social rejection; or trauma. In the accounts of the participants, shame is an emotion that throws individuals into a state of disequilibrium and overwhelms their ability to cope. Shame affects how individuals view themselves as the way they relate to the world suddenly comes under attack.

The study found that shame undermines the individual's self-concept, infecting how they define and perceive themselves. The participants described themselves as 'bad', 'flawed', 'worthless', 'inferior', 'disgusting' and 'unattractive to others', and blamed themselves whilst in the throes of shame. It was also revealed that shame damaged the individuals' connection to others, to the extent that they reported feeling isolated and wanting to run away but felt powerless to act. The participants described wanting and attempting to avoid these feelings by ignoring, denying, forgetting, or suppressing them. Often avoidance occurred by minimising or rationalising behaviour or through self-destructive behaviours, such as drinking or taking drugs that functioned to suppress the feelings. From these accounts, Van Vliet (2008) was able to find five primary processes that enable the individual to recover from the shame event. These are:

- connecting (i.e. connecting with others to break the social isolation and withdrawal behaviour, finding allies that provide unconditional acceptance and social support, socialising with others to feel more connected in the community and to distract from the feelings of shame);
- refocusing (i.e. refocusing attention and shifting priorities to goals, interests, and positive experiences in order to counter-balance the negative judgements and powerlessness associated with shame, focusing on the positive by taking stock of personal qualities and achievements to elicit a sense of pride);

- accepting (i.e. accepting that they need to stop avoiding and instead show a willingness to face and address the shameful event, facing, expressing and understanding one's feelings);
- understanding (i.e. understanding external factors and contributions to the feeling of shame, separating from the shame, creating meaning); and,
- resisting (i.e. resisting against assaults on the self to decrease future vulnerability, rejecting negative judgements, asserting oneself).

Models of recovery

There are many accounts of personal recovery where individuals have taken control in their lives (e.g. Deegan, 1988) which have increased our understanding of the experience of hearing voices (Topor, et al., 2011). Smith (2000) explored the personal narratives of ten individuals who described themselves as either recovered or in recovery from serious mental illness. Five common themes were identified:

- Recovery is an individual process of learning to balance the difficulties of the illness with the desire to achieve positive goals linked to regaining a sense of control, a sense of self-respect and an appreciation for life.
- Recovery is a commitment to acceptance and change.
- Recovery is about addressing the barriers of stigma, symptoms, lack of financial resources, and occasional eruptive responses to life's pressures.
- Recovery required six critical factors; the right medication, a group of supportive people, meaningful activities, a sense of control and independence, a strong determination to remain in recovery, and a positive outlook on the present and future.
- Recovery requires a focus on maintenance. Strategies to aid this maintenance stage include; accept the disability, believe in recovery, ensure stabilisation, accept responsibility for recovery, establish structure in daily life, seek support, take care of oneself, stay active, educate oneself, and protect recovery.

The five stage model of recovery developed by Andressen et al. (2003), drawing from five models found in the literature reviewed (David & Strauss, 1992; Baxter & Diehl, 1998; Young & Ensing, 1999; Pettie & Triolo; Spaniol, Wewiorski, Gagne, & Anthony, 2002, c.f. Andressen, et al. 2003), offers a helpful framework in which to think about the process. The five stages of the model are:

1. Moratorium. This stage is characterised by denial, confusion, hopelessness, identity confusion and self-protective withdrawal.

2. Awareness. This stage is characterised by an initial awareness of and hope for the possibility of recovery. This may be an internal event or inspired by another person.

3. Preparation: The person commits to working towards recovery by considering personal values, strengths and weaknesses, finding out about the problem and services available, becoming involved with groups and connecting with peers.

4. Rebuilding: The person during this stage works towards goals and takes control in order to forge a positive identity.

5. Growth: The person is able to manage the illness and show resiliency. The person lives a full and meaningful life and is able to look to the future.

According to the authors, the constructs of this final stage mirror the dimensions of psychological well-being. Psychological well-being is defined as personal growth, self-acceptance, autonomy, positive relationships, environmental mastery, and purpose in life and could form outcome measures based on SU experience (Ryff & Keyes, 1995, c.f. Andressen, 2003).

Moving from more internal processes, Anthony (2000) explored the responsibility of services to promote recovery. According to this model, a recovery-orientated health care system would need to address the following assumptions:

- Recovery can occur without professional intervention.
- Recovery is a psychosocial phenomenon in that it occurs in the presence of people who believe in and stand by the person in need of recovery.
- Recovery is independent of one's theory about the causes of mental illness.
- Recovery can occur even though symptoms reoccur.
- Recovery is a unique process for each individual.
- Recovery demands that the person has options and that the acknowledgement that one has options is often more important than the particular option one chooses.

In addition, the impact of the consequences of mental health such as discrimination, poverty, segregation and stigma, were noted; something which services also need to consider.

This model is drawing on the professional's role to facilitate recovery and further points to the systemic nature of this process from individual and service, to wider society. Anthony

(2000) also points to the holistic nature of recovery and emphasised the need of a number of services in a recovery-orientated service varying from crisis intervention to self-help and practical support targeted at housing and finance for example.

Jacobson and Greenley (2001) draw together the models by describing a conceptual model of recovery that refers to the interaction between both the internal conditions the person in recovery undergoes (e.g. attitude, experiences, processes of change) and the external conditions (circumstances, events, public and agency policies, and professional practices) that facilitate this process. Qualitative analysis of the experiences of those with serious mental health conditions identified four internal conditions; hope, healing, empowerment, and connection. The research defined: hope as a belief that recovery is possible and a celebration of progress; healing as a separating out the self from the illness and finding ways to self-soothe and cope; empowerment as taking control and making personal decisions; and connectedness as a social process necessary for recovery.

The three external conditions identified are human rights, a positive culture of healing and recovery-orientated services. Human rights include reduction of stigma and equal access to resources such as housing, education and job opportunities. A positive culture of healing develops through a collaborative relationship. This relationship would show qualities such as tolerance, the ability to listen, empathise, show compassion, respect, and provide safety, trust and dignity (Jacobson & Greenley, 2001).

Process of recovery

Pitt et al. (2007) conducted a SU-led study that examined the subjective experience of recovery in people with psychosis. Seven interviews were analysed using IPA and several themes emerged from the data. The results revealed recovery to be a gradual, uneven process that occurs across stages and milestones. It is a relative process unique to each individual. Three key themes emerged; rebuilding of the self, rebuilding life, and hope for a better future. Rebuilding of the self was divided between understanding of self and empowerment, respectively. Understanding of self involves reconciling the past, increasing self-awareness and making sense of mental distress and the effects of the psychiatric system. Empowerment is central to the process of recovery and people with psychosis find many strategies to help achieve empowerment (e.g. seeking knowledge, self-reliance, developing a critique of mental health services, self-motivation). This research further showed that building a life through social support (e.g. family support, social relationships and networks) and active participation in life (e.g. creating a sense of

purpose, finding time for pleasurable activities) is key to recovery. Finally, recovery relates to hope for a better future which involves a process of change (e.g. from social exclusion to social inclusion) and desire for change (user involvement, collaborative approach, wider choice of treatment). This study highlighted that recovery is dependent on both internal and external mechanisms for change; this suggests that a more holistic approach to helping individuals in their recovery process is an essential requirement. In addition, the themes of empowerment, building social support, and a desire for change link to research focused on helping relationships. To this extent, collaborative relationships, where one is willing to learn from the patient, and where the professional displays qualities enabling the individual to engage with the support, are paramount (Pitt, et al., 2007). This would, in turn, enable SUs to have greater choice and autonomy in treatment. This is a valuable SU-led research project presenting participants' subjective experiences of recovery. As with many small-scale IPA projects, the generalisability of the findings comes into question. However, the findings are consistent with those of Deegan (2005) and Van Vliet (2008) who emphasised the central role of meaningful social interactions in recovery. This conceptualisation of recovery and its component parts, i.e. coping and resilience, begins to illuminate the person's role as actor in the recovery process (Davidson, 2003).

The HVN specifically believes that recovery is about learning to live a satisfying life with your voices. From their perspective, voices are messages that communicate emotional trauma in people's lives and are entwined in their life stories (May & Longden, 2007). In order to recover, individuals need to understand, accept and integrate the emotional meaning of the voices through a process which involves learning to cope both with the voices themselves, as well as the original problem central to the experience (May & Longden, 2007). The assertion is that people are able to recover socially and psychologically and live with the voices (McCabe, et al., 2007). There is now a general consensus that recovery for people who hear voices occurs through three phases (e.g. May & Longden, 2007). The first phase, the 'Safety Phase', centres on learning to cope with the fear, anxiety and shock of the onset of the voices, as well as the impending fear of the potentially catastrophic reactions of others. The second phase, 'Making Sense of One's Experiences', focuses on applying the skills from phase one to explore the meaning of the voices. In order to do this, the individual needs to attend to the significance of the voices by considering past and present events, as well as by understanding the underlying emotions that the voices represent. In doing this, the individual may begin to find clues in their voices which identify inner conflict that needs addressing and re-channelling (May & Longden, 2007). The final step, 'Socially Reconnecting', requires

the individual to adapt their relationship with their voices, so that the new meaning can propel the person forward to create a life where the voices can be in synchrony rather than in conflict with the person. As part of this, the individual needs to reconnect through valued activities and roles within society (May & Longden, 2007).

This model has been grounded within the research on recovery from trauma and from hearing voices. However, from the literature reviewed there are few studies which ask people about their experiences of recovery (e.g. Smith, 2000; Pitt, et al, 2007). Much of the evidence is coming from reviews of literature which include SU accounts (e.g. Andressen, et al., 2003; Ruddle, et al., 2010) and these are reviewed according to the focus of the paper.

Aims of the research

From the literature it seems that the role of the individual is to actively embark on a journey of recovery. Whilst all models differ to an extent, a number of change values that support recovery are commonly cited such as hope, empowerment, and social reconnection (e.g. Pitt, et al., 2007; Spaniol, 2001; Jacobson & Greenley, 2001). The individuals' experience and pursuit of recovery does not sit in isolation and research suggests that these internal mechanisms interact with external mechanisms of change. These external mechanisms of change linked to services and wider society include stigma, opportunities to access housing, education, treatment, and job opportunities as well as environments conducive to healing (e.g. Jacobson & Greenley, 2001; Anthony, 2000; Smith, 2000), all of which recovery-orientated services have a responsibility to facilitate and support (Anthony, 2000). At present there is no literature found exploring the individual voice-hearer's experience of support with this interaction in mind.

This study seeks to understand individual voice-hearer's experiences of support and how this links to the participants' experiences of coping, resilience and recovery. Specifically, the purpose is to answer the following two questions;

- What is the experience of support you have received in relation to hearing voices?

- How has this support influenced your coping, resilience and recovery?

METHODOLOGY

Interpretative Phenomenological Analysis (IPA)

IPA has been developed as a distinctive approach to conducting qualitative research in psychology which offers both a theoretical foundation and procedural guide (e.g. Smith, Flowers, & Larkin, 2009). It has been demonstrated to be a valuable tool in health, social and applied clinical psychology research (Reid, Flowers, & Larkin, 2005).

IPA is informed by three key philosophies: phenomenology, hermeneutics and idiography (Smith, et al., 2009).

Phenomenology

IPA is primarily borne out of phenomenological philosophy (Husserl, 1970), which explores meanings, personal accounts and perceptions that particular experiences and events hold for people (Smith & Osborne, 2008). The aim of IPA is firstly to develop an insider perspective by exploring in detail how participants make sense of their personal and social world to clarify situations that occur in everyday life (Smith, et al., 2009). Smith et al. (2009) detail the relative contribution of four major philosophers: Husserl, Heidegger, Merleau-Ponty and Sartre.

The work of Husserl lays the fundamental principle of phenomenology, to go back and carefully examine the phenomenon in question in order to understand it. This central idea was further extended by Heidegger, Merleau-Ponty and Sartre who incorporated the influence of the social world, highlighting how living in this complex system influences both understanding and perception of any lived experience (Smith, et al., 2009).

IPA therefore views and recruits individuals as experts on their own experiences who can offer researchers an understanding of their thoughts, commitments and feelings through telling their own stories, in their own words (Reid, et al., 2005).

Hermeneutics

Hermeneutics is the theory of interpretation and is typically seen as the second theoretical underpinning of IPA (Smith, et al., 2009). The study of hermeneutics originates quite separately; it was initially developed to understand biblical texts. However, the work of three key hermeneutic theorists, Schleiermacher, Heidegger, and Gadamer, provides

theoretical insights into IPA as an interpretative methodology. Schleiermacher conceptualised interpretation as a creative art form which allows one to understand the writer and the text, as well as the wider context that the text was produced in. Hermeneutic phenomenology, coined by Heidegger, draws attention to the effect past personal experiences, assumptions and preconceptions have on our subjective experience and, in turn, our interpretation of it. Gadamer goes on to emphasise the complex and dynamic relationship between the interpreter and the interpreted and how this will both reveal and alter any preconceptions about the experience. The hermeneutic circle is an agreed and well established concept among hermeneutic writers; entry into text can be at many levels and these levels are all interacting but provide unique meaning ranging from the part to the whole. IPA recognises that the production of an interpretative account is a function of the relationship between a researcher and participant, constructed and shaped by their encounter (Larkin, Watts & Clifton, 2006) and for this reason stresses the importance of transparency of the interpretative process through reflexivity. Although the ideal is to gain an insider's perspective of the participant's unique world, the process is complicated by a double hermeneutic of the researcher and participant and this is accounted for within the methodology (Smith & Osborne, 2008). The researcher will have been socialised into a set of norms that may differ from the participant's, and will have a set of preconceived ideas which may frame the interpretation of the results. Access to the participant's world is accessed through the researcher's own conceptions, which in turn enable the researcher to make sense of that individual's personal accounts through an interpretative process (Smith, Jarman, & Osborne, 1999). The acknowledgement of this interactive process enables the researcher to acknowledge their own assumptions, beliefs and experiences and bracket any taken-for-granted assumptions. In this way, the research documents the journey of the interviewee and the researcher to consider how the themes and conclusions were reached, thus providing a real representation of the process (Lester, 1999).

Idiography

Idiography, the final major influence, is concerned with investigating detail and thus understanding how particular lived experiences have been understood from the perspective of a small group of specific people, in a specific context (Smith, et al., 2009). This contrasts with the typical nomethetic approach which attempts to make grand inferences from large samples.

Methodological Considerations

Why IPA?

IPA was chosen as the most appropriate methodology because of its compatibility with the epistemology of the research question. The experience of hearing voices and recovery is controversial and this is reflected in the many service models, goals and opinions on cause, practice and treatment. Recovery is a relatively new concept applied to people who hear voices and policy, legislation and service provision has altered dramatically to incorporate this. However, the word recovery is used to mean different things and is represented by numerous definitions and so the adoption of this varies dramatically (NIMHE, 2005). There is much research presenting recovery frameworks and recovery processes but little direct research asking people about their experience of support and recovery. This research seeks to ask the participants about the support that they have been offered in relation to hearing voices and how this has influenced their coping, resilience and recovery. IPA is suited to exploring individual accounts and perceptions to think about a particular experience and emphasise the importance of going back to the phenomenon in question to do this (Smith, et al., 2009). Given the historical and political context of the treatment of those who hear voices, I wanted an idiographic method that would enable the exploration of differences, similarities and relative nuances of the individual's accounts to remain true to the participant's experience. Finally, I wanted a method that would acknowledge the double hermeneutic in the interpretative process. As a researcher, a clinician and, for the purpose the research, a HVG member, I have a wealth of experience, knowledge and opinion that will influence my interpretation. Whilst I can go some way to bracket that off and be openly reflexive, it is true to say that the accounts will be interpreted according to my own frame of reference. The acknowledgement of this provides the foundations for a transparent interpretative journey important for quality in qualitative research.

Weakness of IPA

One of the relative weaknesses of IPA is that it doesn't ask the participant "why?", and given the expertise that individual has, this could potentially lead to a greater and more fruitful understanding. The difficulty with participant explanation is that it can result in a triple hermeneutic which detracts from the description of the experience bringing in a more critical perspective (Alvesson & Skoldberg, 2000). Also, the method relies on the individual being able to explain the experience verbally. Some experiences linked to trauma, for

example, often lead to lost or distorted memories which may colour the interpretative process (Herman, 2001). However, this research is not concerned with such experiences and care has been taken in the construction of the interview schedule to help people verbalise their experience.

SU Involvement in Research

Given the level of distrust in professionals and general dissatisfaction with the psychiatric model among the HVG members, the involvement of SUs was an integral process in the development of the research. A SU participatory approach empowers the participant in the research process and thus alters the power differential between the researcher and the researched. There are four types of participatory research; contractual, consultative, collaborative and collegiate, with each one differing according to the degree of empowerment that the participant has over the research process. PAR, for example, includes the SU as co-researchers and is considered a collaborative or collegiate approach (Biggs, 1989, c.f., Cornwall & Jewkes, 1995). This research employed a consultative approach in the initial planning and development stages and used IPA for data collection and analysis; this is where people are asked for their opinions and consulted by researchers (Biggs, 1989, c.f., Cornwall & Jewkes, 1995). In this research, participants were asked to consult on a number of different issues and decisions such as the relevance of the research question and the usefulness and accessibility of the information provided in the information sheet. In addition, the group was asked their opinion on, for example, the timing and location of the interviews as well as the support offered after. This ensured the research was relevant and accessible to those who hear voices and enabled the research to take place within the self-help group without undermining group safety.

Design

This study is a qualitative study designed to explore experiences of people who hear voices. Seven participants were interviewed, using a semi-structured interview schedule. Interviews were transcribed, and analysed using IPA.

Participants

Participants were all members of a local HVG. Seven people (4 males and 3 females), aged between 25 and 65, consented to be interviewed. Smith, et al., (2009) recommend interviewing between 4 and 10 participants of an IPA study at doctoral level. This is so that

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one can balance the need for quality and richness in the analysis with practical constraints. A greater number of participants may be overwhelming and lead to losses of meaning and interpretations in the data.

Inclusion and Exclusion criteria

Individuals considered eligible for the study:

- reported having the experience of hearing voices, or voices which other people cannot hear which are not caused by any organic condition;
- were between 18 and 65 years of age;
- attended the Hearing Voices Network Self-Help Group;
- were willing to discuss their experiences;
- were able to consent to participate in a fully informed way.

Attending the hearing voices self-help group was an essential element of the eligibility criteria. This was because someone who lives independently and makes the decision to attend a self-help group is considered able to provide informed consent to participate. They would also be able to consider their own needs if they became distressed, assuming support options are provided. Individuals were excluded from the study if they did not meet the above criteria. Additionally, individuals were excluded if the study had the potential to cause distress that would result in an increased risk emotionally or physically for that individual or the researcher; this was assessed by the group facilitator and responsible clinician. The individuals in the self-help group were all voluntary members and, by the nature of the group, contextual information about individual members is limited. Acknowledging this, the Group Facilitator conducted informal risk assessments based on his knowledge of the group members, and was in a position to enforce this exclusion criterion. During recruitment, nobody who volunteered had to be excluded according to this criterion; in fact, the individuals who seemed most distressed at that time did not offer their involvement. Furthermore, none of the participants required support following the interview.

Recruitment

The participants were recruited from both past and current members of a local HVG. The HVG was a useful forum for recruitment as the members were all voluntary and had insight into their difficulties. Participants were recruited through my weekly attendance at the group and telephone contact. I attended the group for 18-months in total.

Procedure

The group generally varied each week although there was, in the main, a consistent core of people. On average there were about five or six people per week in attendance, all of whom varied substantially in age, ethnicity, religion, socio-economic and mental health status. As group membership and attendance fluctuated significantly, my original plan to consult with the group on certain dates altered. Instead, I began to attend the group weekly or fortnightly to enable me to reach the maximum number of members; this also demonstrated my commitment and genuine interest in the group.

The group is not exclusive and for that reason the research was placed on the agenda each week so that new or returning people could learn about the research and have the opportunity to participate if they chose. The information was presented as a brief summary consisting of what the research was about, why the research was being done, and what participating would involve. If anybody showed an interest I gave them my information sheet and spoke to them at the end of the group. Five of the participants volunteered in the group, and two were previous members who attended irregularly and therefore telephone contact was made. In the first instance, this was conducted by the group facilitator. If they were happy to participate then the call was followed up by myself so that arrangements could be made.

The HVG consulted at each stage of the development of this project. Firstly, they advised on the usefulness and feasibility of the research question, the information pack provided which included the information sheets and consent forms, the research questions, as well as other practicalities such as interview location and support provision. This collaborative approach was adopted following the concerns the group had in relation to academics and professionals, based on prior experiences, to promote engagement, and to ensure that the research would not undermine the group safety. At the initial consultation, there were six members of the group in total and four took a positive interest and provided some feedback. The other members did not contribute to the discussion, showing little interest in the research. The individuals who contributed suggested that they would be interested in taking part if they could consult on the interview questions. This request was borne out of two concerns; firstly that they would not understand the question, or that questions may be asked that were insensitive, irrelevant or too distressing to answer. These members also said that they were happy for me to attend and do the research on the condition that they, as participants, were given confidentiality and anonymity, as well as feedback on the

findings. Seven members of the HVG looked at the information pack and were happy with the content. Five people recommended that I change the font and text size and two people specifically said that they liked the format of the information. Four people consulted on the interview questions and were specifically asked if they felt the questions were relevant and appropriate and they agreed that they were.

Group membership: Process

Membership of, and my acceptance within, the group changed over time. An initial plan to recruit through the group facilitator was not possible because of the group's wariness of people 'using' the group for their own research purposes. Some members felt this was acceptable if the researcher was willing to donate to the group, whereas others felt like 'guinea pigs', and wanted the group to remain a safe exclusive group for voice- hearers only. The group had previously experienced having students attend as the facilitator was supportive of research and is highly sought after by those interested in this area. However, the group had experienced what they described as 'poor attitude' and 'false promises' which they were fed up with. It was at this stage that I was introduced to the group. This climate was not comfortable and it felt clear that the fact that one of my research supervisors facilitated the group did not entitle me to attend. Moreover, I was concerned that they should not feel used by me as this conflicted with my own aims, and views, about the purpose of a support group. Interestingly, I felt inadequate and labelled; labelled as an educated posh professional that knows everything but understands little. I knew that the group facilitator was accepted as a professional because of his own past experience of being a patient within the psychiatric system and his ongoing commitment to the group and message of recovery. I wanted the group to understand my genuine interest and commitment to the research area so I informed them of my own background as a carer and daughter of someone that hears voices and my drive to learn more about the process of recovery, resilience and everyday coping. This not only appeared to legitimise my attendance, but also made it easier for me to recruit their expertise on the research process as a means of closing down the divide between 'us' and 'them'.

Following this initial acceptance from the group and engagement with the research process, I continued to negotiate challenges to usual professional boundaries. For example, the facilitator would open the group by asking each person in the room to say how their week had been. In the main, people would talk about difficulties associated with their experience of hearing voices. The facilitator included both himself and me within this and I had to negotiate my answer to be genuine and fitting without compromising my own

boundaries. In addition, the group discussions certainly challenged some of my own ideas and values and part of my membership of the group involved assimilating some of these ideas to be more open minded, particularly for some of the spiritual and dietary means that some people adopted for aiding recovery.

Over the course of 18-months' membership, I got to know some of the participants very well and had to consider how having a more personal relationship with some contrasted to a snapshot interview with another would impact my interviews and analysis. In terms of the data collection, I interviewed everybody before I got to know anyone more personally and any additional knowledge gained from membership following the interview was used to develop pen portraits of the participants. In terms of the analysis, my membership of the group certainly influenced my overall understanding of the experience and potentially shaped my interpretation; if, for example, there was a discrepancy between what they said and how they appeared. To balance this, however, the one interview that initially heavily influenced my analysis was someone that I had a one-off interview with but who I could relate to personally. These issues were addressed through regular supervision.

Setting

The HVG is held in a room of a large building which provides office space for local organisations such as MIND, supportive housing and legal services. The interviews took place in a side room adjacent to the room used by the group. This was where group members identified that they felt safe and comfortable. The interviews were then scheduled either immediately before or after the group in order to make participation in the study a more convenient process, and enable the provision of immediate support by the group facilitator following the interview if this was required. This set up provided a quiet and private location within a building that was occupied throughout the working day if any problems were to arise.

Data collection

Interviews

The data were gathered from semi-structured interviews. The interview schedule comprised a small (6-7) number of open-ended, non directive questions that afforded participants an opportunity to share their personal experiences (see Appendix 4). The schedule was simply used as a guide, thus allowing the individual to tell their own story. A number of structured prompts were used to elicit more specific, personal accounts of

coping, resilience and recovery. Following the interviews, detailed notes were made recording initial impressions and reactions as well as anything that may have affected the interview, for example interruptions. All the interviews lasted between 30 and 90 minutes and were audio recorded and then transcribed, with all identifying information either removed or disguised.

Data Analysis

The analysis was conducted through a number of stages, as described by Smith and Osborne (2008, see Appendix 5). A considered approach was taken to quality and validity within the analysis. The analysis was guided by research exploring quality in qualitative research (e.g. Yardley, 2008, c.f. Smith, et al., 2009) and monitored routinely through supervision by two experienced clinical psychologists at each stage of the analysis. All of the seven interviews were transcribed and analysed, with the exception of the second half of interview 2, 'Katherine', which failed to record.

Each transcript in turn was read and re-read until familiarity was gained, and notes were written on interesting and significant points in the text. This involved summarising and paraphrasing aspects of the person's accounts as well as making preliminary interpretations (see Appendix 6, Figure 1). These comments were then collated to show any similarities and differences, as well as echoes, amplifications and contradictions. Although commonalities in themes began to emerge, care was taken to acknowledge new issues emerging in each transcript, thus paying attention to ways in which accounts from participants were similar but also different (Smith & Osborne, 2008). Each person's transcript was then colour coded according to the emerging themes (see Appendix 6, Figure 1) and single case themes were drawn as part of a pen portrait (see Appendix 6, Figure 2). The themes were developed within each individual transcript initially then collated across all seven transcripts to elucidate any sub- and master themes. When all seven participants' transcripts were analysed and compared, the master themes and the sub-themes were compiled on A1 paper. This acted as a visual aid for validity checking (see Appendix 6, Figure 3). The master theme table with the sub-themes, emerging themes and verbatim quotes were then drawn (see Appendix 6, Figure 4). The master themes were then transformed into a narrative account to act as a framework to understand coping, resilience and recovery in people who hear voices, illustrated with verbatim extracts.

Ethical Issues

Ethical Approval

The research project was approved by the local University Research Ethics committee (see Appendix 1). All the participants were provided with an information sheet (see Appendix 2) and consent form (see Appendix 3) and approval was granted by the committee before the interviews took place.

There were four main ethical issues that were considered during the research process:

Informed Consent

The group members understood that consenting to participate in the research involved a one-off interview and that my presence in the group would not compromise the typical standards of confidentiality. Someone who lives independently and makes the decision to attend a self-help group is considered able to provide informed consent to participate and consider their own needs if they became distressed, assuming support options are provided.   However, given the potential for change in people's mental health, informal risk assessments were conducted by the group facilitator and it was decided that people would not be permitted to participate if the study had the potential to cause distress that would result in an increased risk emotionally or physically for that individual or the researcher.

Gaining informed consent from the participants was an ongoing process throughout the research given my extended membership in the group. The HVG was not an exclusive group and membership was variable and for this reason weekly or fortnightly attendance was required for the purpose of consultation and recruitment. Permission was sought from the group on a regular basis to attend and explained that this was to maximise the contact I had with different HVG members given the variability in attendance. This was stressed to minimise any pressure to participate given my extended membership and developing relationships within the group. The research was placed on the agenda weekly to introduce myself and the study which provided the members the opportunity to ask questions and consider whether they would be interested in taking part. Although the group understood that I was there as a researcher, the group was informed of my own personal circumstances and each week I was included in their agenda items and discussions. The group actively encouraged carers, voice-hearers and professionals (by appointment) to attend the meeting and to participate in the group to promote greater

understanding. Whilst I was keen to learn more about the experience as part of my own professional and personal development, my research agenda item was an important reminder to the group about my position as a researcher and the aim of my attendance. The research item was placed at the end of the group agenda so not to interfere with the priorities of the group.

If people in the HVG showed an interest in participating they were given an information sheet which detailed key information about the research, responsibilities of the researcher and their rights as a participant. Participants had this written information for at least a week before the interview was booked to provide an opportunity to consider the information.

The HVG did consult on a number of key issues with the planning and development process and any suggestions offered were noted and read back and any changes made in response were discussed with the group. Although the group gave permission for this consultation process to happen, informed consent was not sought for this process as this was done informally within the wider group. The purpose of this consultation was to make the research accessible and relevant as well as maintain group safety and foster engagement in the research process.

Group Safety

The HVG is one of the primary or only means of support for the participants.   As such, an integral consideration was how to gain participation without compromising the function and safety of the group. The research was placed on the weekly agenda. This was essential as membership fluctuated, to the extent that I routinely explained to people who I was, and why I was there and sought their permission to join the group.

Long term membership in the group showed consistency and commitment; however, it also led to the development of relationships within the group context and the negotiation of boundaries that wouldn't typically be seen in a one-off interview. This was something that I was mindful of and in order to manage this I made decisions to limit my participation; for example, not actively offering information about my mother and the personal circumstances that surrounded that relationship, not being overly personal with how your week has been by choosing something general that others could relate to such as being busy or tired.

Confidentiality/ Anonymity

Confidentiality and its limits were clearly detailed in the information sheets and explained verbally to the participants. Participants were informed that the information that they provided me with would be anonymised and discussed only with the research facilitators. They were also informed that all personal identifying information would be removed from written transcripts and any quotes used within the write-up would be sufficiently anonymised. All data was kept securely and confidentially at the author's home. The participants were also told that if they divulged anything that related to them wanting to actively harm themselves or others then this would be discussed with the group facilitator to consider what support they may need and could be offered.

Participant Support

Talking about difficult issues can be highly distressing and, given the level of vulnerability linked to people who hear voices, a number of support options were put in place following the interviews. This was guided by the participants in the consultation. The interviews were scheduled before the group so that they could be supported within the group with any issues or feelings that arose and offered time with the facilitator before or after the group to reflect on the experience and think about any additional support they may need.

Quality in qualitative research

Assessment of quality in qualitative research has received a lot of attention for two reasons. Firstly, quality assessment has been compared with dissatisfaction to the rigour involved in quantitative psychology; and secondly, attempts have been made to alter this discrepancy according to the reliability and validity criteria of quantitative research, which has in turn been criticised for being simplistic and prescriptive for what is required for qualitative research (Smith, et al., 2009). A more sophisticated attempt at assessing quality in qualitative research by Yardley (2000, c.f. Smith, et al., 2009) offers criteria of quality, irrespective of theoretical orientation (Smith, et al., 2009).

Yardley's Criteria

Yardley (2000, c.f. Smith, et al., 2009) presents four principles for assessing quality in qualitative research. These are as follows:

1. Sensitivity to Context

   Yardley argues that good qualitative research will show sensitivity to context. This can be demonstrated in a variety of ways through the research process, for example through showing sensitivity to the;

   - cultural milieu the research is situated within

   - the existing literature

   - choice of, and adherence to, the method

   - interview process

   - analysis process.

2. Commitment and Rigour

   Commitment can be shown in a number of ways. In IPA there is an expectation that commitment will be shown in the degree of attentiveness to the participants during data collection, and the care with which the analysis of each case is carried out.

   Rigour refers to the thoroughness of the study, for example;

   - the appropriateness of the sample to the question

   - the quality of the interview and the completeness of the analysis.

3. Transparency and Coherence

   Transparency refers to how clearly the stages of the research process are described in the write-up of the study. Coherence refers to the logical process of writing it up, for example;

   - Does it present a coherent argument? Do the themes hang logically together? Are ambiguities and contradictions dealt with clearly?

4. Impact and Importance

   Yardley notes that the major test of validity is whether it tells the reader something useful, interesting and important.

Position as researcher

Self-reflexivity

I am a 30-year old white British woman training to become a clinical psychologist. I have worked with a wide variety of people across the lifespan, working with a wide range of mental health problems in a variety of contexts. My preference and natural orientation is to work systemically, adopting a bio-psychosocial approach to mental health.

My interest in hearing voices is personal in that my mother is a voice-hearer, diagnosed with schizoaffective disorder and social anxiety. My primary experience of treatment and perceptions of recovery was observed during the 1980's and 1990's as a child when my mother was undergoing inpatient and outpatient care. The treatment regime appeared harsh and punitive, and the outcome of this was traumatic and damaging to the whole family system, leaving long-lasting residual effects. The understanding of, and treatment in, mental health is constantly changing and updating. I was therefore keen to understand the experience of others who hear voices, learn about the support they received and how this links to their coping, resilience and recovery.

RESULTS

This section presents the results of the IPA of the seven participants' accounts of support relating to coping, resilience and recovery of those who hear voices.

The following section provides a pen portrait for each of the participants. These were derived from a variety of sources; demographic information collected at the beginning of the interview from the person, the interview transcripts, and from my impressions developed from observations within the group. For reasons of confidentiality, all names have been changed. These descriptions have been provided to add individual context to help the reader understand the quotes presented later in the results section.

Participant 1: Lee

Lee is a black British man in his early 40's who attended the group regularly during the last 6 months of my membership. Lee began to hear voices following a traumatic accident when he broke his neck. Lee always attended the group carrying a large diary which he would often refer to, and add to, during the group. He came across to me as an organised man who generally only spoke when he had something to say that he thought would add value to the conversation. Lee was pro-active in his recovery mission and talked about the importance of actively structuring his week and meeting positive goals. He believed in the power of having a positive mental attitude and used this as a strength in fulfilling his part-time job, obtaining his house and pursuing his voluntary position as a prison worker.

Participant 2: Katherine

Katherine is a white British, older married lady who attended the group twice during my membership. She was a polite, quiet lady who only spoke when addressed but who, in my opinion, albeit reluctantly, demonstrated wit and a good sense of humour. Katherine began to hear voices when she was 12-13 years old. She was diagnosed with Anorexia Nervosa as a teenager and hospitalised for this condition, and later diagnosed with Schizophrenia.

Demographic information was not obtained for Katherine and the second half of her interview failed to record; for this reason only half of her interview is included in the analysis.

Participant 3: David

David is a 25-year old white British man. He is an articulate man who comes from a wealthy family and has a sister who also hears voices. David is experimental in his approach to his recovery and tries varying dietary and spiritual methods in order to help him feel less distressed and preoccupied by his symptoms. He spent six months at a Buddhist retreat in order to bring about stability in his life and mental health. David has ambitions to become a Clinical Psychologist and at time of interview was beginning to pursue the top-up qualifications needed to apply for the professional course.

Participant 4: Roshan

Roshan is a 35-year old man who attended the group for the final two months of my membership. His family is from Pakistan and he is of Muslim faith, an important part of his identity. Roshan was a smartly dressed, composed person who struggled to engage with the group. He would be dismissive of the other group members' expertise and instead seek solutions only from the facilitator of the group and clinician.

Roshan experienced isolated visions and voices during childhood which were dismissed as bad dreams and he was eventually diagnosed with Schizophrenia when he was 25-years old. Roshan could be described as a circumstantial historian, that is, he describes in particular detail complete accounts of his past; this seemed to reflect his general level of anxiety. However, in an attempt to be heard within the group he tended to dominate and overwhelm. This may have had a systemic impact making it hard for him to engage in services and receive the help that he needed.

Participant 5: Laura

Laura is a long standing group member who often helps facilitate the group. She is mixed race British, in her early 40's, married with six children, one of whom also hears-voices. Laura was first diagnosed with Paranoid Schizophrenia when she was a teenager. Laura is a strong and helpful person who has clearly come a long way in her recovery. She has learnt many strategies to help with her voices and will often guide other group members. She now runs her own business with a close friend providing and promoting mental health training.

Participant 6: Kamal

Demographic information was not collected from Kamal. Kamal is a Pakistani man, who attended the group intermittently for about 4-months of my membership. Kamal appeared

to have a very depressed persona. As well as hearing voices, he struggled with ongoing pain that made daily activities a constant struggle. Kamal could not think about the future and would only focus on the here and now. He felt very helpless against the power of his voices. He was a subdued and quiet person who struggled with his temper. He found the interview very difficult as his voices were bombarding him with messages that I was the local vigilante, and that the interview was going to be used by the government to 'get him'. He managed to complete the interview but made sure that there was a table between him and me to ensure that if he were to get angry he would not do something that he would regret.

Participant 7: Martha

Martha is a white British woman aged 29 years, who works in a mental health and research setting. She began to hear voices when she was 18 years old. She is an active member of the Post Psychiatry Movement (PPM) and works with renowned writers to promote equality for those who hear voices. At the time of interview she was about to begin her PhD and continue with this work. Martha attended the group once when I was a member but had attended regularly previously.

Master Themes

A total of six master themes emerged from the analysis of these individuals' personal accounts. Below is a table of the master themes with their corresponding main sub-themes. Some of these sub-themes have further discrete topics within them to reflect an added dimension; these are hyphenated in the table and are described further in the analysis.

Table 1: Master themes with the corresponding sub-themes

Master Theme	Sub-Theme
Psychiatry: A form of social control	Social control - Enforcement
	Dehumanising
	Playing the game
	Contempt - Defiance
Psychiatry: A clinical model	A pessimistic and paternalistic system - Disinterest
	A schizophrenic
	Blind faith
Trauma, trauma, and re-trauma	Trauma, trauma and re-trauma
	Stress-vulnerability
Voice awareness	Post-psychiatry movement - An avenue of channelled outrage - A person with potential - Protecting our vulnerabilities
	Hearing voices group: a fellowship - An inspiration
Dancing with voices	I hear voices
	Belief
	Disintegration
	Coping: self-management
	Deconstructing the experience
	Recovery - Voices: learning to live together

Master Theme	Sub-Theme
Relationships: A lack of understanding	Family and friends - Social isolation
	Social acceptance
	Secrecy

The contribution of each participant to the themes listed above is also included (see Appendix 7).

Psychiatry: Social Control

This theme explores the personal experiences of social control within the psychiatric system and how this power has in turn affected these interviewees.

Social control

A strong and recurrent theme emerging from the analysis was the use of psychiatry to control and regulate the behaviour of those with psychosis. Interviewees felt that this method of regulation was too restrictive and, at times, it was likened to being imprisoned. This was most evident with Lee who repeatedly cross-referenced the psychiatric system with the prison system; saying, for example, '*She sectioned me under Her Majesty's pleasure*'. Lee also revealed that he '*went into the psychiatric system after trying to blow himself up*' and further noted in a subsequent part of the interview that:

> *Since then I've had to monitor my behaviour because my psychiatrist wanted to section me under Her Majesty's pleasure so I had to put the suggestions of the voices if they're not... within society's rules then I have to ignore what they say to me.*

Roshan likened psychiatrists to tools used to remove one from society; he says:

> *I think going into hospital is essentially another way of controlling people. So if a person commits a crime the police control them by putting them away, so if you have a mental health problem... Psychiatrists are used as a tool to get you – to move you away from a situation in a community and put you away in a hospital somewhere.*

This cross-referring of psychiatry and the prison service mirrors a belief that people who hear voices are bad and dangerous and need removing from society for theirs and others' safety. Many in the sample note that their freedom is often restricted because of the

danger they are perceived to pose. Roshan said '*there is a safety factor, linked to it that, are you safe to be in the community'*. Here, mental health services are perceived as an over-zealous community risk management enforcer. Roshan goes on to say:

> *The problem with psychiatry is that they're there to look at you from a safety point of view and this and that, so they section you.*

The power to section seems to leave people feeling fearful about what is acceptable to say and do. For example, Kamal comments:

> *If I said this to my, you know, Psychiatrist or my GP then I'd probably be on a section or something... A danger to the community.*

David highlights the debilitating effects attached to the fear of being sectioned:

> *I was arguing... erm... with my parents about what the psychiatrists had been saying, disagreeing with it and feeling, sort of, very powerless, and that I could potentially be sectioned or something.*

Psychiatry is also associated with providing medication:

> Roshan: *that's all what I think Psychiatrists do – it's nothing to do about really healing people properly. 'Cos giving medication that nearly... you know, here there and everywhere, is not really a proper solution.*

This can leave people feeling numbed and out of sorts. Kamal described his experience of being on medication: '*I'm just tanked out on my medication'*.

This seems to leave people feeling that they are in a no win situation, as David describes:

> *I was sort of caught in a trap between wanting to have my symptoms recognised but not wanting to be forced into hospital but wanting to do different things about it and basically that didn't compute with the psychiatrist... and because that didn't compute with her she said I'd made everything up I think.*

This quote demonstrates his frustration of needing and wanting help, but not wanting to be forced into a very linear, prescriptive, clinical help model, and so feeling that the psychiatrist used her position of power poorly in suggesting that his symptoms were contrived.

- Enforcement

Being controlled by a prescribed treatment regime from diagnosis is central to this theme and draws attention to the role of force. David describes his experience of being forced in and out of a system:

> *I've had people try to put me in hospital twice when I was younger, and, erm... they said that there weren't any beds...erm... I've never been into hospitals, erm... and I could – they refused to see me on the NHS, so basically I haven't met many people with similar kind of problems.*

Roshan described his experience of being forced to comply with a particular treatment regime:

> *see I went to see my psychiatrist yesterday 'cos he insisted 'cos I went, because of the psychosis and... medication... so what it was is that like, I'll give you an example, like...erm... what I did was yesterday – they insist that I do things. One is that I go for the blood test, one take the medication, one see them.*

Both these examples demonstrate the pressure individuals are placed under to abide by the instructions of professionals within the mental health system once they are labelled with psychosis or deemed to be 'unsafe' in the community.

Dehumanising

There were times when they felt that all their personal qualities had been reduced to a set of symptoms or a patient number:

> Roshan: *I don't think it's really good to 100% to rely on government because they don't look at you as a whole person – they look at you as just a number.*

Kamal recalls being inspected and interpreted only within the realms of mental health assessment.

> *I find it really strange that, you know, as soon as he's got his piece of paper and he's numbering all these questions, and then I have to give replies to all these questions and then he grades them all, and then I- I'm sure he draws a line like that and adds it up, and if I get x amount of points, and then that's about it*

Playing the Game

In order to escape the system or minimise the control, people described how they needed to learn how to play the game. Collectively, a number of strategies were listed. Laura, for example, described the importance of learning to present the ideal or correct answer:

> *if you talk about voices it's like "[sound of surprise], oh my God, call the crisis team!", you know, so... You just learn to just say "I've had a wonderful week; I've had my tablets and I'm feeling good". That's basically the psychotherapy part. Exactly the same with the Psychiatrist. [ ]...Yeah, the Psychiatrist want to hear "yes, my Haloperidol is being taken every single day; yes my Prochlorozine's taken every day"*

Kamal noted the value of minimising the information given to the professionals:

> *Just go in, answer his questions, give him the least amount of information, and get the hell away from there as fast as possible.*

Some interviewees would talk of being careful, all the time, not to reveal that they continue to hear voices.

> Laura: *"We're just making sure you're not hearing voices" and you'd just say "well, I do still hear voices", so it's like "would you like to come back to hospital?". You know, so you've got to be careful.*

Roshan and David warn of not creating any personal reactions that cause negativity or upset.

> Roshan: *he should've not been on the computer sat in front of me, but I wouldn't want to say, 'cos he maybe had a reason. You know, I'm a bit careful with psychiatrists – this legality thing as well. I mean, you say something and they'll take it as a slur...*

> David: *I didn't know, like how it works or what they did so I thought what I was doing was just normal, but I think she basically was offended [laughs] and decided to say I was making it all up [ ]... Well, I suppose if I'd been a bit wiser about how psychiatry works then I could've been a bit more canny about it.*

While David implied that really you need to be clever in the system to win the game and get what you want and need, Laura, on the other hand, implicitly noted the power of acknowledging her own worth:

> *And I was proud the other week because I was running late, but I turned up. And he says "well I've got time to talk to you actually", and I said "but I don't, sorry, goodbye" [laughs].*

Contempt

At times, participants thought that professionals treated them with contempt, either by disregarding them or, worse, treating them like they were worthless and beneath them. This resulted in feelings of anger and frustration:

> Martha: *she was literally a sadist and has had, or has – I think she's probably still practising – absolutely no right to have that job because it's such a wicked thing to say, I hope she didn't sort of actually, genuinely realise the haunting impact that statement would have.*

- Defiance

It appears that some of the interviewees became defiant in response to being treated with contempt by displaying a challenging and similarly contemptuous attitude toward the mental health system. For example:

> Laura: *Yeah, 'cos they see it as- If you like, they're seeing voices as psychosis, well then I'm psychotic every day so therefore do I belong in an institution? No – I don't think so.*

> Kamal: *Medication doesn't work – it never has done, never will do. I mean 'A' can give you the statistics about, maybe one in, I don't know. But it doesn't – all it does – all medication does is probably sedate you.*

> Martha: *Where's the anti-abuse pill, where's the anti-rape pill – you know, it doesn't exist, erm...*

Others showed a more bold resistance to the authority of the mental health system in their attitudes and behaviour;

> David: *I think I'm actually going to try and sue her but I don't know how that works – it's difficult to sue people, isn't it? Erm...but I shouldn't have to stand for that and I think I must have some decent chance of success because basically it's absolutely ridiculous to say somebody would make up psychosis symptoms*

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Laura: *If a Psychiatrist tries to get in touch and says "Oh, I want to promote a brand new drug for anything – voice hearers –." Even as baby-company as it is he'll be told to f-off quite nicely.*

Kamal: *I wouldn't touch the Crisis Team or the Psychiatrist, they're all crazy. I wouldn't be surprised if they're in on the game – they're part of the plot to get me anyway.*

The lack of control and fear discussed seemed to noticeably divide the participants. For some it challenged them, driven through anger and frustration to succeed through clever rebellion. Conversely, others developed what seemed like a learned helplessness and apathetic position. This level of entrapment made these participants feel tired and unable to fight, like victims unable to help themselves. This weak position was embodied by the person; some lowered their head, were softly spoken, continuously apologised for themselves or literally checked that what they were doing or saying was correct or in line as though they were unsure about how they should be or what constitutes 'okay'. All participants, however, shared a common distrust for professionals and services as they appeared to unanimously feel that the role of psychiatry was to classify and remove the unsafe and dangerous from society.

Psychiatry: A Clinical Model

This theme explores the common consensus about the helpfulness of the current clinical model of psychosis and the associated recommended treatments. The interviewees understand the clinical model of psychosis to be a bio-medical model which classifies hearing voices as a symptom of an illness in need of a pharmacological treatment:

Lee: *The support by the psychiatrist is very institutional, very clinical model-based [ ]... your psychiatrist only recommends the clinical side of things, which is they'll give you medication.*

Martha: *I think sort of medication and silencing the voices is psychiatry's cure response.*

This explanation was as debilitating for Martha as other models that she had considered:

I'd always oscillated between seeing the voices as demonic – you know, some sort of supernatural, paranormal force – to thinking this very passive, helpless, diseased model that I had some sort of brain abnormality and there was nothing I could do about it.

It appears that this quite biologically deterministic model neglects and blankets many other contributory factors and experiences:

>Katherine: *Last few years treated through, you know, by medication for schizophrenia and everything I think. And it was an easy label to put on....*

A Pessimistic and Paternalistic System

People referred to the mental health system as a non-progressive and pessimistic system endorsing a sense of hopelessness. For example;

>Kamal: *I think – there's no cure*

>Martha: *I mean there was one psychiatrist I've already quoted to you who told me I would've been better off with cancer*

Martha goes on to describe the effects of the pessimistic and paternalistic model:

>*I'd been left with it for so long in this very pessimistic and paternalistic mental health system that didn't encourage me to do anything to help myself or to have hope or to take charge of my situation or be encouraged to believe this was something I could get through.*

Absorbing such a view of hopelessness may make any efforts or thoughts of something better appear futile:

>Lee: *If you fill something with water you get out water and if you fill something with negative aspects of mental health and mental health system, you can make yourself more poorly.*

This pessimistic outlook was considered by interviewees to be infectious to individual patients and the staff. For example:

>Laura: *Clinical support's at zero.*

>Martha: *they all shared this very, very pessimistic, paternalistic approach to practice which was that this is a brain disease and there's not really much you can do except take medication.*

This whole mentality was considered unhelpful.

>David: *Psychiatrists aren't helpful, the way they talk, depending on who they are. The one that I had in X wasn't very helpful –... she was very negative when I talked to her – a lot of times. So... it didn't help*

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> *because it increased your stress levels, you know what I'm saying, paranoia.*

Interestingly, those individuals who adopted the traditional clinical model would often use language that pertained to illness, for example:

> David: *I haven't been severely ill – I've been quite ill at times but it's been quite mild compared to what other people have put up with.*

> Katherine: *I would say that I could have a bit of psychosis and be functioning very well.*

- Disinterest

A number of interviewees felt a noticeable lack of interest from doctors:

> Kamal: *I've seen GPs, you know as soon as you walk through the door, they've got their book open on the next page and you're saying this, and they're flicking through to [ ]... they seem to have already made a decision over.*

Roshan comments '*that's the only time I've seen a Psychiatrist being flexible'*. This gives the impression that this flexibility and tailoring is an anomaly and generally practices are more prescriptive. Such a detached position may make people feel ambivalent and despondent about the purpose of the process.

> Roshan: *I'm not really interested in all the psychiatry thing – I swear to God, you know, what it is is that I've seen 10 of them, Psychiatrists – I'm being serious – I've seen 10, 12, 15 of them, consultants, this and that. They say all the same thing.*

Roshan goes on to describe his experience of attending an appointment where the psychiatrist appeared disinterested and unfocussed, and then gives an account of another time when he felt disregarded or unheard:

> *I went to see the psychiatrist and he wasn't used to- I shouldn't really say it – I went in there in a meeting to sit with him and the CPN sat down and he was sat on the computer and he was more focused on the computer rather than asking me the question [ ]... 'cos he was doing some other work with it, you know what I'm saying?*

> *I used an advocate about... for a year in X... through X Mind and they just passed... 'cos you write letters through the advocate to the doctor. She just*

> *passed it off. She didn't want to hear, she didn't really... I would leave it at that, 'cos there wasn't really much I could say, do.*

This overwhelming disinterest in the person may make the relationship between professional and patient feel robotic and manualised. This may have a serious effect on both engagement and motivation, which may in turn indirectly feed into the pessimism of the system.

A Schizophrenic

Being labelled a schizophrenic was described as a debilitating process that envelopes identity and suffocates any personhood.

> Martha: *he asked me to tell him a bit about myself and I said "Oh hi, I'm X, I'm a paranoid schizophrenic"*

She talks of when she was at her lowest point, when she described herself as embodying the worst possible image of madness:

> *I was an absolute state, you know – just the embodiment really of what psychosis should look and feel.*

This bio-medical model appears to lead to a pre-determined treatment plan*:*

> David: *he said that I was schizophrenic basically and, erm... gave me, sort of, very heavy medication.*

Martha goes on to describe the damaging effects of being labelled with schizophrenia:

> *it was just like a catalyst for sort of, you know, discrimination, and verbal abuse and physical and sexual assault*

and for this reason:

> *you were encouraged to keep very quiet about, erm... and that was something... sort of shameful, and stigmatising.*

Being labelled with this disorder seems to have the effect of dismissing the past, corrupting any hopes for the future, and disabling personhood. Therefore, it appears to be a diagnosis one would wish to avoid:

> David: *Basically I went to see him to see if I could get a more suitable diagnosis... erm... more for the sake of my family and people... erm... so they don't have to look at me as being schizophrenic.*

Blind Faith

Unlike more conventional medicine there is no biological marker that demonstrates the efficacy of medication treatment; for example, Roshan says:

> *see this is the problem with psychiatry and medication and mental health, you know, you don't know whether the medication – there's no gauge, like you have diabetes, you take, you know, you've got to inject all the time ...[ ]*

As a result a number of people said that they don't like taking medication; Roshan says, for example:

> *I don't like general psychiatry as such 'cos it's very, to me, very ad hoc, you know, it's not fully developed. They give you medication for stuff they don't know that will work properly. It's trial and error. They don't know what voices are really, you know as much as, like, if they knew what... asthma was or leukaemia is...[ ]*

In practice, medication is prescribed and adjusted until it is considered effective in reducing the symptoms. David illustrates his experience:

> *Now had this medication not been right after three years of taking it, two years, they'd have put me on another one, then another one, then another one. They've kept me static on it – my body's become used to it. I'm not on a huge amount of dose. I'm being looked after in terms of the side effects and the blood tests.*

This approach to treatment, however, comes under scrutiny by many. Kamal, for example, describes his psychiatrist;

> *He's got this attitude just prescribe prescribe prescribe – he doesn't know jack about anything...and... he doesn't know anything about anything really.*

This brings into question professional capabilities. For example, Martha believes;

> *they were only a product of their training, so, they just literally didn't know how to help, and they didn't understand what voice-hearing was, how you can support someone to deal with it [ ]... they just didn't have the resources, and sort of almost have the knowledge of how best to help.*

Having limited confidence in the ability of the psychiatrist was also displayed by David, who said:

I went to see an NHS Psychiatrist – Dr. J [ ] – and, erm...– she basically told me- said that I was making it up and told my family that I was making it up. Obviously that's bad...erm... And then they started to refuse to see me on the NHS so I went to see a private Psychiatrist, Dr. M... erm... told him the exact same things that I'd told the other psychiatrist – he said that I was schizophrenic basically and, erm... gave me, sort of, very heavy medication. One basically said that there's nothing wrong with me and did nothing and the other one said that there's everything wrong with me and did everything [laughs].

The participants all described a pessimistic system that they had either struggled to engage with or had felt unheard and let down by. Some participants almost showed a level of frustration that had been overtaken by a greater sense of apathy. This, for example, demonstrated itself through either compliance or else a complete opting out of the system. This contrasted significantly with those participants that showed anger and bitterness in response to the disinterest and negativity. Being labelled with schizophrenia was viewed wholeheartedly by the participants as being a catalyst for even greater difficulties and felt that any personhood or distress was overshadowed by this diagnosis. The role of psychiatry came under scrutiny for being dismissive or overcautious and some participants stressed that they struggled to have any confidence in their opinion. In contrast, some people felt that medication could be helpful but that there should be greater choice and a wider variety of support offered.

Trauma, trauma and re-trauma

This theme captures the traumatic and painful experiences that were described by interviewees. Although some of the interviewees made reference to abuse in childhood, most of the examples of trauma were linked to service provision.

Martha described how the mental health system reduced her ability to cope, and exacerbated the traumatic experiences:

it was after getting into services and being told that these voices weren't an experience, they were a symptom, and they were a symptom of schizophrenia, erm... I became just very fearful, and also very avoidant and the voices became a lot stronger and more aggressive and that started a deterioration, erm... debilitation – I lost a lot of years and it got to the point where I was so, sort of, tormented by my voices that I literally did try to drill a

hole in my head with an electric drill to get them out, you know, it was that
bad.

The treatment by professionals in services has a lasting impact affecting how individuals engage, and relate to people in authority. Katherine details the distress of her hospital treatment as a teenager diagnosed with anorexia:

> *– I was sectioned because I'd gone down to four stone two and erm... the*
> *way I was treated then...[ ] I had to stay in bed and I was force fed three*
> *meals a day... [ ] Once I was sick over my meal and they scraped it off and*
> *said I had to eat the rest of it. [ ]... and then some of the doctors I've seen...*
> *erm... One I've never forgotten it – said I was very manipulative... and that,*
> *I'm sure, it's etched upon my soul because that hurt so much.*

David recalls an experience with a psychiatrist that caused him significant stress and consequently impacted on all future engagement with services:

> *I've had a very dysfunctional life which was created by that situation – where*
> *I was told everything that I had made everything up it just... erm... ruined*
> *everything with all my family and all my friends...[ ] I suppose I've got post-*
> *traumatic stress from it now, in a way. Erm... and that's a barrier because I*
> *find it stressful going back to the same situations.*

The interviewees have discussed how poor professional attitudes and ill-treatment within the service can cause substantial trauma mirroring and exacerbating previous traumatic experiences. Martha draws from her experience to describe her views on trauma:

> *your whole life just becomes a battle, you know, for survival – surviving all*
> *these horrendous things that happened to you – and it's not just the voices*
> *and the visions or the unusual beliefs, but it's the mental health system itself*
> *and society, suspicion and disgust ... you know, being invalidated, being not*
> *having an opportunity to express yourself, your needs, you know it doesn't*
> *have to be as extreme as, you know, being sexually or physically abused – it*
> *can be much more subtle than that. And they're just being re-traumatised*
> *over and again by the very services that purport to help them.*

> *- Stress-Vulnerability*

The accounts provided appeared to validate the Stress-Vulnerability Model.

> Martha: *well, these are a stress response and they make sense in terms of*
> *what's happened to me in my life.*

However, at the time when the voices appear, most people do not understand them in this way. Martha goes on to describe her voice-onset:

> *I literally couldn't cope any more with the way I was feeling – that's when the voices turned up – I found it so overwhelming and just couldn't sort of deal with it anymore. Erm... and I guess I did have a lot of very difficult memories, beliefs and emotions that I'd completely buried, just because I wasn't sort of attending to them on a conscious level didn't mean that sort of subconsciously they weren't having a huge impact on me.*

David also describes stress increasing his symptoms:

> *I mean, going psychotic is the worst case scenario and then being told you're making it up and people telling your family that you made it up is... just makes it a lot worse. And it's when I've been particularly stressed out it's got worse and... symptoms have got worse.*

The layer upon layer of torment, abuse, disrespect, and disregard was voiced across a number of the participants' personal stories in varying degrees. Most noticeable was the way trauma and stress has been mirrored or exacerbated in services. This had led to a number of the participants to either opt out of formal treatment or keep services at a distance. It was clear by some of the graphic descriptions given that some of these experiences had not been heard or validated and the anger and frustration caused continued as a stressor.

Voice Awareness

Voice awareness is recognising that the voices are meaningful. Laura noted the importance and value of professionals being voice-aware. The way she described this ideal was reminiscent of the gay rights movement particularly with the reference to 'coming out'.

> *You need to kick their arses and, you know, sort of like – I call her a new age one, because there is in these little pockets of mental health there's these new age Psychiatrists coming out, and CPNs and things, and they are voice-aware, so it's a good thing.*

Post-Psychiatry Movement

The PPM provides an alternative understanding of voice-hearing to the conventional bio-medical model. This is linked to both critical and anti-psychiatry models which laid the

foundations to the HVN. The HVN is the provider of the HVG. Martha, an active believer in, and contributor to, the PPM, recalls her introduction to the movement and the associated professionals:

> *but meeting a psychiatrist who saw the voices as meaningful – who saw recovery from the distress of voice-hearing as a complete, you know, not a vague notion but a practical reality [ ]... reading about the recovery stories of other voice-hearers, erm... finding about the work of Mario Escher and the Hearing Voices Network and again sort of realising that these experiences do make sense, rather than just being fixated on getting rid of them, erm... but by accepting the experience and trying to understand it and trying to interpret it, erm... that you can change the relationship with your voices and that was just a complete revelation to me and, I think, saved my life really.*

The description seems to demonstrate how hope and validation of experience can powerfully build a foundation to individual recovery and change. It seems that the PPM encourages people to stand up and be counted, to be proud of their ability to cope and to survive their experience:

> Martha: *what I'd been through was like a badge of honour almost – it was something impressive and positive, erm...*

In addition to offering a framework of understanding, she describes the potential power of the work as the provision of hope, and potential progression toward real emancipation for voice-hearers.

> *when a small group of determined people get together and decide that they're going to change the world [laughs] you know really amazing things happen it's someone taking a stand and reclaiming power and that's what the hearing voices is very much about.*

   - An Avenue of Channelled Outrage

The PPM has been central to Martha's recovery as a healthy avenue to relieve pent up frustrations by focusing attention toward practical change:

> *I think getting involved in, you know things like the Hearing Voices Network, erm... the Anti-psychia- well, Post-Psychiatry Movement, ... was a really sort of constructive and productive outlet to channel some of this outrage into trying to make a difference. And being part of this, you know, wonderful camaraderie, but also this sort of sense that this was a group of really*

dedicated people working together to change things, erm... and the excitement of that almost, that this is a really – this is an important civil rights movement, and to be sort of part of that, and to contribute to that,

For David, the PPM has helped him to recognise and work towards changing problems in the mental health system:

Erm... I want to be more involved in this movement in general... erm... because I mean I'm a convert now, I'm convinced but... there's massive abuses going on in the psychiatric system.

In both cases the PPM was a constructive vehicle offering hope and practical support to change, using individuals' collective skills and experience to reach out and drive change. Some of the interviewees buy into the ideas of the PPM more than others; given the link this HVG has in relation to the HVN and thus the PPM, I have included the following two ideas drawn from the analysis. Although this is a unique theme linked to Martha, elements of these ideas resonate with the HVG. For example, a number of the interviewees opted out of more formal treatments in favour of the group facilitator's help with understanding the voices.

- *A Person with Potential*

This theme focuses on the influence of people that were able to see beyond the diagnostic label to work with the person hidden beneath.

Martha describes:

I said "Oh hi, I'm Martha, I'm a paranoid schizophrenic". His, sort of, reply was, "I don't want to hear what other people have told you about yourself – tell me about you". And he sort of really focused on my accomplishments, my potential, you know, he said that the person who had succeeded so much in, [ ]... was still there and she was going to come back"

She goes on to describe these professionals as:

...[ ] very compassionate, very empathic, very supportive, very empowering.

and continues to describe a pivotal time of change:

it was just two people who just related to me as a human being, erm... and who supported me and, you know, encouraged me and, sort of almost, and in A's case sort of gave me a – helped find me a platform.

The support was particularly humanistic, as Martha goes on to describe:

...[ ] he didn't save me – he did something even better than that as he let me save myself, erm... So I think he was a really crucial form of support 'cos he planted the seed almost and sort of encouraged me to dream.

Ultimately, it seems these people started with the premise that the label of schizophrenia actually represents a person first and foremost, someone who can develop and bloom under the right conditions.

- Protecting our vulnerability

This theme describes two ways in which Martha tries to protect her vulnerability; she describes the fear and reluctance that she felt when considering and starting therapy:

[ ]...and I think it was fear that stopped me really and finally, sort of about six months ago I did look for a therapist and found a really, really great one and that's been an incredibly positive experience – it was quite difficult at first, erm...

On one hand she demonstrates pride in her ability to bring about positive change without therapy and on the other she recognises its value. This may reflect an internal battle between 'I can do this alone' and 'I need some help'. She describes her barriers to accessing therapy:

I really put off 'cos I was just – I think scared of what would come up, but also it was almost this idea that I needed therapy it must be an indication that there was something wrong with me – and actually realising that what it actually was was this continuing commitment to my own healing, really.

While Martha can appreciate the positive experience that therapy has had, she also takes a more critical position:

sometimes people think that to recover you need, sort of, sophisticated therapies and, you know, elaborate techniques – and certainly those things can be great and I'm not devaluing them, but I think when the implication is that those sort of things are essential then, you know, we de-skill the whole community, you know so that to support a distressed person you need a postgraduate diploma is facile and wrong.

It is here she appears to reject the sophisticated therapies and elaborate techniques. This ambivalence may reflect an inner conflict where, based on her experience, she knows that therapy is useful but it is sourced from a mental health system that she distrusts. As such she may be protecting her own vulnerability by attributing her

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progress and success to her hard work. Or she may be simply acknowledging the more human, intuitive, uncomplicated and non-technical forms of support.

The next excerpt describes her elevated position as a recovery guru in the PPM and the discomfort she experiences as a result of the message given to others:

> *There was a time when people almost were... really sort of put me on a bit of a pedestal – you know, like a sort of recovery guru and it felt so uncomfortable, because it's disempowering for them because if people set me up as something special, then it implies that only special people recover and that is not true...[ ]*

This suggests that her pedestal is essential for her survival; in public she appears to be a recovered, successful person. Such a persona may make her feel untouchable and protected from the mental health system. But, in private, she feels she is ordinary:

> *I still go home and like cry and stamp my feet and smoke loads of cheap, nasty menthol cigarettes, erm... and, you know, feel down, feel overwhelmed.*

She seems at odds with herself; on one hand her public persona is of someone successful who earned her recovery and this contrasts with her fundamental belief that recovery is for anyone who wants it. This may continue because her public persona and allegiance to the PPM may be serving to protect her vulnerability from a system that she fears and distrusts.

HVG: A fellowship

The HVG is viewed as *"the only real form of support"* by many of those interviewed. A number of reasons were given describing the benefits of attending the group. Interviewees felt that they were with other people who genuinely could understand and empathise, for example:

> Katherine: *The Hearing Voices Group, obviously, you know... That's helped, because you suddenly realise you're not alone; other people in the same boat and... erm... there's a sort of fellowship there that helps.*

> Roshan: *I've gone to this Hearing Voices Group. And... the thing is that there's a lot of people in the group that hear voices, so... it's quite... relaxing and all this... to a certain degree, you know what I'm saying...[ ]*

Trusting relationships are encouraged and nurtured to create a refuge for people.

>Laura: *The only safe place is, like, talking to voice-hearers which, perfect place is in the group. Obviously I know a lot of voice-hearers outside, so... we kind of like talk about voices and then, if their voices talk about my voices they'll sort of have an argument between voices and then we take the piss out of the fact that the voices are having an argument.*

The group was described as a means of breaking social isolation, for example:

>Roshan: *You can discuss about things and know that people around you have got the same situation...[ ].*

>David: *I think basically because when you're not around people with... who've had similar problems...who have got similar problems...erm... you're taking it on all by yourself, aren't you? And, it's just being able to sort of discuss it with other people – it's just very supportive – it's good.*

>Laura*: Yeah, because, I mean when I first arrived here I'd had two years of not coming out the house – ever. So, it was like, seeing somebody who's a voice-hearer was like 'God, there's other people out there'. I mean I knew in the back of my mind there would be but actually physically coming into a room and meeting them – it was good.*

In public, voice-hearers will often worry about what they say and how it will be perceived and this means of support facilitates a trusting, non-judgmental arena for real discussion.

>David: *people can kind of have a go at you and be unconstructive when you're in that situation and you're around people who don't understand it themselves. And that sort of vanishes if you go somewhere like that, and you feel like everybody understands what's going and there's no judgement and you're not going to be, kind of harassed, erm... in any way.*

>Kamal: *I know I'm secure here and I know whatever I say here is not going to be used against me – like these ideas of burning the next neighbour down, or set fire to X, Y, Z, or... you know. 'A' supports me and gets me through this, whereas if I said this to my, you know, Psychiatrist or my GP then I'd probably be on a section or something...[ ]*

Voice-hearers, like other diagnosed groups of people, want encouragement, hope and possibilities for a better future and this group provides both inspiration and practical solutions:

> Laura: *I once was not sleeping for four days and the group usually has an agenda but it kind of all turned to me which, you feel tight about at the time but everybody will chip in to get you out of the crisis and stuff like that. And, of course then the infamous 'A' puts it down on paper and draws it up and gets everybody's opinion and by the end of your session you think "yeah, you're right – there's an answer to it".*

> *- An Inspiration*

It seems that having a real and inspirational icon gave a sense of hope and possibility to some of those interviewed. When you are at rock bottom it is hard to believe that you can amount to anything, so to see a highly successful doctor who hears voices provides a potent message of hope and belief.

> Roshan: *'A' had psychosis when he was young – he doesn't look as though he's had it now. But he's gone through it his whole life – he's much older than me. And he's got a PhD and this and that, and he's a doctor and he's... he's kind of done that, you know what I'm saying, 'cos he recovered from it... So you can do anything.*

The interviewees also valued having someone who is approachable and truly understands the experience:

> David: *'A' appeared on the television one day [laughs] and I just went and found him and he basically helped me out... erm... so I mean I find it's wonderful to be able to come and see 'A' – it's definitely – 'A' really inspires me, motivates me.*
>
> Roshan: *Having somebody that's been in the situation themselves is just something that's truly very helpful.*

All of the participants noted the value of the group as a means of support. The engagement the participants had with the group and its facilitator seemed to demonstrate the integral foundational needs such as compassion, positive relationships, validation, hope, feeling safe and understanding. Active means of coping and recovery were discussed and language such as motivate, relax, inspire, hope and belief were used by the participants inferring a level of positivity and longevity in effort. Participants were aware that the HVG sat in isolation; some

identified this in relation to the onus placed on holistic support whereas others understood this in the context of the divide between the PPM and more traditional psychiatry. One participant discussed very similar support means but was set apart by her niche position within the HVN to inspire others, promote recovery and actively pursue the emancipation for voice-hearers. This was echoed by another participant, less involved with HVN but who pioneers for greater awareness of mental health, who provided a strong message of the need for mainstream services to adopt the ethos and values held within the support group.

Dancing with Voices

This section is entitled dancing with voices to describe the dynamic relationship the individual has with their voices and how this changes throughout the course of recovery.

I Hear Voices

The initial experience of voice-hearing is shocking and profoundly frightening:

> Laura: *I know it's scary – it's absolutely terrifying when you first get them. And you think you're going mad – you think "this is it, what's the point in being alive" because you think you're going mad, you really do.*

> Martha: *the sense of this entity intruding and imposing on you is really frightening.*

The voices seem to represent different personas and can remain distressing:

> Katherine: *Yeah, there's the main voice – I call it the Devil .. And, err... and then there's ... there's a voice called Fifi and there's a voice called Chloe as well. Fifi's the extravert and Chloe's like a young child.*

The most dominant voice for Katherine, by virtue of the reference to the 'devil', seems to be tormenting and persecutory. This seemed to be a common experience among the interviewees:

> Kamal: *They threaten with me – they said they are watching me, the government is conspiring to get me. I had an episode today when I felt strongly that a Volkswagen, a black Volkswagen estate was following me and there was two men in it and they were watching me and... and my voices were saying that "they're the government, and*

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> *they're planning to get you – they're going to... erm... conspire*
> *against you, they're gonna lock you up, erm... blah blah blah"...[ ]*

Katherine:*[ ]... and he tells me that I'm wicked, evil; everyone knows that I'm wicked,*
> *I'm evil, I'm a whore, I'm, you know whatever.*

Individuals will often try to seek an explanation for the voices.

> Martha: *[ ]... that's when you can get into the really scary realm of these,*
> *erm... you know demons or devils that, the voice of God, they are this*
> *very powerful, external presence that they are egosyntonic, they are*
> *not magic...erm... and that's when you start to feel very powerless,*
> *erm... and very fearful and very much under the control of the voices.*

Belief

The explanation that people adopt, coupled with the strength of the voice persona,
tends to affect the level of belief that people have in the experience:

> David: *I was taking it literally – I was very scared that something was going on*
> *with her – that there was something supernatural going on.*

> Kamal: *I think they're definitely out there, and they're definitely out to get me and at*
> *times when they're strongest they can influence things that are around me*
> *and that are happy.*

The level of belief appears to feed into how individuals cope with their voices and their
recovery pathways.

Disintegrated

Some people appeared to have a lack of a planned approach to coping and instead
simply reacted to the commands from their voices; maybe to dampen the volume or to
abide by the control, subservient to the belief in power:

> Katherine: *I used to be quite religious – I used to believe in a God... and then*
> *found that when the Devil came along – my devil – he wouldn't allow*
> *me to believe in a God any longer... so there's a sort of hole there*
> *really.*

> Kamal: *You just lose it and get violent – smash things, break things...*
> *verbally abuse your neighbours I suppose [laughs].*

Coping: Self Management

Some people talked about self-management almost at a surface level; for example:

> David: *I mean you could try and do things to help you cope with it – without having that kind of realisation, it would still have an effect and it would calm you down.*

A number of self-management strategies were described; David talked about not indulging in certain behaviours to help him manage:

> *I have been known to misbehave... erm... you know if I smoke dope or something... which I really shouldn't do. Erm... that is a barrier come to think of it because basically everyone's been biting their heads off while I've been ill and unable to do it and now I've gotten a bit better it is tempting to start recurrently getting drunk but that's just going to make it worse – that is a bit of a barrier.*

Lee discusses proactive ways of self-management and learning.

> *I read in a book the other day there's like... there's different aspects of your life that you're supposed to target, you know like sport, recreation, leisure, work, rest, play and all stuff like that. So I'm really focussing on my coping strategies and how to keep sane, if you know what I mean.*

In addition, Roshan describes ways that he finds to relax and reduce his anxieties:

> *But one thing I can say to you is that sometimes when I get really anxious about the day, or I'm in the flat and I ain't got nowt, or whatever, I usually go up to the mosque nearby, you know what I'm saying, from that point of view – I've been to churches and that, but because I'm of a certain religious group I sit in a mosque in an afternoon or a prayer at night and I sit down and I'm so relaxed in that place.*

Others describe more creative means:

> Laura: *But I usually just, sort of, do a pterodactyl thing and it calms me down. It sounds absolutely bizarre on the tape probably but it's the way of coping – it's my coping mechanism [this is where she does a movement and noise that imitates a pterodactyl]*

Some more preventative coping strategies seem more linked to general resilience.

Katherine, for example, discusses her ongoing commitment to self-care and enjoyment:

Again it depends on how I'm feeling. Sometimes if I'm feeling that I really am wicked and evil and that... then I won't allow myself things like bubble baths and I won't allow myself to, you know, be kind to myself. But other times I try and do things like that. Just try and be a bit kinder and, sort of, allow myself some chocolate and that sort of thing, you know

Deconstructing the Problem

Some people talked about learning about and deconstructing the experience to understand why they have the problem:

Katherine: *through doing therapy with 'A', erm... I learnt that the voices were there because the abuse I suffered when I was a child. And because that hadn't been worked through; that was why the voices were there because...[ ] showed me that something needed to be worked on...[ ]*

This process helped individuals to organise their ideas about what their voices represent, for example:

Martha: *I realised quite quickly that this voice, although the content was always quite benign the way it expressed itself was, erm... was reflective of how I was feeling, so if I was angry, erm... or... particularly strong emotion and the- the sound of the voice reflected that, so it would sound angry, even though it was saying the same thing, erm... and interestingly it was always around emotions that I found difficult to express because at that time I found very strong things like anger, like resentment, even sadness very difficult to articulate – it was almost like the voices externalising that.*

For some people, this change in understanding has led to new ways of approaching their voices.

David: *I started challenging my symptoms rather than taking them literally, because I had some insight after seeing him as to where it could come from, and it sort of gave me reasons not to take it literally.*

Recovery

The interviewees described recovery as a process. For some a process of acceptance:

David: *nothing really has to happen with the reduction of symptoms – it's just if it's upsetting you – if it stops upsetting you, basically, then you've recovered*

Laura: *if you accept the fact that you hear voices, I think it helps.*

According to Martha, recovery is an active process:

[ ]... I mean for me in a nutshell recovery was almost like sort of getting control of it; getting ownership of it and getting on with it.

Some people described what they think recovery looks like or what it is that they aspire to be:

Laura: *Recovery to me is going to be in place by helping other people – the more people I help the more better I'm feeling towards myself.*

Laura has set up a business which promotes mental health by providing workshops and courses and this has empowered her and allowed her to put something back into society:

[ ]... we possibly will have to go to be a social enterprise 'cos we're putting back into the community.

Her experience of recovery has enabled her to encourage others as a role model:

But if you can just baby-step each day then you'll find you're fine.

David looks to the future, aspiring to do new things:

I think when I'm on my degree, and I'm coping with it, and doing well and I'm kind of performing to somewhere that's near my potential, and I'm happy and...sort of busy, active person I'd say about...that would be when I'd recovered.

Martha goes on to summarise her views on recovery:

[ ]... fulfilling your potential, whatever that is, you know. It's completely self- defined, it's what... you know... fulfilling, living your dream.

The theme of dancing with voices was an attempt to represent this very fluid movement people exhibit en route to becoming a happy and less distressed person. Self-management is about coping methods that are thought out and deliberate, whereas recovery seems to be more related to self-actualisation. The fundamental difference seems to lie in the extent to which one believes in the voices and the level of insight in the experience; this may reflect a recovery continuum.

- Voices: Learning to live together

This theme describes the way people have described building a relationship with their voices:

> Martha: *Erm, it was scary to start with, from the beginning, but now it's like, it's an everyday thing, so... We have to learn to live together, if that makes sense [ ]... it's changed hugely the relationship with the voices, erm... it's quite, quite different now to how it was – what has changed is the way I relate to them, and it's changed very much, certainly for the better it's been a process almost of negotiation rather than modification.*

The voices appear to adopt different personas. Laura, for example, seems to liken them to how you might discipline a child:

> *If they're good they're very good, but if they're annoying I'll treat them like naughty children and just ignore them.*

In another example, she seems to treat the voice as a companion:

> *Yeah – they are a major barrier, but I think if they were to disappear completely, I genuinely think I'd miss them. Cos I'm never alone.*

Laura suggests that learning to live with your voices is an enduring process of negotiation that requires thoughtful action and flexibility:

> *I try to... negotiate a time with them where I'm, like, prepared to talk to them but they're very rude, my voices. So it's like, they'll just come in at any time. Erm... if I ignore them they get worse, so I have to, like, talk back with – I try to do it quietly.*

The participants' journeys all varied tremendously and their emphasis provided a good indication of where they were themselves in their journey of recovery. Some participants talked about the difficulties of having a believable, tormenting powerful voice and how at times it was easier to just give in to its commands to gain a little respite. A number of people talked about coping; one participant for example discussed a wide range of deliberate self-help strategies that he employs that enable him to meet society's expectations and find a semblance of normality, whereas another finds ways to manage his arousal and has a number of ways to calm and relax himself. Other participants discussed the importance of understanding the voices and have all spent time marrying the links between their

life history, key relationships and their voices to varying degrees. This has enabled them to develop more sophisticated and tailored tools that allow them to understand and cope with their voices, connect more widely in society and move towards the aspirations they hold for their future. Putting these individual accounts together has given a broad and dynamic framework for understanding the journey of recovery. It was difficult to determine how people made these transitions; cited means included through attending the group, individual sessions with the group facilitator, positive experiences with 'new age' psychiatrists or involvement with the HVN. Common to all the accounts was the effort and determination it took for people to cope with and recover from the experience of hearing voices.

Relationships: A lack of Understanding

This theme explores the relationships that the interviewees described with their family and friends and more widely within society. The relationships, be they positive or negative, show a general lack of understanding about the experience of voice-hearing.

> David: *people can kind of have a go at you and be unconstructive when you're in that situation and you're around people who don't understand it themselves.*

Family and Friends

Family and friends were cited as a valued source of support. Martha describes her family as a sole source of unconditional love and belief:

> *there was literally no support at all, with the exception of my Mum and my sister who... never gave up on me, and... I think my Mum always felt very strongly that this was something I was going to overcome*

> Katherine: *Yeah, family have helped...support me a lot. My husband...erm [ ]...he's very good.*

She describes a more practical support given by her husband despite his difficulty understanding:

> *With the hearing voices, he tells me "Stop being so silly – just ignore it". You know – he finds it hard to understand that it's a bit difficult to "just ignore it"... and that. I've tried to explain to him. But he's given me the support – there all the time.*

She also explains how friends and family outside the home have also been helpful;

> *My friends – I have a friend who I talk to on the phone every day. Erm...*
> *she's very supportive. And I speak to my father on the phone every day.*
> *Erm... only for five or ten minutes, but, you know, keep in touch. Just*
> *"How's your day been?" and, you know, that sort of thing.*

Similarly, Roshan discussed how valuable his dad had been with help with daily chores and appointments:

> *I mean, there was no psychiatrist that was going to... help me with my*
> *travel costs if I got a taxi for me there, so... my Dad helped me out.*

> *- Social Isolation*

This theme captures the levels of social isolation described particularly when family and friends struggle to understand and opt for minimal contact:

> Kamal: *I've only got four friends left and I only see them maybe once a*
> *month, erm... and that's because we go out to lunch once a month or*
> *whatever, and the rest of the time I keep myself to myself...[ ]*
>
> David: *I've had to support myself to a large degree – I mean what*
> *happened with my family and going to see the psychiatrist before*
> *was just absolutely horrendous really...*

Social Acceptability

This theme draws out all that is considered socially acceptable, and what is expected from someone that hears voices or is considered 'mad' in society. Laura, for example highlights a common expectation:

> *I think they want me to act like I've got Tourette's or something like that,*
> *you know, by screaming out loud and swearing.*

Interestingly, she adds:

> *I don't think anybody can understand it. Erm... you can't go down the*
> *pub and say to somebody "excuse me a minute, I've just got to talk to my*
> *voice".*

As a result of public ignorance, one needs to hide and talk only where voices are accepted. This view is shared by Roshan who worries about people's reactions if they were to know that he hears voices.

Well, if I give you an example, like I go to a shop – like Body Shop I'm talking at – if I said to them I hear voices to the lady with the card – I've been going for the past, like, six months to buy stuff like soaps there – I said that she'd think I'm strange 'cos she didn't experience it herself, you know what I'm saying.

He notes that people just wouldn't expect it, perhaps because the public image of those who hear voices does not extend to someone who gets on with their everyday tasks. Katherine describes her experience when she felt like a social outcast:

I find stigma when I [pause] sometimes when I go by taxi to [place] or something or other...erm... from the drivers – they don't talk to you because you're a nutter, you know, and everything [laughs]. And that's a bit hard sometimes.

Secrecy

Some of the interviewees described times when they decided not to tell because they didn't think that the person would understand:

Katherine: *[ ]...Yes, Yeah. I didn't tell anybody professional about my voices... and the sexual abuse I suffered as a child till I was 33... because of the treatment I'd had earlier from doctors and things. And I just thought no one would believe me and everything*

Katherine's eventual disclosure seemed to function only to explain away behaviour:

[ ]... my nei- my neighbourhood is not known really about me... and, erm... I prefer to keep it that way, you know. I just don't work, but there's no reason why I don't work or anything like that.

This demonstrates how much of herself she hides herself away from other people like she is something that is wrong and should be segregated.

The participants had split views on the support offered by family and friends; for some they were a valuable source of support both practically and emotionally, whereas others felt notably let down and abandoned. Common to all participants, however, was the relative lack of understanding which led to some people feeling alone and separate even when contact was regular. Participants also talked about not feeling that they are able to be honest about their experience of hearing voices or moreover use coping means in public for fear of attracting unwanted attention.

One participant targeted common ideals linked to his understanding of being a 'normal' man such as leisure and work so that he could live within society's expectations. Another participant highlighted the value and function of keeping the voices a secret because of the devastation and fear caused to others when people do not understand the complexities of the problem and the associated distress.

DISCUSSION

The main findings will now be discussed in relation to the research questions and the literature reviewed. This study explores the voice-hearer's experience of support and how this has influenced their coping, resilience and recovery. The following section will discuss the findings in relation to the two research questions:

- What is the experience of support you have received in relation to hearing voices?

- How has this support influenced your coping, resilience and recovery?

What is the experience of the support you have received in relation to hearing voices?

The main sources of support discussed by interviewees were provided by the HVG, family and friends and within the context of the psychiatric system.

HVG

The HVG was viewed as helpful both in its own right and in relation to other support modalities. The group was seen positively by the interviewees because it provides the conditions that support building resilience and recovery: that is; it provides a refuge, offers useful coping strategies and means of understanding, reduces isolation by enabling the development of trusting relationships, as well as helping people to integrate into safe communities. These findings support the literature exploring the mechanisms of change within support groups (e.g. Meddings, et al., 2004; Newton, et al., 2007, c.f. Ruddle, et al., 2010). The addition of having a real, inspirational icon as group facilitator who offered hope, belief, possibility and a tangible story of success was particularly significant to the interviewees. This same individual, also a local clinician, was also able to offer individual exploration of the voices through, for example, voice dialogue. This exploration was valued by the interviewees and enabled them to critically review their voice-hearing experience. This process seems particularly pertinent and is central to whether the interviewees 'disintegrated' or progressed further in their recovery. The evidence suggests that the changes in beliefs surrounding the perceived power of the voice may mediate distress reduction (Ruddle, et al., 2011; May & Longden, 2007). This may further be affected by changes in other variables such as personal coping strategies, self-esteem and social activities (Ruddle, et al., 2011).

Psychiatry

By comparison the support from psychiatry was viewed unfavourably and was described as both pessimistic and paternalistic, endorsing a sense of hopelessness. From this perspective, being labelled 'a schizophrenic' was experienced as being marked as broken and deficient. This in turn led to significantly lowered expectations regarding personal capability, prognosis and potential, leading to feelings of worthlessness and being stigmatised by society. The confounding of psychiatry and prison by one participant equated the disordered patient to a criminal, 'bad and dangerous', which would justify segregation and punishment, thus reinforcing societal stigma.

Access to services is based on the diagnosis of a disorder, with treatments then prescribed or recommended accordingly. Participants reported experiences of being forced into using medication, hospital or therapy; this prescriptive treatment regime is disempowering, dehumanising and potentially can foster dependency. It stands in opposition to the cited mechanisms of change in recovery such as empowerment and personal involvement (e.g. Pitt, et al, 2007; Spaniol, 2002). Whilst medication was understood by the participants to be the principal cure, opinions were mixed, and there was a general lack of understanding regarding prescription. Some interviewees described medication as 'psychiatry's cure to silencing voices'; others thought that the side effects caused more distress than the voices themselves; and some people viewed medication more positively, considering it a useful treatment option as part of a wider holistic programme. Interestingly though, it seems that regardless of the participants' opinions of, or compliance with taking medication, they had learned to 'play the game' and say that they were adhering to the professional's prescriptions in order to minimise or avoid further psychiatric intervention. This demonstrates that diagnostic labels should be an anchor to guide support, and not a reason to prescribe a mode of treatment.

This linear, prescriptive approach of treatment was viewed by interviewees as controlling and neglectful. This corresponded to another major theme from the findings, that of psychiatry as a form of social control to regulate behaviour and thus enforce social standards. This power differential was typical of the traditional psychiatric system prior to de-institutionalisation, which is worrying, given the political drive to, and momentum for, change (e.g. DoH, 1999, 2001). The ability and decision of psychiatrists to section not

only represents a power differential but also an underlying threat, particularly if the person fails to respond or becomes non-compliant to treatment, hence the participants' inclination to 'play the game'.

The participants discussed experiencing disinterest and contempt in consultations with some health professionals. This lack of care also appeared to cause significant reactions, including defiance and 'playing the game'. Disinterest displayed by staff, may make the relationship between professional and patient feel robotic and manualised. This type of attitude towards those with serious mental health problems is invalidating, dehumanising and stressful and is cited by the interviewees as increasing the person's ordeal. Topor, et al. (2011) drew attention to the idea that people judged the whole of their care in terms of relationships with key professionals. The findings related to whether SUs were treated according to their label, to themselves as a person or a patient, and further by the lengths to which the helper had gone to support them. The qualities upon which these mental health professionals are being judged are also the attributes that SUs most value. Borg and Kristiansen (2004) found from their qualitative study of people living with serious mental health problems that some of the pivotal factors in the helping relationship centred on hope, shared power, availability, openness and the professional going the 'extra mile'. However, this may sit uncomfortably with many practitioners for two reasons; firstly the 'extra mile' may be deemed as unprofessional and as a relaxing of boundaries; and secondly, working as co-experts with the SUs requires a relinquishing of power and expertise, which goes against the premise of the typical doctor-patient relationship (Topor, et al., 2011). It should further be noted that collaborative working requires investment from the SU as well as the professional and 'playing the game' will potentially sabotage any genuine support efforts.

The participants seemed to describe psychiatry as standing alone, separate from the clinical team as indicated by their use of the term 'bio-medical' when referring to any clinical support. In their view this reflects a dominant theme in the clinical model, of which psychiatry is, ironically, only one part. This could be a result of either the powerful decisions that psychiatrists make, or simply the logistics of psychiatry holding satellite clinics. This may represent the niche position of the mental health multidisciplinary clinical teams nestled within a stringent medical model of disease which may undermine the broader bio-psychosocial approach to understanding and treatment.

The fundamental difference between these two support systems is the onus placed on safety, validation, empowerment, hope and social connection, which are the essential ingredients in people's ability to cope, show resilience and actively pursue their recovery (e.g. Spaniol, 2001). A number of positive references were made to a select few psychiatrists and mental health professionals; those who were deemed voice- aware. Voice awareness is believing that the voices are meaningful and linked to a person's life story (May & Longden, 2007). Within the literature on the recovery process, the essential step is to understand and integrate voices into the lives of those who experience voice-hearing (e.g. May & Longden, 2007). One participant described voice-aware professionals as a small pocket of people who are 'coming out'. This is reminiscent of the gay rights movement and this collective pride could have a pivotal influence in an anti-stigma campaign on a systemic level from individual through to wider society. Indeed, we see a political drive to support the recovery of those with serious mental health conditions. This may need to be lobbied from the 'bottom-up' perspective where SUs and clinicians come together to target residual stigma. The bleak and hopeless story typified by the very traditional medical model is being superseded by increasing examples of stories of personal recovery. These include stories of those who have been in a position of disadvantage and marginalisation as a result of mental health going on to have valued and respected roles. Such narratives offer hope and possibility to SUs, professionals and society as a whole, fuelling a drive toward recovery and social acceptance.

PPM

The support of the PPM was also noted by one interviewee. The HVN regard themselves as part of this movement, positioning themselves outside of the mental health arena to recognise that hearing voices is part of the human condition (May & Longden, 2007). Although the political position of voice-hearing is not being discussed, it is useful to contextualise the group experience and how this contributes to the values that are discussed. It is important to recognise that some of the participants actively opt out of support provided by the health services and instead only engage with the HVG or the HVN in this interviewee's case. This particular support group has members that actively support the PPM, and their accounts may therefore illustrate a more critical view of health services and psychiatry than might be seen among SUs of mainstream services. On this basis, one could argue that the sample is more attuned to these ideas and methods and this may be the reason for their general neglect of more formal therapies. Alternatively,

this may be indicative of a general residual distrust of the system and efforts to 'protect their vulnerability'. So whilst someone is 'playing the game' they are not actively involved in accessing that support. Moreover, because they do not regard the support favourably they choose to opt out, at least on a psychological level. This also corresponds with the paradox identified by many of the participants; that you can't opt out of formal treatments such as medication and prescribed therapies without being labelled as 'non-compliant' and so forced to adhere.

Family and Friends

Family and friends were also cited by the interviewees as valued support. They were able to help with daily activities, keep people connected and were grounding, providing markers of normality. In addition, they were able to offer love, hope and, furthermore, were able to place emphasis on having a relationship with the person, which was seen by the interviewees as offering a sense of belief and humanity.

Wider Discussion

The favouring of the HVG and family and friends may be indicative of the interviewee's stage in recovery. Andressen's, et al. (2003) stage model noted that those in the final stages of recovery (3-5) have a greater focus on personal resilience and self-determination. Considering this in conjunction with the work of Rosenheck, et al. (2005), who explored the changing outcome priorities for people with schizophrenia, it may be that the support most aligned to these priorities like social connection, for example, are preferred.

Psychiatry is often the first point of contact in services (NICE, 2010) and it may be that they are set up to work with fear, confusion and perceived powerlessness as per the interviewee's description. On this basis, the immediate response is typically to issue medication that alleviates the symptoms, which has been shown to be what SUs want and need at that time (Fisher, et al., 2002). However, as people progress in the recovery process, clinicians may need to adapt their style and intervention to suit these changing priorities. This might prevent people feeling as though they were watched, inspected and interpreted only within the realms of mental health assessment, as described in the study. Similarly, it may be that some SUs view the reduction or cessation of medication as a marker to their recovery and this needs to be understood by the clinician. According to models of recovery, part of recovery is about control,

independence (Smith, 2000) and options (Anthony, 2000) and this is something that should be discussed if recovery is going to be facilitated by the clinician.

The recovery-orientated service model (Anthony, 2000) presumes that recovery occurs independent of one's theory on causes, and it may be that mental health professionals in a recovery-orientated service need to adopt a more holistic perspective in order to facilitate recovery. Furthermore, it may be that clinicians require greater training on the 'cultures of healing' (Jacobson & Greenley, 2001) as this has typically fallen into the remit of only certain professional groups (e.g. psychologists).

How has this support influenced your coping, resilience and recovery in relation to your voice-hearing experience?

A person first

Recovery was viewed by participants as an active process through which they pursued their goals and fulfilled their personal ambitions. Interestingly, unlike many operational definitions of recovery (e.g. Harrow, et al., 2005), it did not centre on symptom reduction or abstinence, except in the form of feeling less distressed by voice-related experiences. Ironically, much of their effort involved learning to integrate the voices into their lives. Being seen as a person with potential was another major support mechanism in recovery for the one interviewee and this they associated with the support provided by the HVG through the focus on hope, belief and potential to recover.

Hope was cited as an essential ingredient by participants and echoes the recovery literature on facilitating positive change and enhancing personal resilience (e.g. Spaniol, 2001; Andressen, et al., 2003). The findings further point to the facilitatory role of an inspirational figure as a model and someone that is able to instil a sense of hope for, and belief in, change. This particular HVG is fortunate to have an inspirational figure as a facilitator and local clinician. This was recognised by the participants as contributing to individuals' hope for, and commitment to, recovery and wider change, thus reinforcing the power of disseminating stories of individual transformation to inspire others. The premise here is that a focus on hope becomes internalised to augment individual self-perceptions of being a capable person (Lopez, Floyd, Ulven, & Snyder, 2000) and facilitates a purposeful life with meaningful goals (Spaniol, 2001). Cheavens, Feldman, Gum, Michael and Snyder (2006) applied a brief hope therapy intervention to individuals diagnosed with Major Depressive Disorder and found improvements to hope, life

meaning, and self-esteem as well as reductions in symptoms of depression and anxiety. The five stage model (Andressen, et al. 2003) highlights the pivotal role of the communication of hope from the services and the wider community. The interviewees describe a number of interactions with psychiatrists where this message of hope was not heard.

The findings point to social connection as an important factor for both personal resilience and recovery. Family were particularly important and, for some participants, offered practical help and a connection to the person that may be lost in the midst of coping with the novel and frightening experience of hearing voices. Conversely, in the absence or sudden loss of good friends and close family, one may find that the social calendar is characterised by clinical appointments and contacts. Social isolation and personal segregation can constrict personhood and individuality, and this can often precipitate symptom exacerbation and mental health distress (Topor, et al., 2011). Herman (2001) emphasises that recovery can only take place in the context of relationships, thereby highlighting the integral need for social connectedness. People who have experienced trauma through the ordeal of voice onset or abuse, for example, need to recapture some of the abilities that were lost in this process such as the basic capacity for trust, autonomy, initiative, competence, identity and intimacy (Herman, 2001). Therapeutic relationships have a unique role here; the patient submits to an unequal relationship where the therapist has superior power and status, not unlike in times of trauma. At this time the therapist should use the patient's feelings of dependency and vulnerability to foster recovery not abuse (Herman, 2001). With consideration to the examples of prescriptive treatment and enforceability, it may be that the set up of psychiatry in terms of the separateness and limited access may further reduce opportunities to build this type of therapeutic relationship, thus leaving a negative impression relative to other services.

The process of recovery

The theme 'dancing with voices' shows a dynamic pathway between coping with and managing voices, deconstructing the problem, and recovery and self-actualisation. From this perspective people can either learn to live with their voices, integrating their many selves or else disintegrate into a chaotic submission to the voices. These findings are in accordance with the model of recovery proposed by May and Longden (2007) who posit that people go through three stages of recovery; the safety phase, a

period of understanding, and finally social reconnection. This pathway is very much mediated by belief in the power of the voices and understanding these voices in the context of life history (May & Longden, 2007).

The coping or management phase denoted in the research findings consists of coping with the very frightening experience of voice onset and the exacerbating effects caused by the reactions of others. The consequent stigmatisation and marginalisation, coupled with the frightening and tormenting nature of the voices, indicates the level of distress and arousal that the person needs to manage. For some of the participants, coping was about reducing the anxiety and finding ways to relax; for others it was about ignoring the commands of the voices and learning to live by busying themselves with tasks that were viewed as socially acceptable. By and large, self-management is about finding ways to help manage the symptoms and thus the distress. Two of the participants found this hard, primarily because they believed in the power that the voices had over them and responded to their commands. This linked to research demonstrating that the capacity to cope is linked to belief about voices (Chadwick & Birchwood, 1994). However, the process is not linear; some people were able to demonstrate strength and resilience even amid times when they felt unable to cope. The difference between these interviewees and the others lies in the degree of fragility in relation to the voices and their ownership of coping mechanisms. Those who believed in the omnipotence of the voice coupled with few coping strategies experienced a greater rollercoaster of reactions and emotions.

Some of the coping mechanisms discussed in the accounts fit with Roe's et al. (2006) model which stated that people use different coping strategies at different times. Those relating to self-management were examples of reactive coping strategies, going somewhere (e.g. the mosque) to reduce anxiety, or performing a cathartic 'pterodactyl' movement. There were also anticipatory strategies (e.g. not drinking alcohol) and proactive coping methods such as personally set goals and targets. Interestingly, preventative coping seems more linked to general resilience and included strategies such as setting limits and an ongoing commitment to self-care and enjoyment.

According to participants, deconstructing the experience was another pivotal stage in the recovery process. This is about unpicking the nature of the voices and the root causes of the distress. The participants found that they were able to approach their voices differently as a result of increased insight and understanding. There are many support

options and therapies to help people begin this process such as CBT, HVG or Voice Dialogue but interestingly, although participants noted the importance of this process of understanding, few discussed how this actually happens. Some referred to talking to Arthur, the group facilitator and clinician, and others talked about the group as a source of understanding.

For people in this study, the meanings of recovery were diverse but can be encapsulated as a process of acceptance, and a journey wherein people can learn to live with their voices and fulfil their potential with less distress. For some participants, this involved working voluntarily, having a house and car, studying for a PhD, becoming a psychologist or owning a business. The final part of this journey relates to personal identities and aspirations. Trauma and illness can have a stop effect on normal psychosocial development and this stage involves a reconnection to the developmental trajectory, enabling individuals to find their place and role in society and build relationships with others. However, this needs to be done in conjunction with the voice-hearing experience. This may involve employing a range of coping strategies to make daily tasks more bearable, showing a continued commitment to self-soothing, and understanding, or dedicating time to tasks that make survival meaningful and educative. The point here is that recovery is self-defined and positioned at a level where the person feels that they can meet their individual potential and minimise their distress.

Trauma and shame

The participants illustrated times when services contributed to stress and trauma. Examples included when people felt disbelieved, degraded, unheard, and treated with contempt. This at times seemed to feed into memories of their childhood experiences of abuse, their need to live with the secrecy and resultant shame which were, in turn, mirrored by the voices themselves. The consequences of such trauma can be wide ranging and could lead to increased distress, a worsening of symptoms, post-psychotic social anxiety (e.g. Birchwood, et al., 2000), depression (Pallanti, Quercioli & Hollander, 2004), or complete withdrawal. Furthermore, patients with psychotic disorders are known to be at a higher risk of traumatisation and posttraumatic stress disorder (PTSD) (Mueser, Goodman, Trumbetta , Rosenberg , Osher , Vidaver , Auciello & Foy, 1998). Seedat, Stein, Oosthuizen, Emsley and Stein (2003) reviewed evidence for the link between PTSD and psychosis, and found that assessment and treatment of trauma within this population is largely neglected.

Shame is strongly associated with abuse and trauma. Lewis (1971) asserts that shame encapsulates a body of feelings such as humiliation, embarrassment, low self-esteem, belittlement and stigma, all of which are central ingredients in experiences of being alienated, defenseless, powerless, flawed, exposed, weak, and stupid. Whilst none of the participants explicitly referred to feelings of shame, the experience of continual trauma, be it from childhood abuse, being labelled 'a schizophrenic' in a 'pessimistic and paternalistic system', or from the subsequent spiralling degenerative effects of living with voices and the associated stigma, may result in some level of internalised shame.

Shame is often avoided and rarely talked about in society; in fact it is often considered shameful to feel shame (Byrne, 2000). As a result, shame is rarely acknowledged by ourselves or others. The adaptive response to private and public shame is secrecy; secrecy, however, acts as a barrier to the presentation and treatment of mental illness (Byrne, 2000) as indicated by one of the interviewees. Research suggests that this feeling has a central role in mental health problems, causing debilitating feelings and an overwhelming urge for individuals to hide and withdraw from social contact (Van Vliet, 2008). Such behaviour is maladaptive as it promotes social isolation and prevents individuals from accessing the social support and professional help that may alleviate psychological distress (Van Vliet, 2008). Wang et al. (2005) have shown that many people with mental health problems delay seeking and accessing treatment for periods of time because of ignorance, shame and other by-products of stigma.

Talking about the voices and, furthermore, about trauma, needs careful and skilled practitioners to provide a helping relationship tailored to individual need. Disclosure at this level can be deeply shameful and without careful consideration can be re-traumatising in itself. There is extensive research exploring trauma and how to interact therapeutically with a traumatised person (e.g. Hermen, 2001) and it may be the case that this focus on trauma may be largely lost when working with someone who hears voices. For example, the service pathway for working with someone diagnosed with schizophrenia refers to assessment, diagnosis, medication, risk management and access to psychosocial therapies (NICE, 2010). However, given the causal link between adverse life circumstances and stress vulnerability it may be as important to consider how this process is managed in terms of the person feeling as in control as possible, as would be the case with someone diagnosed with PTSD (Seedat, et al., 2003). In many ways, this links to needing to create safety and reduce arousal as a first step, and finding

suitable interventions to support people with high levels of arousal and shame. Gilbert's model of Compassionate Mind may offer a useful approach here (e.g. Gilbert & Irons, 2005).

Historical aftermath

Recovery-orientated services and political reforms are embedded in a historical context of institutional segregation, degenerating disability, and stigmatisation (e.g. Pitt, et al., 2007; DoH, 1999, 2001). This foundation makes it difficult for new ideas to permeate the system, limiting the effectiveness of strategies designed to support coping, resilience and recovery. For example, people who experienced treatments characteristic of the traditional psychiatric system may continue to feel their dehumanising effects. Similarly, professionals and members of the public may still be influenced by the 'schizophrenic' stereotypes of madness, irrationality and dangerousness. These ideas may still pervade as a direct consequence of the continued powers and procedures associated with times of institution (e.g., sectioning).

This links with the views of participants who thought of psychiatry as a means of social control, to dampen or remove the bad and dangerous. Sadly, this image is damaging for any helping relationship in terms of engagement, trust and a healthy working alliance. Furthermore, this public image may hinder community and service efforts to help integrate people who hear voices within society. As highlighted by the participants, this results in them feeling they have to keep part of themselves in secret or in safe places like the HVGs.

Generally participants thought there was ignorance around voice-hearing, and that as a rule it was unaccepted within society. One participant wrestled with her public and private personae which worked to protect her vulnerability. This may in part have been borne out of a fear of rejection, from the lack of control and hope within services, and as a reflection of the rising bar of 'normal'. It is largely recognised in the recovery literature that there are therapeutic benefits of being a valued member of society, building relationships and enjoying pleasurable activities (e.g. Pitt, et al., 2007; Spaniol, 2002; Deegan, 2005). However, this is at odds with negative attitudes held by some in society which emphasises blame (Angermeyer, et al., 2004), embarrassment (Huxley, 1993) and shame (e.g. Oestman & Kjellin, 2002). This corresponds to Jacobson and Greenley's (2001) conceptual model of recovery which emphasises the interaction of both

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internal conditions that the person undergoes in recovery and the external conditions (e.g. stigma).

Societal stigma is recognised as a problem that needs addressing within government documentation and national campaigns (e.g. Shift, 2011, Time to Change, 2011) have been put in place to actively combat it. The difficulty is that a large proportion of this effort is aimed at more socially acceptable conditions such as anxiety and depression, rather than those conditions that evoke negative reactions in people (e.g. schizophrenia). The lack of an encompassing approach to mental health could increase discrimination for those considered to have a severe mental health disorder. This, in turn, could decrease their opportunities in relation to employment and active engagement in society (Topor, et al., 2011). A number of agencies, such as the HVN, try to combat this by actively working with people who hear voices, and using their recovery stories to educate and inform through television and workshops.

Person-centred working

The theme 'dancing with voices' reflected the dynamic relationship with voices and recovery; some people wanted symptom management, some wanted to understand, and others want to learn to live with their voices. This journey is unique and individually timed and corresponds to the person's personal conceptual model of recovery and their desired outcome for treatment. Desired outcome for treatment alters according to the individual's clinical status and well-being (e.g. Rosenheck, et al., 2005). With this in mind, working in a person-centred way is essential in terms of reflecting people's goals and managing risk, whilst working within the individual's framework of understanding and network of support.

These findings highlight that professionals have a responsibility to link in to people's support mechanisms, whether they are spiritual and religious or family and friends. In this way they would be working from that person's secure base to build resilience and indirectly combat the effects of stigma by creating a sense of hope, belief and change. Such person-centred working promotes positive images of mental health for both the person with the disorder, and the professionals, whose own examples of good practice can be lost when working with a highly marginalised group of people.

Factors that contribute to a positive outcome are hard to gauge. However, working in a timely and collaborative manner can create a manageable relationship with boundaries,

goals and expectations that help to increase the individual's sense of empowerment and involvement. These factors support increases in self-esteem, identity, coping strategies, and therefore resilience, in the face of personal distress (Deegan, 2005; Spaniol, 2001). Such a working alliance could serve as a positive framework for increasing people's involvement within the community which essentially involves negotiating ideas, building relationships and actively engaging in society. Furthermore, a good therapeutic alliance could act as a secure base from which one can explore. Unfortunately, when professionals are encouraged to work defensively to 'protect' the person from harm this can narrow opportunities for honesty, growth and encouragement (e.g. Topor, et al., 2011). Instead:

'therapy requires a collaborative relationship in which both the professional and patient act on their implicit confidence in the value and efficacy of persuasion rather than coercion, ideas rather than force, mutuality rather than authoritarian control' (Pg 136, Herman, 2001).

Clinical Implications

This study was concerned with finding out how people who hear voices experience the support offered to them, and how this has influenced their coping, resilience and recovery. The personal narratives of these participants highlight individual commitment to recovery from the learning and use of coping strategies and the strengthening of personal resilience (e.g., to socially connect and develop peer relationships with the HVG). The interviewees also revealed a number of other factors including having a safe environment, being offered hope and inspiration, validation of their experiences and distress, as well as the opportunity for empowerment. Research is suggesting that it is the interaction of these internal and external mechanisms that enables recovery (e.g. Jacobson & Greenley, 2001). From the participant accounts it is clear that further work in the following areas is required.

Training

Front line staff in the mental health service need greater training in the conceptual frameworks and models of recovery in order to increase the 'healing culture' (Jacobson & Greenley, 2001). Given the onus on recovery at political, economic and service levels, it is important that we understand the issues in relation to our role. There are a number of sectors in a recovery-orientated service (Anthony, 2000) and each of these

services is likely to have a differential role and focus in the help they offer. Knowing how the systems interact and who is responsible for what will inevitably create efficiency by reducing duplication. Training all staff in these models will enhance people's awareness of these issues enabling them to critically evaluate their value base and capabilities.

Further understanding of the process of recovery (e.g. Andressen, et al., 2003; May & Longdon, 2007) can help clinicians tailor the work to that individual's stage or place within their notion of recovery. Thinking about them in relation to the transtheoretical change model developed over many years by Prochaska and colleagues, the clinician can think about their role and goals within the person's frame of reference at that time and adjust as the individual evolves.

A focus on family

Given the value placed on the support of family and friends by the interviewees and the recovery literature highlighting the integral role of social connection (e.g. Pitt, et al., 2007; Spaniol, 2001), services may need to place greater emphasis on the family. Research has begun to elucidate the needs of the family and the burden placed on family (e.g. Hall & Purdy, 2000). Attention is often given to the role of family in assessment; however, it may be important to incorporate their views and further their ability to manage, particularly when major changes occur, to ensure their continued support and well-being.

A focus on collaborative working

Building a collaborative, non-judgemental working alliance which demonstrates empathy is essential in helping people to access and engage with services, and this is everybody's responsibility. Such alliances, involving genuine and trusting relationships, can be therapeutic in themselves. This requires professionals to understand people's individual frames of reference, their explanations, goals, belief systems, support and lifestyle structures during assessment and to use this information to guide any intervention. Enhancing choice and autonomy in treatment will increase compatibility of working and help create better joint planning of risk management. A shared risk management plan, to which both SU and professional network sign up, will result in increased autonomy, involvement and, ultimately, control. Many of the contributions to the maintenance of recovery fall outside the limit of health. To prevent the loss of an agreed relapse prevention plan, commitment to an inter-professional agreement which

contains communication thresholds and responsibilities could form part of the individual care plan.

A focus on meaningful and relevant outcome measures

Outcome measures are increasingly used to reflect the 'consumer' of care rather than the 'patient' (DoH, 2009-2010). The emphasis on common factors like the therapeutic allegiance in relation to treatment efficacy and recovery would be valuable for a number of reasons. Firstly, they would illustrate the discrepancy between what is offered and what is received (Kovess-Masféty, et al., 2006), and secondly they could strengthen the role of SU expertise and help dispel the stereotypical vision of the incompetence of the 'schizophrenic person' to make rational decisions and judgements (e.g. McCabe, et al., 2007; Topor, et al., 2011). Using SU feedback to improve services will further bridge the gap between SU need and provision (Kovess-Masféty, et al., 2006). Research (e.g. Andressen, et al., 2003) suggests that measures of psychological well-being are comparable with the recovery literature and the use of such tools may act as a gauge for progress to inform the intervention and provide meaningful feedback to the SU.

Methodological Considerations: Quality in Qualitative Research.

Sensitivity to context

The group's positioning was an ongoing consideration; it was important to acknowledge that the HVG is affiliated to the HVN which positions itself in conflict with traditional psychiatry. Although this group is not explicitly set up in opposition to psychiatry, it does provide a safe haven from traditional services, families and even voices, and offers an alternative discourse to those more commonly presented in services. Coming in as a researcher from a clinical background could have 'contaminated' the group and therefore sensitivity to the group milieu was an integral focus. This was achieved through a number of means such as working with the group over time, developing a consultative participatory approach in the designing of the research, and by routinely asking the group permission to be there. The aim of working in this way was to reduce barriers and promote engagement whilst demonstrating commitments to the importance of the research and to the group itself. This extended membership, however, provided a forum to gain a more inside perspective gaining greater knowledge of certain participants, issues and ideas through relationships with those seen across groups compared to those

seen for a one-off interview. However, this position did not compromise the data collection; the interviews provided by more long-standing members were completed at the onset of my membership and therefore comparable to those interviewed once for the purpose of the research. Any additional information gained from being part of the group was used either to develop the personal pen portraits or as a frame of reference for understanding in the analysis. These different relationships did occasionally affect my interviewing skills, engendering empathic responses rather than probing curiosity, which may have had a closing effect on the narratives. Furthermore, my own personal involvement may unwittingly have brought about a difficulty in maintaining distance and a degree of objectivity in the analysis, because of a belief that these people's experiences need to be more widely heard and understood. Routine supervision, however, was sought to discuss these issues and to reflect on the interpretative process of the data analysis.

Rigour and commitment

Care was taken during the collection of the data and throughout the analytical process to ensure that the interpretation and coding was based on each individual participant. The semi-structured format of the interviews enabled the questions to be used as a guide only allowing each person the space and freedom to talk about their own experiences within the remit of the interview protocol. The familiarity of the transcript and initial interpretation phase of the analysis was conducted after each interview and visual pen portraits were devised to capture visually any themes and individual personality that was perceived. The pen portraits coupled with the initial themes from each analysis benefited the interpretative process across transcripts as it helped me to hold in mind the person and their accounts when considering the representation of the themes. The interpretative process was discussed and broadened where required with the research supervisors at each stage of the analytic process to maximise quality and rigour; this included each transcript, pen portrait, sub-ordinate and master theme.

Transparency and Coherence

Transparency and coherence given the interpretative process and double hermeneutic was an integral step and, to ensure quality, all aspects and stages of the research were considered and reflected upon with research supervisors and the university ethics board. This process was fully documented in the research along with the important decisions,

considerations, reflections and audit trails to clearly demonstrate stages of development and progression within the research. This then enabled the research to be read and understood within the practical and political constraints that it was written in. Whilst there was no agenda set up in terms of the historical and political remit, this no doubt infiltrated services, practice, and perception and thus was noted. Similarly, whilst every effort was made to bracket off any preconceived ideas and attitudes during the process of data analysis, ultimately this was conducted within my own frame of reference. Whilst this was discussed and broadened within supervision this was certainly a practical constraint; it may be that if someone else was to analyse the same transcripts they may find other interesting themes and clinically relevant implications. Finally, in terms of transparency with the participants, given the interpretative process, I did not share my final write-up with them although summaries were made available. This was not through fear that they would not agree but more the possibility of the damaging effects of being interpreted within someone else's framework given what some of them said about being viewed in terms of mental health assessment. On that basis, I do not feel that the research process was truly transparent.

Impact and Importance

The research sought to find out about coping, resilience and recovery in people who hear voices. In some ways, one could argue that the research identified the political dynamic between the PPM and more traditional psychiatric services. However, not all of the participants were so acutely aware of this context and the group itself promoted and discussed all sources of support and, as such, neither membership of the group nor the interviews seemed overly politicised with just one participant being an exception to this. One could therefore argue that this research has highlighted a number of values and factors that are pertinent to individual recovery which should be dissipated and heard along with the implications to all those working with people who hear voices.

Reflections

Being a part of the group challenged me to reflect on my own position both personally and professionally. From an ethical perspective, I questioned how the prolonged membership to the group would affect recruitment and whether people would feel additional pressure to be involved or, moreover, whether it would jeopardise the group safety. As group membership varied and people's presentation was changeable, a

number of procedures were put in place to protect the group and alleviate my anxiety such as placing the research on the weekly agenda so that it could be discussed and the group given an opportunity to ask me to leave. Also, when people did show an interest, I would hand them the information sheet and then give them a week before setting a date for the interview so that they could think about what involvement would mean for them. Conversely, from a personal perspective, being asked how my week was as a member of the group, for example, challenged my typical boundaries and required ongoing negotiation to balance my professionalism with my relationship within the group.

Attending the group gave me a unique insight into the stigma of having a serious mental illness. For example, prior to the group one week, I was sitting on the floor reading the handouts when two people came in at separate intervals to check that I was alright and suggested that I might want to sit on a chair, which felt both intrusive and paternalistic. Membership of this group made me review many of my own preconceived ideas. An example of this was when an external figure came in to the group to discuss advocacy; he spoke to me as another group member and therefore as somebody who hears voices. This felt very uncomfortable to the extent of wanting to clarify my role; this I believe reflected my own fears of being judged and labelled. Before attending the group I considered myself to be open-minded. However, this was challenged by discussions about the supernatural world and through the demonstration of new techniques in working with voice-hearers like Voice Dialogue; ideas that I hadn't even considered before.

Most of all, my attendance at the group allowed me to connect with the people that hear voices and this is something that I have tried to reflect throughout the course of this research. Making sure that each participant was equally represented given that some were met only for a one-off snap shot interview and others were known within the group over the course of membership was an ongoing consideration. Those who I recruited from the group, I interviewed early on in my membership and thus any other information gained during the meetings was only used as part of the individual pen portraits to portray their individual characters and running themes. Obviously ideas, attitudes and opinions that participants reflected in the group did influence the analysis but in a way to broaden my own thinking more generally. However, each of the participants during the interviews had a different effect on me and this did at times permeate the analysis. Martha, for example, was given too much space in the research relative to other

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participants and I think this may be because I could relate to her; she was able to verbalise some of the injustices that I had experienced with my mother but wasn't able to voice. Martha, as a participant, also created a challenge to this methodology. As a highly academic researcher of the experience of voice-hearing, she has developed elaborate theoretical models that dominated much of her interview. Her focus on explanation rather than experience not only added an additional hermeneutic dimension but functioned to detract me from the focus on experience. My ability to 'bracket off' any preconceived ideas was at times compromised by my relationship with her narrative. The quality of the analysis was checked by research supervisors to ensure that when this occurred, a more objective view could be taken, and the impact on the quality of the research was minimised.

The polarity in the findings made me particularly uncomfortable and I had to consider why this was. I initially questioned whether the results simply reflected a political agenda of the group but with the exception of one participant, who was actively involved in the PPM, the group in practice did not actively engender any individuals towards particular treatment modes and the personal accounts told were based on their unique experiences rather than opinion. I then considered whether the position of the group attracts those individuals who had felt let down or damaged as a result of poor service intervention affecting the results. I also wondered, given my experience with my mother, whether it would be assumed that I had a personal agenda and dislike. Although my understanding and opinion of services with my mother were not positive I do believe they were typical within that historical period and since have had the opportunity to work in clinical settings with a wide range of professionals who I believe are providing good services. I spent a lot of time trying to understand the polarity of the findings in relation to the wider literature and believe that this reflects a greater need for services to understand the process of recovery and moreover where they fit in relation to this.

Conclusion

The aim of this study was to explore the experience of support offered to people who hear voices and how the support affected coping, resilience and recovery. Individual factors such as coping, resilience, belief systems and current service provisions have been discussed within the developing context of the mental health system and wider society. The participants highlighted the support provided by the HVG and help provided by family and friends. This was considered in contrast with psychiatry which was viewed unfavourably. The primary difference in the experience of support perceived as either helpful or unhelpful was linked to the emphasis on specific factors that the interviews considered to influence their process of recovery. These included being in a safe and non-judgemental environment, being offered hope and validation of their experiences, as well as having a means to socially connect and empower their position so that they can be more active in their own recovery. The research suggests that more training in the conceptual frameworks and models of recovery, a greater focus on working with the family and wider support, enhanced collaborative working, and more tailored outcome measures would help services to better meet these individuals' needs during the recovery process.

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APPENDICES

Appendix 1: Ethical Approval

Miss J.Webb
Clinical Psychology
Leeds Institute of Health Sciences
Charles Thackrah Building
101 Clarendon Road
Leeds LS2 9LJ

9th September 2009

Dear Miss Webb

Thank you for submitting your research proposal and supporting documentation for ethical review.

I am pleased to inform you that the LIHS/LIGHT Research Ethics sub-committee has approved your project entitled "Coping, Resilience and Recovery in Voice-Hearers".

Kind Regards

Laura Stroud

Co Chair LIHS/LIGHT Research Ethics sub committee

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Appendix 2: Information Sheet

Information about the Research
Hearing Voices: Resilience, Coping, and Recovery

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study? What are the possible benefits of taking part?
This study seeks to understand people's experience of hearing voices and the forms of support that have been helpful and unhelpful. By understanding these experiences it may be possible to influence current service provisions to think about what they offer.

Why have you been invited?
You are being invited to contribute to this study because you have the experience of hearing voices and understand how this affects you in your everyday lives and in society. In addition, you have an understanding about the types of support that have been helpful and unhelpful and why this was. A total of eight to ten people will be invited to talk about their experiences.

Do you have to take part?
No. It is up to you. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason.

Will your information be confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence.

What will happen to you if I take part?

If you agree to participate we will arrange a meeting time. This will take place before the support group in the same building. The session will last approximately 1 hour. You will be asked to consider the forms of support you have found helpful/ unhelpful and how you think this relates to how you understand your experience of hearing voices (see the question sheet).

The information will be gathered from semi-structured interviews, and explored using Interpretative Phenomenological Analysis (IPA).

Phenomenological psychological research aims to clarify situations that are lived in everyday life through the qualitative exploration of the meanings, personal accounts and perceptions that particular experiences and events hold for people.

The session will be audiotaped so that it can be transcribed. The tapes and transcripts will be kept anonymously, names will be excluded, and they will be kept locked and destroyed at the end of the study in line with the Data Protection Act (1998).

What support is available if you find the interview difficult or distressing?

If you are distress by the issues discussed in the interview, the meeting will be held immediately before the Hearing Voices Network Support Group so that the group is available for support and discussion. In addition Arthur (group facilitator and clinician) and Joanna Webb (Psychologist in Clinical Training) will be available for support following the meeting.

What will happen to the information?

The information will be submitted to the University of Leeds as a thesis document and will be available online. In addition, there are a range of possibilities for disseminating the findings further, from local to national conferences e.g. MIND, ISPS and also publication possibilities e.g. new ISPS Journal "Psychosis".

Expenses and payments

The Hearing Voices Network Support Group will receive a donation for their ongoing involvement in the research of £150. Participants will also receive any out of pocket expenses incurred such as travel costs.

What happens if you have any questions, concerns or have a complaint?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions

Joanna Webb: 0113 432732

Arthur: 01274 494194

If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Appendix 3: Consent Letters

Hearing Voices: Resilience, Coping, and Recovery

Consent Form

I confirm that I have read and understand the information sheet.

dated ....4.|\\.|05... for the above study described on the information sheet.

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I understand that the report may include brief quotations from the group discussion and have been assured that no one will be able to identify me from these. I agree to the use of comments I make in the report.

I agree to take part in the above research study.

| Name of Participant | Date | Signature |

| Name of Person taking consent (if different from researcher) | Date | Signature |

| Researcher | 4 \\ 05 Date | Signature |

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Appendix 4: Interview Schedule

Research Questions

Can you tell me about your experience of hearing voices and how you have come to understand this experience?

-Does the way that you understand your voices influence your coping strategy?

Can you tell me about the forms of support that you have received?

-What forms of support have you found helpful?

-What forms of support have you found unhelpful?

What does recovery mean to you?

What are your hopes and inspirations?

-What do you think would help achieve them?

What do you think are your biggest barriers to recovery?

What is the relationship between the voices and the emotions that you experience? E.g. anger, fear.

-How do you approach managing this?

Have any spiritual beliefs influences how you cope and understand your experience of hearing voices?

Appendix 5: IPA Analysis

The analysis will be made through a number of stages, as per Smith and Osborne (2008). These are detailed below:

- *Looking for themes*

The transcript will be read a number of times in order to gain familiarity with the text. The left-hand margin will be used to annotate what is interesting or significant about what the respondent said. There are no rules or restrictions about what is commented on and may include association or connections that come to mind, preliminary interpretations and summarising and paraphrasing. As this process develops comments on similarities and differences, echoes, amplifications and contradictions will also be made.

The right-hand margin is used to document emerging theme titles. The initial notes made are now transformed into concise phrases that capture the qualities of the findings. These will thread back to what the participant said as well as the researchers initial responses.

- *Connecting the themes*

The emergent themes are listed and reordered and clustered as the researcher tries to make sense of the connections between the emerging themes. These will be checked against the actual words of the participants. The researcher will compile a directory of the original phrases to support the related themes. A table of themes will then be produced which lists the themes with their super-ordinate themes along with an identifier. The identifier indicates where in the transcript instances of each theme can be found by giving key words from the particular extract plus the page number of the transcript.

- *Continuing the analysis with other cases*

The super-ordinate themes will be used to begin to make sense of additional transcripts. At this stage it is important to discern repeating patterns whilst acknowledging new issues that are emerging throughout the transcript. Once each transcript has been analysed, a final table of super-ordinate themes is constructed.

- *Writing up*

This is concerned with translating the themes in to a narrative account. The themes become expansive as they are explained and illustrated. The table of themes forms the basis of the account and includes narrative argument interspersed with verbatim extracts from the transcripts.

Appendix 6: Audit Trail

A number of documents have been included in the audit trail to illustrate the process of analysis.

Figure 1: A sample transcript

This is Katherine's transcript with interpretative notes and colour coded quotes.

Figure 2: A sample pen portrait

This is Katherine's pen portrait. A pen portrait was drawn for each of the participants to pictorially represent the emerging themes.

Figure 3: Photographs of the Master themes, 'Dancing with Voices' and 'Voice Awareness' with the sub- themes and quotes.

This is sample of photographs taken of the A1 Compiled themes and their verbatim quotes used for validity checking.

Figure 4: Master theme table – 'Dancing with voices'

This is one of the master theme tables which show the master themes, sub-theme, evolving themes and verbatim quotes from the interviews. A table like this was drawn for all 6 master themes.

Figure 1: A sample transcript

Interview 2 - Katherine

4-5: Where the voices productive?	1	**JW:** OK, so, firstly I'm just going to ask you...erm... if you can tell me a bit about your experience of hearing voices.
		XX: Yeah. I first started hearing voices when I was about 12 or 13 years old. Erm... but they weren't really a problem at that age – not till I got older and it became a lot more destructive and domineering. Erm... So, all my adult life I heard voices.
	5	

4: A very timid lady but very articulate and confident in describing her experience.

5: What's it? The voice, the abuser?
4-5: weren't a problem in childhood – were they a comfort?
6: Voices b-c a problem when they are destructive and domineering.

JW: Is that like voices telling you what to do and how to behave?

XX: Yeah, there's the main voice – I call it the Devil. Erm. ___ has told me it's more of a demon voice than the.. you know it's not the devil himself or anything. Erm.. and he tells me that I'm wicked, evil; everyone knows that I'm wicked, I'm evil. I'm a whore, I'm, you know whatever. And, err... and then there's ... there's a voice called Fifi and there's a voice called Chloe as well. Fifi's the extravert and Chloe's like a young child. But the devil's the main one... that I have day to day.

10: The main voices = devil – significance?
11: I maybe indicative of a submissive demeanour.
10-12: Distinguishes between the devil and demon – why?
14: whatever...sounds very blasé...like she is accustomed to hearing how bad she is.
16-17: Fifi – a name linked to sexuality, promiscuity. Chloe sounds more pure, innocent – these could reflect differing personas. Contrast to the devil, a well depicted, iconic figure linked to religion.

JW: So how, over these years, have you come to understand why you experience these voices?

XX: Only through ___ Up until then I think I was... Last few years treated through, you know, by medication for schizophrenia and everything I think. And it was an easy label to put on... and everything like that. And then, through doing therapy with ___ I learnt that the voices were there because the abuse I suffered when I was a child. And because that hadn't been worked through;

21: Through religious connotation
22-24: get the impression that she thought very little about the treatment. Everything...blanketing An easy label
21-26: difference in the way she talks. Talking about medication...more fragmented, more dismissive. Talking about therapy she is more definite and knowledgeable.

	Transcript	Analysis	
	that was why the voices were there because... showed me that something needed to be worked on... you know..	29: Onus on the self as a resolution. 29: you know...?	
30	JW: So, that's been quite a big support for you... Can you tell me about other things that have been a helpful support for you?	[jw: leading question....should have been..can you tell me more about that]	
35	XX: Erm... I see a CPN and she's helped... quite a bit. Erm... and then medication... has been a help, but like many of the others, I've found I put weight on which, you know, I don't really like. [pause]. And I find I don't like the way the medication can be sedating as well. But... erm... The	33-39: Acknowledges the helpful role of the cpn and medication but does she know why they were helpful? She doesn' expand. This contrasts to her explanation of the role of the hvg. 35-37: Notes side effects of medication.	
40	Hearing Voices Group, obviously, you know... That's helped, because you suddenly realise you're not alone; other people in the same boat and...erm... there's a sort of fellowship there that helps.	40: hvg helpful – realise your not alone. Get a sense of her feeling isolated 41-42: Same boat, fellowship – religious connotation? Being in the same boat?	
	JW: Mmm...How long have you been coming to the group?	*bc has the grp* [jw: can you tell me more about that]	
45	XX: Erm... a couple of years. I go through stages where I come, sort of, quite regularly and then, for whatever reason, I get scared of coming and then I don't come for weeks again. But... Yeah, about two years I've been coming on and off now.	47: Scared – why?	
50	JW: Is there any other things that have supported you over the years? I'm thinking about, sort of, things like family, or maybe belief systems that you might have – sort of, wider things...		
55	XX: Yeah, family have helped...support me a lot. My husband...erm... .he's very good. With the hearing voices, he tells me "Stop being so silly – just ignore it". You know –	55-56: Husband sound very commanding. Does she have a submissive role in this relationship?	

130

he finds it hard to understand that it's a bit difficult to "just ignore it"... and that. I've tried to explain to him. But he's given me the support – there all the time. You know, when I'm having bad days and that he doesn't run out the door and say "Get on with it" you know. And my family, growing up, were very supportive. Erm... I used to believe in... I used to be quite religious – I used to believe in a God... and then found that when the devil came along – my devil – he wouldn't allow me to believe in a God any longer... so there's a sort of hole there really.

JW: So have you, because of that voice, almost stopped believing or put it one side?

XX: Erm... it depends on how I'm feeling. Bad days I've definitely stopped believing – because, you know, how can somebody put you through so much pain and things... and then, when I'm going through better times I've just laid it on one side really. Hopefully, when I get this devil on a better footing...erm... you know I'll be able to ...erm... perhaps start believing again.

[Pause]

JW: So how does, like, your husband or your family or friends help you cope on a daily basis?

XX: Erm... my husband by being... he'll always listen to me and if I get upset, or if I get angry or anything like that; as I've said he's not – he doesn't walk out the door. He'll try and be supportive and try and understand... and, erm... gives me cuddles, you know [laughs], which we all need sometimes. My friends – I have a friend who I talk to on the phone every day. Erm... she's very supportive. And I speak

56: a yorkshire attitude – men practical – the provider/ protector. Women = emotional, needy
55-60 – he's supportive but doesn't understand. Does this contribute to feeling isolated?

61: Suggestive of people leaving when they find out

64: Differentiates between 'the devil' and 'my devil'. Suggests she knows that it relates to her demons and not the devil depicted in XXX
65: Her devil still very powerful, won't let her believe in God. ?? Does this relate to her distrust in God? (see 70-71)
66: Without God there's a void in her life
66: ? Use of the word 'hole': Space where there shouldn't be, maybe relate implicitly to her experience of sexual abuse.
70: Use of the word definitely – seems less her, more decisive. Does she feel obligated to say that for fear of upsetting the 'devil' voice.
70-71: and things...more blasé in contrast.
72-73: seems more her/honest – faith lying dormant. Laid on one side = image of turning back on her faith. Has her faith let her down (71)?
73-74: better footing – notes her own role and responsibility.
74: Hope; personal achievement; personal responsibility.
75: Start believing – do you really stop/start believing or do you question/ experience confusion..???

81: suggests everyone else runs/ walks away/ can't cope
81-82: tries to be understanding and supportive – suggests doesn't really.
83: cuddles – sounds childlike
83-84: acknowledges she needs the say comforts as everyone else.
85-89: talking, contact – helpful: normal,

		to my father on the phone every day. Erm... only for five or ten minutes, but, you know, keep in touch. Just "How's your day been?" and, you know, that sort of thing. [pause]. So, you know, that's been helpful.

everyday things – how's your day?

JW: Is there any other things that you do for yourself that you find make a difference?

90

XX: Erm... [pause]... Again it depends on how I'm feeling. Sometimes if I'm feeling that I really am wicked and evil and that... then I won't allow myself things like bubble baths and I won't allow myself to, you know, be kind to myself. But other times I try and do things like that. Just try and be a bit kinder and, sort of, allow myself some chocolate and that sort of thing, you know. Erm... different things like that.

95

92-96: Interesting use of I – she is feeling, punishing and depriving. Why?

94-95/98: quite childlike – bubble baths/ chocolate..

96-97: Notes important role of being kind to self.

JW: And that's harder to do when you're having really bad days?

100

XX: Yeah.

JW: How do you get through those really bad days?

XX: Sometimes try and sleep. Quite often if Geoff's gone to work – some days I'll just stay in bed and not bother to get up... and everything. [pause] And... [pause] when Geoff's at home we try and go out somewhere to keep me involved with going out – because I get scared of going out – and if I leave it too long it becomes too big a – an insurmountable thing, you know. So we try and go out somewhere...

105

110

104-106: Sleep, shut the world out

107-111: Frightened to go out alone, husband helps.
Links - (155-160) she talked about the fear of people knowing about her voices in her neighbourhood and the stigma of having to go to the psychiatric ward in the taxi and noted how the taxi drivers treat you differently.

JW: OK. So, are there things that you've tried or people

have done over the years that you've found really unhelpful?

115   XX: A lot with doctors [laughs] ... psychiatrists and that. When I was in my teens I was anorexic – I was sectioned because I'd gone down to four stone two and erm... the way I was treated then – I mean this was in the seventies so it's probably changed – you know, the treatment today.

120   But, I had to stay in bed and I was force fed three meals a day – metatone, complan, cream cakes – and everything like that... Once I was sick over my meal and they scraped it off and said I had to eat the rest of it. You couldn't wash your hair until you put on certain weight, couldn't have

125   visits till you reached certain weight. And you were meant to feel , you know, really [pause],you know that you were so bad and everything to be like that, you know, and wasting everybody's time and everything. Erm... and then some of the doctors I've seen... erm... One I've never forgotten it –

130   said I was very manipulative... and that, I'm sure, it's etched upon my soul because that hurt so much. You know, and that. Luckily the last few years I've been quite lucky with psychiatrists and that and they've really tried to understand more and everything, so... [pause].

135   JW: With those, sort of, bad experiences, did it make it harder for you to engage, sort of, with them later on when you wanted, maybe, other help?

   XX: Yes, Yeah. I didn't tell anybody professional about my voices... and the sexual abuse I suffered as a child till I

140   was 33... because of the treatment I'd had earlier from doctors and things. And I just thought no one would believe me and everything. And...erm...it was psychiatrist up at   He...erm... I'd been seeing

Unhelpful = doctors and psychiatrists: poignant laugh – powerplay? Belittles/undermines the system in place to help.

116: Anorexic – ??? is it easier to talk about this experience or did this really lay the foundations to her opinion of mental health services/ engagement and her voices? She talks about being force fed, controlled, made to eat, professionally abused – is this experience like the original sexual abuse and trauma that triggered her mental health problems.

Meant to feel bad/ wasting everybody's time – This is a common experience e.g. self harm in casualty, suicide, eating disorders...when medics deal with things that they believe are self inflicted. Obviously this is a major contrast between those effected by disease, illness...and thus maybe required a different approach/ system/ set-up. Notes 70's characterised by conditioning, token economy, ect – punishment and medical procedures cure mental health – what message does this give? It's your fault!

124-125: you can't do x...unless you do what I say – this sounds similar to paedophile grooming/abuse techniques..

130-131: Manipulative...etched on my soul...hurt – shows the power that professionals flippant comments can have and the long term damaged that is caused.
Etched...links to devil connotation in some way – How?????

132-134: suggests she has experienced a positive change in psychiatric views, although she attributes this to luck – query indicative of a lack of belief in the system/ professionals...
138-141: Notes how her poor experiences when she was sectioned

easier bk it pushed her had to close secret	145	him for about five or six years until I plucked up the courage and... since it all came out, things have been a lot easier in a way, because it's explained to other people why I was behaving in certain ways... and everything... But it's a long time of your life to live a lie, in a way... you know, having to keep a secret like that all the time.

Right column (typed notes):

silenced her and hindered future engagement – didn't tell her psychiatrists about her experience of sexual abuse or her voices – having to keep her secret (again mirrors abuse).

144: plucked up the courage – suggests silenced by fear of what might happen/ what people might think.

145: became a lot easier – is this because she provided a just reason for her behaviour or because medics truly now understand the role of trauma/ vulnerability in mental health?

148-149: live a lie/ keep a secret....??????

154-155: Noted peoples struggle to understand
155-157: notes others' choice and role and sadness relating to loss of friends.

158-162: the reality of people knowing about voices - stigma

161: nutter

Neighbours don't know about me – another example of living a lie/ keeping a secret.

Main transcript:

JW: Yeah, definitely... Do you... Would you say that you've experienced...sort of... any forms of stigma over the years because you hear voices?

XX: Erm... Some friends aren't such good friends... unfortunately [laughs]. They find it hard to understand...erm... But they have a choice, so I just keep in touch with them when they want to keep in touch with me...and... But that's sad. You know, and other friends have been very supportive... erm... I find stigma when I [pause] sometimes when I go by taxi to Lindfield Mount or something or other...erm... from the drivers – they don't talk to you because you're a nutter, you know, and everything [laughs]. And that's a bit hard sometimes. Erm... and [pause]... it's not, you know... my nei- my neighbourhood is not known really about me... and, erm... I prefer to keep it that way, you know. I just don't work, but there's no reason why I don't work or anything like that.

JW: Does that, kind of, attitude put you off of, sort of, joining in, sort of, groups and activities, like with Mind for example.

XX: Yeah, yeah, because...I think...

Lost the remaining interview.

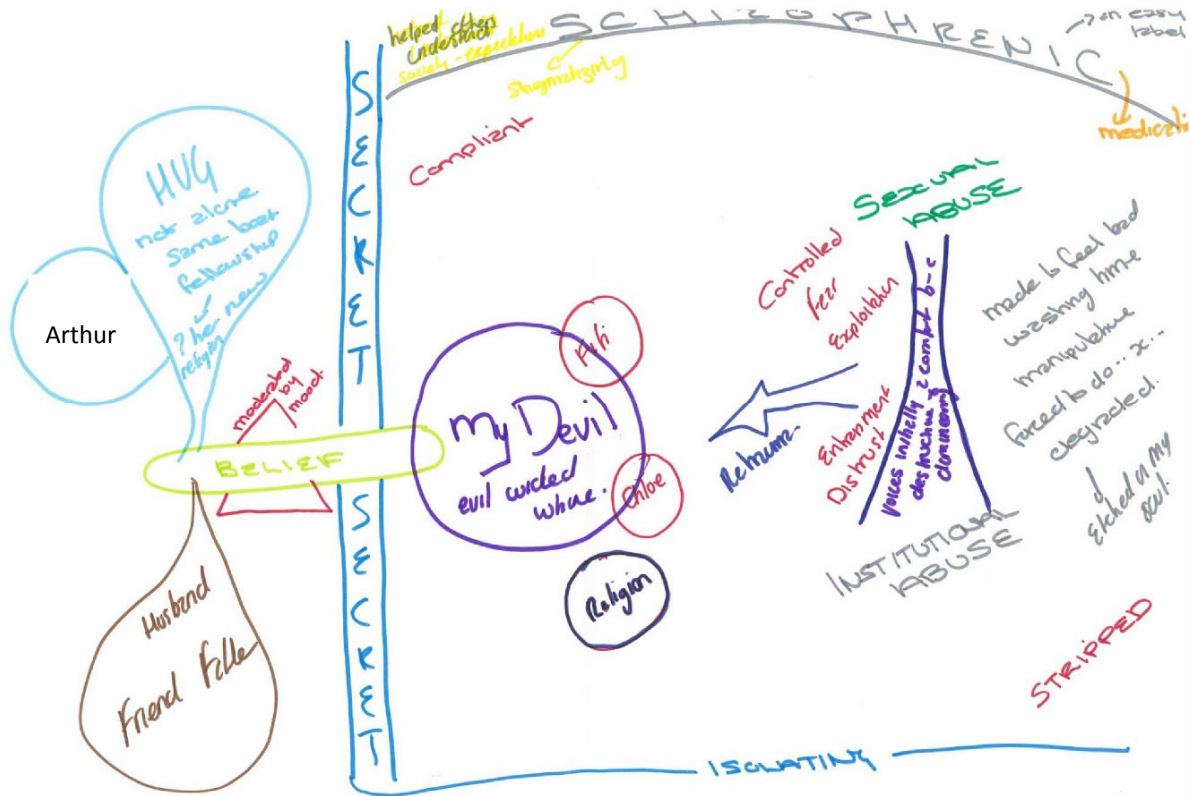*Figure 2: A sample pen portrait - Katherine*

Figure 3: Photographs of the Master themes, 'Dancing with Voices' and 'Voice Awareness' with the sub- themes and quotes.
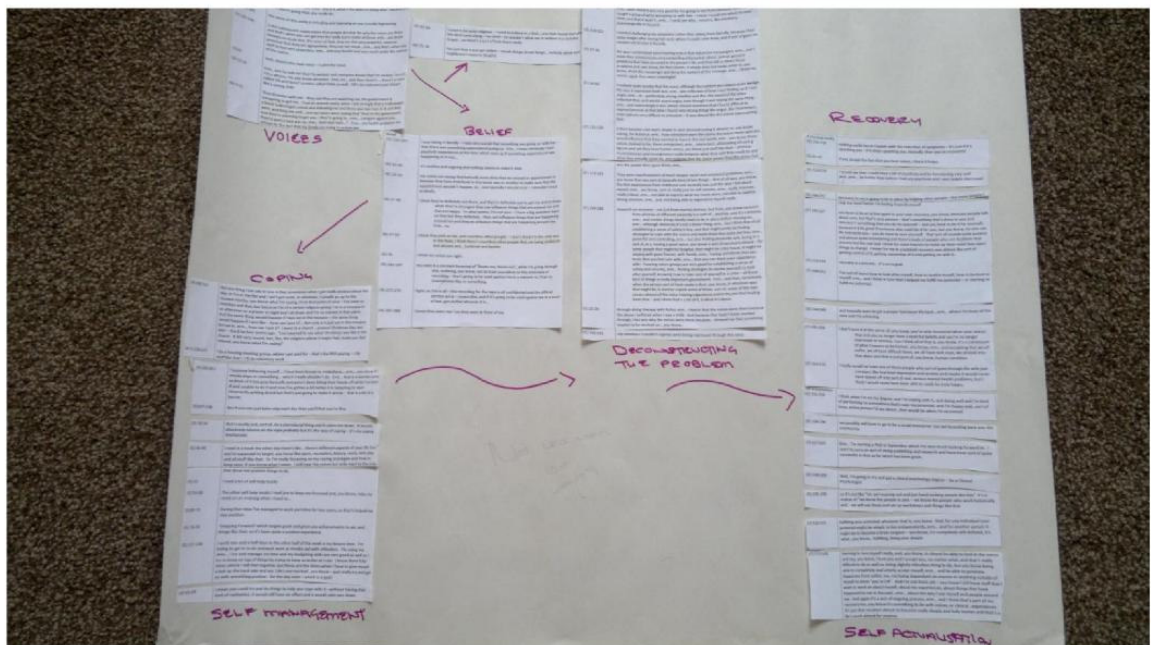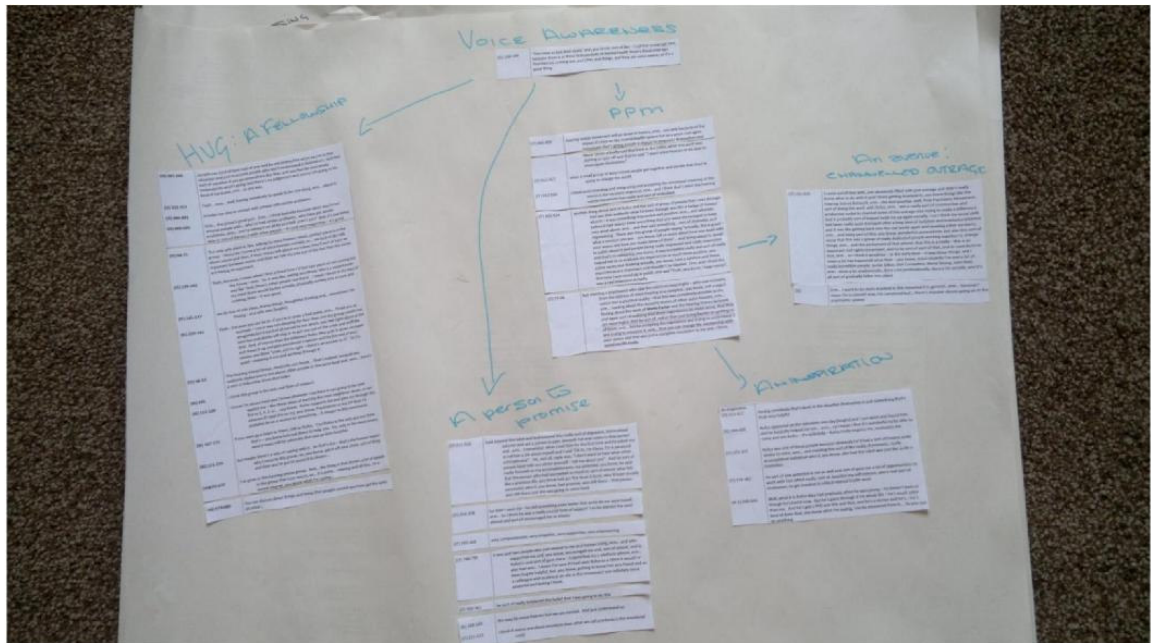
Figure 4: Master theme table – 'Dancing with voices'

Master Themes: Dancing with Voices			
Sub-theme	*Emerging Themes*	*Participant and line*	*Quote*
I hear voices	A frightening and tormenting experience	Laura: 244-247	I know it's scary – it's absolutely terrifying when you first get them. And you think you're going mad – you think "this is it, what's the point in being alive" because you think you're going mad, you really do
		Martha: 233-234	the sense of this entity intruding and imposing on you is really frightening
		Katherine: 13-14	[ ]..and he tells me that I'm wicked, evil; everyone knows that I'm wicked, I'm evil, I'm a whore, I'm, you know whatever
	Adoption of personas	Katherine: 10/15-18	Yeah, there's the main voice – I call it the Devil .. And, err... and then there's ...there's a voice called Fifi and there's a voice called Chloe as well. Fifi's the extravert and Chloe's like a young child
	Adoption of explanations	Martha: 239-246	[ ] that's when you can get into the really scary realm of these, erm... you know demons or devils that, the voice of God, they are this very powerful, external presence that they are egosyntonic, they are not magic... erm... and that's when you start to feel very powerless, erm... and very fearful and very much under the control of the voices

Master Themes: Dancing with Voices			
Sub-theme	*Emerging Themes*	*Participant and line*	*Quote*
Belief	Past belief that something was happening	David: 102-105	I was taking it literally – I was very scared that something was going on with her – that there was something supernatural going on
	Current belief that the voices influence	Kamal: 37-40	I think they're definitely out there, and they're definitely out to get me and at times when they're strongest they can influence things that are around me and that are happy.
Disintegrated	Being stripped of your beliefs	Katherine: 62-66	I used to be quite religious – I used to believe in a God... and then found that when the Devil came along – my devil – he wouldn't allow me to believe in a God any longer... so there's a sort of hole there really
	Loss of control	Kamal: 75-78	You just lose it and get violent – smash things, break things... verbally abuse your neighbours I suppose [laughs].
Coping: Self Management	Knowing that strategies can calm you down	David: 61-64	I mean you could try and do things to help you cope with it - without having that kind of realisation, it would still have an effect and it would calm you down

Master Themes: Dancing with Voices			
Sub-theme	*Emerging Themes*	*Participant and line*	*Quote*
	Avoiding things that make your voices worse	David: 642-651	I have been known to misbehave... erm... you know if I smoke dope or something... which I really shouldn't do. Erm... that is a barrier come to think of it because basically everyone's been biting their heads off while I've been ill and unable to do it and now I've gotten a bit better it is tempting to start recurrently getting drunk but that's just going to make it worse – that is a bit of a barrier
	Self-help strategies	Lee: 43-48	I read in a book the other day there's like... there's different aspects of your life that you're supposed to target, you know like sport, recreation, leisure, work, rest, play and all stuff like that. So I'm really focussing on my coping strategies and how to keep sane, if you know what I mean.
	Ways to relax	Kamal: 698-706	But one thing I can say to you is that sometimes when I get really anxious about the day, or I'm in the flat and I ain't got nowt, or whatever, I usually go up to the mosque nearby, you know what I'm saying, from that point of view – I've been to churches and that, but because I'm of a certain religious group I sit in a mosque in an afternoon or a prayer at night and I sit down and I'm so relaxed in that place.

Master Themes: Dancing with Voices			
Sub-theme	*Emerging Themes*	*Participant and line*	*Quote*
	Coping mechanisms	Laura: 50-54	But I usually just, sort of, do a pterodactyl thing and it calms me down. It sounds absolutely bizarre on the tape probably but it's the way of coping – it's my coping mechanism
	Being kind to yourself when you can	Katherine: 92-98	Again it depends on how I'm feeling. Sometimes if I'm feeling that I really am wicked and evil and that... then I won't allow myself things like bubble baths and I won't allow myself to, you know, be kind to myself. But other times I try and do things like that. Just try and be a bit kinder and, sort of, allow myself some chocolate and that sort of thing, you know
Deconstructing the problem	Voices linked to unresolved trauma and abuse	Katherine: 25-29	through doing therapy with A, erm... I learnt that the voices were there because the abuse I suffered when I was a child. And because that hadn't been worked through; that was why the voices were there because... showed me that something needed to be worked on...

Master Themes: Dancing with Voices			
Sub-theme	*Emerging Themes*	*Participant and line*	*Quote*
	Voices represented difficult emotions	Martha: 54-66	I realised quite quickly that this voice, although the content was always quite benign the way it expressed itself was, erm... was reflective of how I was feeling, so if I was angry, erm... or... particularly strong emotion and the- the sound of the voice reflected that, so it would sound angry, even though it was saying the same thing, erm... and interestingly it was always around emotions that I found difficult to express because at that time I found very strong things like anger, like resentment, even sadness very difficult to articulate – it was almost like the voices externalising that.
	Understanding the voices helped him to challenge them	David: 31 8-322	I started challenging my symptoms rather than taking them literally, because I had some insight after seeing him as to where it could come from, and it sort of gave me reasons not to take it literally.

Master Themes: Dancing with Voices			
Sub-theme	*Emerging Themes*	*Participant and line*	*Quote*
	Voices as messengers link to past problems	Martha: 27-36	the way I understand voice hearing now is that voices are messengers, erm... and I think they communicate very compelling information about, sort of, genuine problems that have occurred in the person's life and they tell us about those problems and, you know, for that reason, it simply does not make sense to, you know, shoot the messenger and deny the content of the message, erm... I think my voices, again they were meaningful
	Voices linked to problems in the past and how she feels about herself	Martha: 259-288	They were manifestations of much deeper social and emotional problems, erm... you know that was sort of, basically kind of two things – first of all was, you know, the first experiences from childhood and secondly was just the way I felt about myself, erm... you know, sort of, really just no self-esteem, erm... really insecure, really critical, erm... not able to express what my needs were, not able to express strong emotion, erm... just, not being able to experience myself really
Recovery	Feeling less upset	David: 726-729	David: nothing really has to happen with the reduction of symptoms – it's just if it's upsetting you – if it stops upsetting you, basically, then you've recovered

Master Themes: Dancing with Voices			
Sub-theme	*Emerging Themes*	*Participant and line*	*Quote*
	Acceptance	Laura: 41-42	if you accept the fact that you hear voices, I think it helps
	Taking control	Martha: 114-117	[ ] I mean for me in a nutshell recovery was almost like sort of getting control of it; getting ownership of it and getting on with it
	Helping others, giving something back	Laura: 268-271/ 269-271 /204-206	Recovery to me is going to be in place by helping other people – the more people I help the more better I'm feeling towards myself. [ ] we possibly will have to go to be a social enterprise 'cos we're putting back into the community.
		Laura: 247-248	But if you can just baby-step each day then you'll find you're fine.
	Achieving your potential	David: 713-719	I think when I'm on my degree, and I'm coping with it, and doing well and I'm kind of performing to somewhere that's near my potential, and I'm happy and. ..sort of busy, active person I'd say about...that would be when I'd recovered.
	Fulfilling your potential	Martha: 515-521	[ ] fulfilling your potential, whatever that is, you know. It's completely self-defined, it's what... you know... fulfilling, living your dream.

Master Themes: Dancing with Voices			
Sub-theme	*Emerging Themes*	*Participant and line*	*Quote*
Voices: Learning to live together	Changing the way they relate to their voices	Martha: 5-6/ 12-13/22-24	We have to learn to live together, if that makes sense …it's changed hugely the relationship with the voices, erm... what has changed is the way I relate to them, and it's changed very much ...certainly for the better it's been a process almost of negotiation rather than modification.
	Voices become an everyday thing	Laura: 7-9	Erm, it was scary to start with, from the beginning, but now it's like, it's an everyday thing, so...
	Voices taking on a role: Likened to children	Laura: 29-31	If they're good they're very good, but if they're annoying I'll treat them like naughty children and just ignore them.
	Voices likened to a companion	Laura: 230-232	Yeah – they are a major barrier, but I think if they were to disappear completely, I genuinely think I'd miss them. 'Cos I'm never alone.
	Negotiating time with your voices	Laura: 13-18	I try to... negotiate a time with them where I'm, like, prepared to talk to them but they're very rude, my voices. So it's like, they'll just come in at any time. Erm... if I ignore them they get worse, so I have to, like, talk back with- I try to do it quietly.

These tables show the relative contribution of each participant to the themes.

Theme	Lee	Katherine	David	Roshan	Laura	Kamal	Martha
Psychiatry: Social Control	x		x	x		x	
Enforcement			x	x			
Contempt				x			x
Defiance			x		x	x	x
Dehumanising				x		x	
Playing the Game			x	x	x	x	

Theme	Lee	Katherine	David	Roshan	Laura	Kamal	Martha
Psychiatry: A Clinical Model	x					x	x
A Pessimistic Paternalistic System	x		x	x	x	x	x
Disinterest				x		x	
Blind Faith			x	x		x	x
A Schizophrenic		x	x				x

Theme	Lee	Katherine	David	Roshan	Laura	Kamal	Martha
Psychiatry: Trauma, trauma, and retrauma		x	x				x
Stress-Vulnerability			x	x			x

Theme	Lee	Katherine	David	Roshan	Laura	Kamal	Martha
Voice Awareness					x		
Hearing Voices Group: A Fellowship		x	x	x	x	x	
A Person with Promise							x
Post-Psychiatry Movement							x
An Avenue: Channelled Outrage					x		x
An Inspiration			x	x			x

Theme	Lee	Katherine	David	Roshan	Laura	Kamal	Martha
Dancing with Voices							
Voices		x			x	x	x
Belief			x	x		x	
Disintegration		x				x	
Coping: Self Management	x		x	x	x		
Deconstructing the Problem		x	x				x
Recovery			x		x		x
Voices: Learning to live together					x		x

Theme	Lee	Katherine	David	Roshan	Laura	Kamal	Martha
Relationships: A Lack of Understanding							
Friends and Family		x	x	x			x
Social Isolation		x	x			x	
Social Acceptability				x	x		
Secrecy			x	x			