THE LIVED EXPERIENCE OF OLDER ADULTS WHO HAVE HEARD VOICES THROUGHOUT THEIR LIFESPAN FOLLOWING EARLY-ONSET PSYCHOSIS: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

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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

Research into the subjective experiences of hearing voices has increased over the past two decades, and has had important implications for the treatment of people who are distressed by their voices. However, most research has focussed on adults of working age, whilst little research has been done to understand older people's subjective experiences of voices. This is particularly so for older adults who have heard voices since an early onset of psychosis.

Five participants (two male, aged 68-75) who had heard voices since an early onset, were recruited from the local community mental health team. They were interviewed about their subjective experiences of hearing voices. Transcripts were then then analysed using IPA, individually and then for the group.

The results of the analysis yielded four master themes and eleven superordinate themes. The master themes showed that participants were *'experiencing a relationship with the voices'* characterised by their negative perceptions of the voices as powerful and controlling, and leading to varied emotional and behavioural responses. Secondly, the voice-hearing experience resulted in an *'alteration to sense of self in the world'*, where participants felt a sense of loss, stagnation and alienation. At times participants were also *'struggling to understand'* their voice hearing experience as they sought to make sense using various frameworks. Finally, participants also displayed both *'improvement and hope'* and *'deterioration and despair'* when looking back over their lives and considering their futures.

The main themes found in the study are discussed in relation to existing literature regarding subjective understandings of voices, the changing models and approaches to psychosis that have occurred during participants' lifetimes, and literature on the course of schizophrenia and lifespan development. Implications for clinical practice and future research are also made, the most fundamental being the value of opening up dialogue about subjective understandings of the voice hearing experience.

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ABBREVIATIONS

ACT	Acceptance and Commitment Therapy
APA	American Psychiatric Association
CAT	Cognitive Analytic(al) Therapy
CBT	Cognitive Behaviour(al) Therapy
CMHN	Community Mental Health Nurse
CMHT	Community Mental Health Team
DoH	Department of Health
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders (Version 4, Text Revision)
ECT	Electroconvulsive therapy
FACE	Functional Assessment of Care Environment
HVN	Hearing Voices Network
IPA	Interpretative Phenomenological Analysis
LYPFT	Leeds and York Partnership Foundation Trust
NHS	National Health Service
NICE	National Institute of Clinical Excellence
NIMHE	National Institute for Mental Health in England
MHRN	Mental Health Research Network
SASB	Structural Analysis of Social Behaviour
WHO	World Health Organisation

<center>**Chapter One**</center>

<center>**INTRODUCTION**</center>

The following chapter will firstly outline the current context of older adult mental health service provision, noting the need to understand lifespan development and specific mental health issues of older age. The chapter will then narrow its focus to schizophrenia in older age that has endured a chronic course from an early onset. A brief review of some of the different models of schizophrenia that have evolved over the 20th century will then be given, to set the mental health service context that older adults with early-onset schizophrenia may have experienced, or been influenced by. As there was a move to a symptom approach to psychosis towards the latter part of the 20th century, the more specific theories of hearing voices are then outlined, followed by the growing research into the subjective experience of hearing voices.

Older Adult Mental Health and Psychosis

Older Adult Mental Health

The National Service Framework for Older People (DoH, 2001) highlights that one fifth of the population is over 60 and that by 2025 the number of people over 90 will have doubled from what it was in 1995. Approximately three million older people in the UK experience a mental health difficulty, which is set to increase to four million by 2021, with one in fifteen people then estimated to be an older person with a mental health problem (Age Concern, 2007). This will increase pressure on older adult services, and will require services to be efficient and responsive to the specific needs of this ageing cohort of people.

It has been increasingly recognised in a number of documents (e.g. Everybody's Business (DoH, 2005); Improving Services and Support for Older People with Mental Health Problems (Age Concern, 2007); National Service Framework for Older Adults (DoH, 2001)) that mental health care for older people has not received the same

emphasis, funding or innovation that working-age adult services have seen. According to the National Service Framework for Older People, prior to its publication in 2001, there were no national standards for this population and at worst, services were poor and unresponsive to their needs. Everybody's Business (DoH, 2005) and Improving Services and Support for Older People with Mental Health Problems (Age Concern, 2007), stress the need to address older adult discrimination in mental health service provision and meet older people's complex needs in a person-centred way. The Healthcare Commission (2009) has shown, however, that despite these documents that have been published since 2001, there is still a lack of awareness and variable quality in the provision of a full range of services that address the specific needs of older people. They estimate a further two billion pounds would need to be spent to address age discrimination in older adult mental health service provision, and stress the importance of a continued effort to address the needs of this population.

The baby-boomer cohort entering older adulthood now, may come with higher expectations for mental health care than previous generations (Laidlaw and Pachana, 2009). This, along with the greater heterogeneity within the older adult population as longevity increases, will mean that services need to gain a greater understanding of older peoples' subjective experiences to provide good quality person-centred care. It would therefore be useful to consider cohort effects of the specific age groups entering older-adulthood and the experiences and historical events that cohorts may share. This may include certain societal and cultural values, the experience of World War II, the transition from an industrial to a post-industrial economy, political changes, recessions, and typical gender role expectations. Laidlaw and Pachana (2009) pointed out that as longevity increases, the increasing age difference between therapists and clients can result in poorer treatment outcomes due to inexperienced therapists lacking understanding about cohort experiences and holding pessimistic assumptions about aging. However, this is contrary to the findings that many older adults report a happy and positive quality of life (Laidlaw, Power, Schmidt *et al.,* 2007). This stresses the importance of understanding older people's mental health in context of their lived experiences.

Lifespan Development and Older Age

      To help think about the lived experiences of older adults, it can be helpful to recognise the developmental tasks involved in the older person's current and previous life stages.

      A Humanistic View of Development. Maslow (1962) posited that humans have a basic instinct to strive to meet a hierarchy of needs, starting with basic physiological needs, moving on to those of safety, belongingness, love, self-esteem, and finally self-actualisation needs. Individuals are motivated to fulfil the basic needs before striving for the next level in the hierarchy, with self-actualisation (i.e. realising and fulfilling one's true potentials and capacities), as the ultimate goal. Idiosyncratic internal factors primarily affect a person's potential for self-actualisation, but Maslow noted that culture and society can weaken and suppress a person's inner drive to self-actualise. Maslow believed that in earlier adulthood, socialisation and fitting in with culture can be the priority, but that in later adulthood the focus turns inwards and more towards independence and self-actualisation.

      Erikson's Eight Stages of Development. According to Erikson's (1959) model of lifespan development, older people will have had to negotiate earlier life challenges of 'trust versus mistrust', 'autonomy versus shame', 'initiative versus guilt', 'industry versus inferiority' (all in childhood), 'identity versus confusion' (in adolescence), 'intimacy versus isolation' (in younger adulthood); 'generativity versus stagnation' (in middle adulthood); and may currently be in a state of conflict between 'integrity and despair', evaluating and reflecting upon the years that have passed. Erikson spoke of young adulthood as a time of broadening and deepening relational connections to others, following the prior adolescent stage of preoccupation with the self and forming an identity. Without an adequate sense of identity, Erikson believed that intimacy with others could not truly be attained and could lead to isolation. In middle-adulthood, Erikson believed that the focus was on guiding and caring for the next generation, whether with one's own children or through parental concern and creativity for others generally. Failure to develop a sense of generativity can lead to stagnation or interpersonal impoverishment, and an overindulgence in personal needs (Erikson,

1980). Finally, the stages of late adulthood bring about an internal conflict of 'integrity versus despair', when the older person reviews and reflects upon their life. This can result in feelings of disgust and regret about the past, and/or can bring about a sense of meaningfulness, satisfaction, and *"acceptance of one's one and only life cycle… as something that had to be that, by necessity, permitted of no substitutions"* (Erikson, 1980, p104).

The Lifespan Model of Developmental Challenge. Hendry and Kloep (2002) proposed a model of lifespan development, whereby a person has their own unique resource pool, which interacts with task demands at various life stages and can result in development, stagnation or decay. Resource pools consisting of biological dispositions, social resources, skills in various domains, self-efficacy and external structural resources, can vary throughout a person's life, and either further develop or decay depending on the person's success with different challenges. Hendry and Kloep note some different types of challenges a person may meet during their lifespan. These can be normative challenges which are expected for the majority of people (such as maturational development; social norms of working, retirement, etc.), or non-normative and idiosyncratic challenges (e.g., having a serious illness). Challenges can also be unpredictable and off-time (such as early or late marriage; divorce; unexpected bereavements), and they can be associated with specific cohorts and historical events (e.g., war, economic changes). Life challenges may also come in the form of an absence of an event (e.g., not getting married or having children when this was wished otherwise). The negotiation of these challenges throughout life, and the consequent reciprocal effects on the person's resource pool, are likely to influence the complex picture of difficulties that older adults may present to services.

Accommodation and Assimilation over the Lifespan. Brandtstadter and Rothermund (2002) proposed a two-process framework of goal attainment that bears relevance to development over the lifespan. They begin by noting that goals are important for life-satisfaction and meaning, but can be a source of distress, hopelessness and depression if they become unattainable. At this point there is a need for adaptive flexibility, to either disengage from unattainable goals and readjust them, or recruit

more effective ways of reaching the goals. The choice between these can be affected by beliefs of self-efficacy and control, as well as access to resources that can help. The authors stated that assimilative processes are integral to life-long development, and often the focus tends to be towards promotion and optimisation, shifting to a preventative and compensatory focus later in life. There is also an increasing reliance on accommodative strategies in later life as resources decline. Importantly, the authors note that it is the interplay between the two strategies that promotes wellbeing, whereby the individual can utilise accommodative strategies to readjust goals where necessary, to then be able to redirect assimilative strategies towards more feasible goals. Over-reliance on one or other strategy can result in hopelessness and depression.

Psychosis in Older Adulthood

The most common, and researched, mental health problems in older age include the dementias and depression, whilst other disorders have received less attention (Woods, 1999). Everybody's Business (DoH, 2005) stated the average prevalence figures for mental health difficulties experienced by older adults in UK health districts, to be as follows:
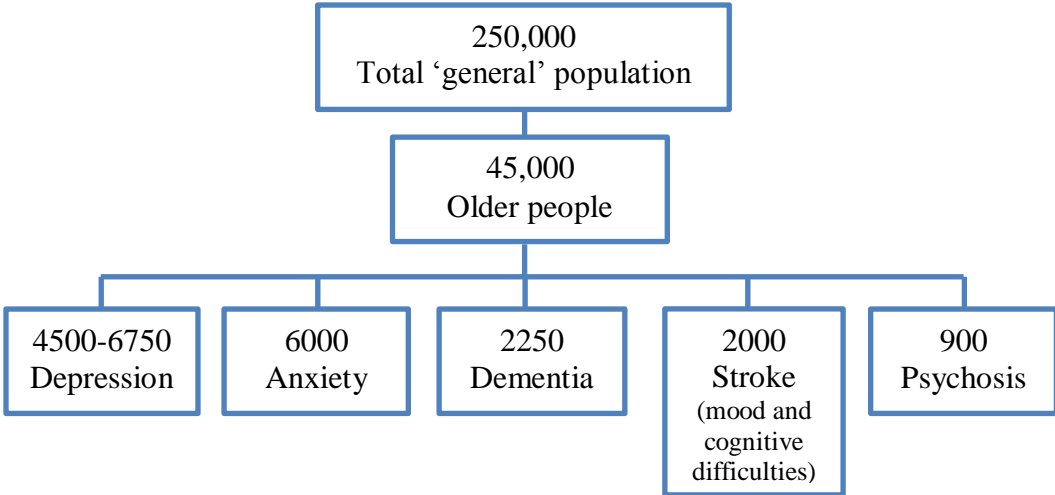
Figure 1. Prevalence of psychological difficulties in an average UK health district (statistics from Everybody's Business, DoH, 2005; Figure from Little, 2009)

Psychosis can therefore be seen as the least prevalent mental health problem for older people when compared with depression, anxiety, dementia and stroke related difficulties. This may be why the area has been less-well researched. However, the figures prompt a reminder that a substantial minority do experience psychosis.

The broad prevalence rate for schizophrenia in later life appears to be around 1% (e.g. Sigstrom, Skoog, Sacuiu, Karlsson, Klenfeldt *et al.,* 2009; Age Concern, 2007). In broader national figures this translates to a total of approximately 70,000 older people in the UK who experience schizophrenia; this is set to increase to 91,000 by 2021 (Age Concern, 2007). The economic costs of the older adult population with schizophrenia at the time of the Age Concern (2007) report, was estimated to be £1.5 billion per year.

Psychosis in older adulthood can present in the form of primary psychotic disorders or as secondary psychotic disorders to the dementias and medical illnesses such as Parkinson's and retinal disease (Desai and Grossberg, 2003). The DSM-IV-TR (APA, 2000) includes the diagnoses of schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder, brief psychotic disorder, shared psychotic disorder, psychotic disorder due to a general medical condition, substance-induced psychotic disorder, and psychotic disorder not otherwise specified, as the main psychotic diagnoses. Of these diagnoses, schizophrenia is the most prevalent and chronic of the diagnoses, with symptoms that can be categorised as shown in Table 1. The DSM-IV-TR classifies delusions and hallucinations as the 'psychotic dimension', and disorganised speech and behaviour as the 'disorganisation dimension' of the positive symptoms. Within the psychotic dimension the DSM specifies the definitions outlined in figure 2.

Two or more of the symptoms listed in Table 1, must be experienced for a significant portion of time during a one-month period for a diagnosis of schizophrenia. However, if delusions are deemed 'bizarre' or if hallucinations consist of voices conversing or keeping a running commentary, then only that one symptom needs to be present for the diagnosis to be made.

Table 1. DSM-IV-TR symptoms of schizophrenia

Positive Symptoms *An excess or distortion of normal functions*	**Negative Symptoms** *A diminution or loss of normal functions*
Delusions *Distortions in thought content*	Affective Flattening *Restrictions in range and intensity of emotional expression*
Hallucinations *Distortions in perception*	Alogia *Restrictions in fluency and productivity of thought and speech*
Disorganised Speech *Distortions in language and thought process*	Avolition *Restrictions in initiation of goal directed behaviour*
Grossly Disorganised or Catatonic Behaviour *Distortions in self-monitoring of behaviour*	

Delusions: *"are erroneous beliefs that usually involve a misinterpretation of perceptions or experiences. Their content may include a variety of themes (e.g. persecutory, referential, somatic, religious, or grandiose)… Delusions are deemed bizarre if they are clearly implausible and are not understandable and do not derive from ordinary experiences."*

Hallucinations: *"may occur in any sensory modality, but auditory hallucinations are by far the most common. Auditory hallucinations are usually experienced as voices… that are perceived as distinct from the person's own thoughts."*

Figure 2. DSM-IV-TR definitions of delusions and hallucinations

The median age of onset for schizophrenia according to DSM-IV-TR (APA, 2000) is early to late twenties. However, schizophrenia (or primary psychotic disorders) in older age can also occur as a 'late-onset' with symptoms beginning between the ages of 40 and 60, or 'very-late-onset' psychosis with symptoms beginning after age 60, or as continuing psychotic symptoms from an earlier-onset psychosis prior to age 40 (Palmer, Nayak and Jeste, 2003).

Jeste, Wetherell and Dolder (2004), estimated that 80% of older adults with schizophrenia have endured a chronic course since an early onset. Age Concern (2007) reported that 75% of older adults developed psychosis in their teens or twenties, 15% between ages of 40-60, and 10% after the age of 65, as Figure 2 below illustrates.
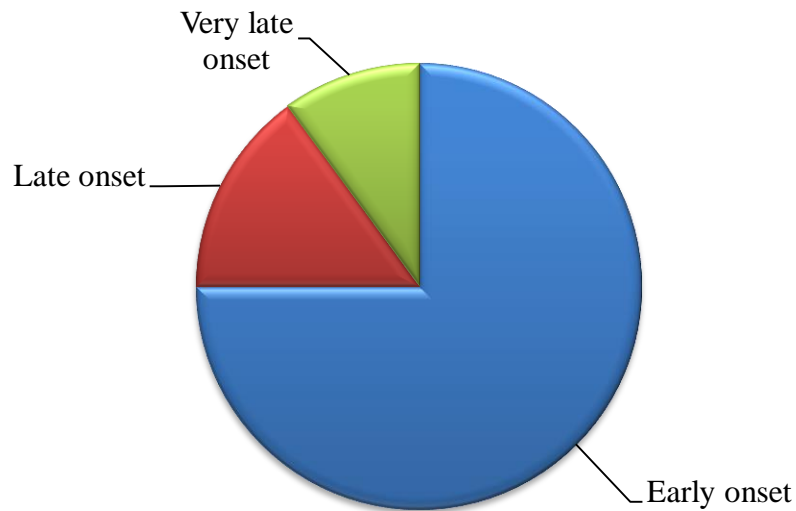
Figure 3. Percentages of early, late and very late -onset presentations of psychosis in the 2005 UK population of older adults with psychosis (figures from Everybody's Business, DoH, 2005)

There are some similar clinical features between early and later onsets of schizophrenia, such as the experience of hallucinations and delusions. However, there are also some phenomenological differences, such as more "bizarre" and persecutory delusions being associated with later onsets of schizophrenia (Reeves and Brister,

2008). Furthermore, there is often an absence of thought disorder, disorganised behaviour and blunting of affect in late-onset schizophrenia, compared to early-onset presentations (e.g. Harvey, 2005). Another difference is that premorbid functioning is often less impaired for those with late-onset schizophrenia compared to early-onset schizophrenia, with patients having worked, married and maintained adequate social functioning (Harvey, 2005). The early 20th century ideas of Kraepelin (outlined later in this chapter), included reference to 'paraphrenia' as a late-onset of psychotic symptoms which was thought to be different to schizophrenia, in that there was no deteriorating course and emotional expression was not affected.

Psychosis over the Lifespan

The traditional Kraepelin assumption (see below) of the development of psychosis over the lifespan is one of progressive deterioration, with complete remission considered unlikely according to earlier versions of the DSM (Harding, 2003). However, some of the earliest longitudinal studies by Manfred Bleuler (1972) and Ciompi and Muller (1976) (both cited in Barham and Hayward, 1990) showed that the course of schizophrenia was highly variable; between a quarter and a half of those with schizophrenia completely recovered or had only minor residual symptoms, a small minority had severe and acutely psychotic courses, and over half tended to experience a fluctuating course that alternated between episodes of psychosis and periods of recovery. Similarly, Huber (1997) found that only 20% of people with schizophrenia experienced deterioration in symptoms over the lifespan, 60% experienced a stable course, and 20% actually experienced an improvement in symptoms. Palmer, McClure and Jeste (2001) also cite a number of studies suggesting up to 30% of patients improve during the course of schizophrenia. Further reviews of more studies that support the varied outcome and possibility of improvement in the course of schizophrenia are cited in Harding (2003).

Most deterioration is reported to be seen in the first 5-10 years after onset, which is then often followed by a gradual improvement or stabilisation (e.g. Bleuler, 1972; Reeves and Brister, 2008; McGlashan, 1988). Harvey (2005) discussed how there is mixed evidence on whether there is a remission of psychotic symptoms in older age or

not. It has been suggested that positive symptoms of schizophrenia may decrease in older age whilst negative symptoms increase (e.g. Bridge, Cannon and Wyatt, 1978). Davidson, Harvey, Powchick, Parrella, White *et al.* (1995) however showed that positive symptoms are present in older age, but are less severe.

Further explanations that have been suggested for the improvement noted above, include neurobiological age related changes (Jeste, Wolkowitz and Palmer, 2011), as well as more psychological explanations of increased acceptance and more efficacious coping. Solano and Whitbourne (2001) found that people who live with schizophrenia into old age use similar coping strategies to younger populations, but the effectiveness of the coping strategies improves with ageing as individuals become better able to recognise their symptoms and accept their 'illness'.

Shepherd, Depp, Harris, Halpain, Palinkas and Jeste (2010) conducted a grounded theory analysis on interviews with 32 adults over the age of 50. The researchers found that participants perceived their early stage of schizophrenia to be characterised by confusion, positive symptoms and losses, but that this was followed by improvement, insight, motivation to manage their symptoms, and adaptation of their social networks. However, despite the improvement in positive symptoms, Shepherd *et al.* (2010) found there was considerable heterogeneity in the later life stages with regard to functional recovery; some older adults felt hopelessness and despairing, others felt acceptance and resignation, yet others felt hopeful and optimistic.

Two styles of recovery from psychosis have been proposed which are thought to predict functional outcome; 'sealing over' and 'integration' (McGlashan, 1987). Sealing over is characterised by isolating and separating off the psychotic experience, which is seen as a negative inconvenient disruption to life. People with this type of recovery style prefer not to engage in talking about or exploring their psychotic experiences. Conversely, the 'integration' recovery style is defined by an awareness of the continuity between non-psychotic and psychotic states, and people who adopt this style are also able to curiously explore their psychotic experiences as sources of understanding about themselves. People with this recovery style are able to seek help and support from others in exploring and developing their understandings. McGlashan (1987) showed that

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both recovery styles are correlated with good functional outcomes, but there tend to be superior outcomes for the integration style. Tait, Birchwood and Trower (2004) found that sealing over was common to those who have an insecure identity, are anxious about rejection, perceive that others see them as worthless, and are less resilient and more vulnerable to life-changes.

McGlashan (1987) suggested that the two recovery styles were stable and enduring trait characteristics. However, it has since been thought that an individual's recovery style can change over time, perhaps adaptively, to manage the differing demands of onset and stabilisation (e.g. Thompson, McGorry and Harrigan, 2003). In light of the findings of Tait *et al.* (2004), the available resilience and support the person perceives they have, could also influence changes in their recovery style. This is interesting when considering research by Davidson and Strauss (1992) that showed that developing an efficacious sense of self that is an active responsible agent with an internal locus of control, provides an important foundation for the tasks of coping and recovery. The authors describe a four stage process of firstly a gradual recognition of the possibility of a more efficacious sense of self, to finally utilising it as a source of initiative and agency to take an active role in social and vocational rehabilitation. They noted how the process of building this efficacious sense of agency is gradual, fluctuating, and influenced by social support and feedback on outcome. For example, at times when the sense of self is tentative and fragile, negative outcomes in coping can result in a diminished sense of self and thus a return to hopelessness and passivity. Conversely, positive outcomes can increase hope in, and help build further, the sense of self as an efficacious agent in recovery. Furthermore a supportive social context can facilitate the development of this sense of self, compared to a highly critical or overinvolved social context which can undermine it.

The evidence therefore suggests that recovery is multifaceted and influenced by a number of factors, including ways of relating to schizophrenia (e.g. acceptance and adaptation), recovery styles of 'sealing over' or 'integration', support from others, and believing in oneself as an active efficacious agent of change.

With regard to the physical and cognitive course of schizophrenia, Jeste, Wolkowitz and Palmer (2011) noted the evidence for accelerated physical ageing and mortality for those with schizophrenia. They reported that mortality rates are up to twelve times that of the general population, and rates of suicide, metabolic syndrome and coronary heart disease are also elevated in those with schizophrenia. The authors acknowledge different explanations for this, such as increased substance use, smoking, poorer self-care, and the use of antipsychotics, as well as the specific biology of schizophrenia itself. Harvey (2005) noted that suicide risk is significantly elevated in the first ten years following onset of schizophrenia, and that iatrogenic factors pertaining to the treatment of schizophrenia (such as medication side-effects) can decrease life expectancy.

In the same paper, Jeste *et al.* (2011) also noted the common perception that cognitive functioning is thought to deteriorate significantly throughout the course of schizophrenia, akin to traditional Kraepelin views (see below) that schizophrenia is a degenerative dementing illness. However, Jeste *et al.* (2011) noted that although there is often a mild cognitive impairment and decline from pre-morbid to post-onset stage, this impairment then stabilises. Further cognitive decline is related instead to 'normal' cognitive decline associated with general ageing.

These studies are interesting, but typically they have involved participants who are cared for in the community and are well enough to participate. This may mean participants were reflecting upon the lifespan from a stage of relative wellness which may have biased their recollections of earlier experiences. However, the general pattern for older people who have survived schizophrenia into older age seems to be that for a substantial minority an improvement in clinical symptoms is seen across the course of schizophrenia, and the majority experience stable symptomology (e.g. Huber, 1997; Barham and Hayward, 1990). Studies noted above have suggested this may be due to efficacious coping, adaptation and acceptance of symptoms (e.g. Solano and Whitbourne, 2001; Shepherd *et al.,* 2010), recovery style (e.g. McGlashan, 1987), and developing an efficacious sense of self (e.g. Davidson and Strauss, 1992); all of these have significant implications for the focus of treatments. This is interesting in light of

the evolving theories and treatments of psychosis that may have impacted on their care and understandings of their symptoms.

Theories and Treatments of Schizophrenia

The following section outlines some of the theories that have been proposed to explain the aetiology of schizophrenia, and provide the underpinnings for treatments and interventions. It is beyond the scope of this thesis to provide a comprehensive review of all theories and treatments, since the area is vast and complex, with generally poor agreement or synthesis of ideas. Therefore a brief flavour of some different theories will be presented, and the reader is signposted to useful references for more in depth reviews on this area. Read, Mosher and Bentall (2004) outline the history of models of schizophrenia and the associated symptoms, from very early 2000 BC ideas of gods causing madness, to current late 20th and early 21st century ideas of trauma models of psychosis.

Recent Historical (post-17th century)

In the 18th and 19th centuries, people deemed 'mad' were considered dangerous, abnormal and irrational, and were therefore locked up. There was little psychological understanding or empathy at this time. At the turn of the 19th century there was a shift towards treating such people with biologically theory-driven treatments of the time, such as blood lettings and spinning chairs. There was also a move towards 'moral treatment' in some asylums, pioneered by the York Retreat where it was thought that talking to people could help them regain their sanity. There was a huge increase in the number of people incarcerated during the 19th century and there has been much debate on whether asylums were moral in their treatment or whether they continued to be inhumane (e.g. Porter, 1990, versus Scull, 1993).

Biological

By the end of the 19th century, madness had started to be categorised, resulting in the introduction of Kraepelin's (1893) 'dementia praecox', and Bleuler's (1911) 'schizophrenia' (both cited in Read *et al.,* 2004). The causes of the illness were largely

unknown and it was regarded as a degenerative, dementing disease. The beginning of the 20th century then saw the rise of biological explanations of schizophrenia along with a variety of treatments, including inducing fevers, insulin coma therapy, ECT and brain surgery.

Genetics. Studies regarding the inheritable nature of schizophrenia came as early as 1917 (Kendler and Diehl, 1993), a time when key figures such as Bleuler were suggesting the use of sterilisation as a possible solution for preventing and eradicating schizophrenia. It is also noteworthy that the holocaust of World War II resulted in the mass murder of many people with schizophrenia in the first half of the 20th century. Such radical thoughts and actions of the time may have had a significant impact on how schizophrenia was thought of by the general population. Cardno and Murray (2003) reviewed a number of studies on the genetics of schizophrenia, and note how even the most rigorous of family studies (e.g. Kendler, McGuire, Gruenberg, O'Hare, Spellman, and Walsh, 1993) suggest a 9.2% lifetime risk of schizophrenia for those who have siblings with schizophrenia, and 1.3% for those whose parents have schizophrenia, compared to a 1% risk in the general population. Reviews of twin studies (e.g. Gottesman and Sheilds, 1982, cited in Cardno and Murray, 2003), show a concordance rate (i.e. if one twin has schizophrenia, the lifetime risk the other twin will also have schizophrenia) of 46% for monozygotic twins (who have the same genes) compared to 14% for dizygotic twins (who have only about half the same genes). This shows there is clearly a genetic influence, but that other factors must mediate this since monozygotic twin concordance is not perfect. Cardno and Murray (2003) conclude that there is likely a polygenetic-environment interaction, whereby a number of genes may produce a vulnerablity to schizophrenia that when combined with other environmental factors may result in clinical symptoms.

Neurochemistry. With the advance of science in the latter half of the 20th century, theories of brain chemistry developed, and with these the development of antipsychotic treatment arose. This treatment was based on the hypothesis that there was an over-activity of dopamine in the brains of people with schizophrenia, and that blocking dopamine receptors in the brain reduced positive psychotic symptoms. The

first antipsychotics were released in the 1950s and statistics indicate 250 million people had been prescribed antipsychotics by 1970 (Jeste and Wyatt, 1979). However, these first types of 'typical' antipsychotics (e.g. Haloperidol) had numerous side effects such as; sedation, weight gain, and Parkinsonism (e.g. shuffled gait, tremors and rigidity), which led to the development of newer 'atypical' antipsychotics (e.g. Olanzapine) that produced fewer side-effects (e.g. Castle, Tran and Alderton, 2008). The introduction of antipsychotics was thought to have helped the move to close down the large asylums, and moving psychiatric care out into community (Open University, 2010).

Antipsychotics have been subject to a considerable amount of criticism however. Ross and Read (2004) critique the claims that antipsychotics have made community care possible, are better than placebos, and have therapeutic effects that outweigh the side effects. They note some severe side effects even with newer anti-psychotics, including cardiac arrest, weight gain, uncontrollable movements, lowered immune systems, sexual dysfunction, and reduced consciousness. They also note the associated stigmatisation that something is 'biologically wrong' with the person. Terry and Mahadik (2007) have also found evidence for long term negative side-effects of both typical and atypical antipsychotics, on cognitive functioning, specifically on memory and information processing.

Murray, Grech, Philips and Johnson (2003) reviewed the impact of drugs as an aetiological factor in schizophrenia, and noted that the issue is subject to much debate. They cite some studies which showed that for 80% of people with schizophrenia who used drugs, their drug misuse predated the onset of their psychotic symptoms (Hafner, 1999; cited). Murray *et al.* (2003) also cited studies which showed that cannabis increases dopamine in the brain (e.g. Patel *et al.,* 1985; cited), and a dose-response relationship has been observed in that heavier cannabis users are at more risk of developing schizophrenia (Andreasson *et al.,* 1987; cited).

It should also be noted that prenatal and perinatal risk factors have been implicated in the biological aetiology of schizophrenia, via their impact upon the baby's developing brain. These factors include; maternal influenza and other infections during

pregnancy, maternal stress during pregnancy, and birth complications, to name a few (see overview by Cannon, Kendell, Susser and Jones, 2003).

Social

Family Theories. Theories continued to be developed as the twentieth century progressed, including family theories such as the 'double bind' hypothesis introduced by Bateson, Jackson, Haley and Weakland in 1962, which developed further into theories which are still relevant in clinical practice today, regarding communication disturbances in families (Tienari and Wahlberg, 2008). In a review by Goldstein and Strachen (1987) of early family studies, a substantial common finding was evidenced; poor parental communication (in regard to clarity and accuracy), poor ability to share a focus of attention, and poor ability to understand other people's perspectives.

A number of studies in the 1950s (reviewed by Parker, 1982) also reported a causal link between schizophrenia and being parented by 'overprotective' mothers, who were described as emotionally cold, rejecting, domineering and aggressive, which became known as the 'schizophrenogenic mother' hypothesis. The reciprocal nature of this relational pattern was suggested to be elicited by the 'genetically vulnerable' child. Parker noted the many methodological flaws of these studies (such as the interview method of data collection seeking to confirm interviewers' biased expectations and theoretical ideas). Consequently the theory has been criticised for unjustly placing blame on both those with schizophrenia and their families, and this type of research on family dynamics in schizophrenia declined after the 1950/60s (Tienari and Wahberg, 2008).

Research still continued on theories of 'high expressed emotion' however, which were also introduced in the 1950s. Theories of expressed emotion (e.g. Vaughn and Leff, 1976) suggested an interactional process in which families become highly critical, hostile or emotionally overinvolved towards the relative with schizophrenia in response to their 'illness' presentation. This pattern of interactions is well evidenced as a risk factor in relation to the future course of schizophrenia and relapse (e.g. Kavanagh, 1992), but also as a factor in the aetiology of schizophrenia (e.g. Goldstein, 1987).

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Implications of this approach for interventions included psycho-education for the family and "family therapy" to understand more about the psycho-social and inter-personal aspects of schizophrenia, and to aid and maintain recovery.

Other social theories of schizophrenia that have been put forward include the claims of the 1950s that low social class was causal risk factor for schizophrenia (e.g. Hare, 1955, cited in Boydell and Murray, 2003). Although since disputed, there may be a moderate influence of socioeconomic status (e.g. Bresnahan and Susser, 2003). Studies have shown that the incidence of schizophrenia is increased in inner city areas. However, this could be more of an effect than a causal factor (i.e. social deprivation consequent from poorer employment opportunities may lead to a forced choice to live in deprived inner-city areas). Other possible causal factors that may underlie the inner-city effect could be increased psychosocial stress and increased drug use (Boydell and Murray, 2003).

Psychological

Psychodynamic. Psychodynamic models of schizophrenia were also being developed throughout the 20$^{\text{th}}$ century, with the earliest viewpoints being offered by Freud who originally thought people with schizophrenia could not be analysed, and Jung who contrastingly claimed that schizophrenia could be completely cured psychodynamically (Silver, Koehler and Karon, 2004). The psychodynamic field is vast and includes within it a number of different schools of thought, therefore only a flavour is presented here.

Silver, Koehler and Karon (2004) outline some of the basic concepts of psychodynamic theories of schizophrenia. These include the notion of schizophrenia as a defence against the fear of annihilation, and other unbearable intense emotions. Martindale and Summers (2013) similarly talk about psychosis being an understandable defence against unbearable realities. They note how people may unconsciously create a more acceptable reality, and repress or deny intolerable realities, serving a self-preservative function. Defences of projection and splitting are implicated, where undesirable parts of the self are split off and disowned, and then projected externally

onto others, the world, and 'voices'. The manic defence is also implicated, where feelings such as low self-esteem can be converted into the opposite, such as grandiosity. Thought disorder is also explained by an unconscious motivation to disintegrate thought and language, to protect from the painful reality that ordered thought and language would convey. Overall, Martindale and Summers (2013) advocated through their discussion of these defences, that the symptoms of schizophrenia are meaningful, and understanding this meaning is the key to helping the person integrate and manage painful realities and parts of themselves, in order to dispense with psychotic defences and enable recovery.

Further psychodynamic models have been discussed by Jardim, Pereira and de Souza Palma (2011), such as Bleuler's early theories of 'ego splitting' which was thought to lead to a disintegration of thought and emotion, and then to the secondary symptoms of delusions and hallucinations. The same authors also discussed Lacan's contributions in the second half of the twentieth century, with his theories of 'transitivism', in which the person does not distinguish between experiences that belong to them (ego) and those that belong to others (non-ego).

A more detailed discussion about different psychological theories and approaches to psychosis will be discussed in the later sections pertaining to the individual symptom of 'auditory hallucinations', since it is the symptom-approach to schizophrenia that has been adopted by most explanatory psychological models such as CBT (e.g. Haddock and Slade, 1996).

Bio-Psychosocial Model

Towards the latter part of the twentieth century, theories began to draw together biological, social and psychological theories of psychosis, e.g., Zubin and Spring's (1977) stress-vulnerability model. This model assumes a genetic predisposition to schizophrenia, which makes a person vulnerable to stress. Later significant life events are then thought to precipitate the onset of psychotic symptoms in the biologically vulnerable person. Although still widely used, this model has been seen as reductionist and still emphasising the pathological 'illness' model of psychosis, with the biological

component taking primacy, and invalidating the important role of psychological and social factors (e.g. Read, Mosher and Bentall, 2004). Myin-Gerneys and VanOs (1997) have shown, however, that sensitivity to stress can occur without a biological predisposition, and Martindale and Summers (2013) provide a detailed account of how vulnerability can be determined by a number of psychological factors. Such psychological factors include insecure attachment and experience of early uncontaining or abusive interpersonal relationships which can determine the use of defences implicated in psychosis such as splitting and projection. However some bio-psycho-social thinking still advocates a central role for biology; Kandel's (1998) view places biological processes as the underlying pathway to symptoms, whereby social and psychological processes affect genetic expression, which in turn affects neuro-chemistry, which then causes the symptoms of psychosis.

Critical Perspectives

Antipsychiatry. The 1960s saw a revolt against psychiatric diagnostic labels, and the treatment of people in institutions and their social exclusion. Crossley (1998) gives an overview of the 'antipsychiatry movement' of the 1960s and 70s, and various British critics' challenges as to whether there is a distinction between sanity and insanity. Laing (e.g. Laing, 1960; 1982) was a key influential critic of the time, who perceived a continuum of human potentiality, and thought it incomprehensible to even consider a need to 'treat' or 'cure' such potentiality, because it is not a pathological 'illness'. He believed psychiatry was an oppressive form of social control, whereby societal norms require the repression of difference in order to function effectively. The antipsychiatry movement proposed that people experiencing what psychiatrists deemed 'schizophrenia', should be supported in understanding and experiencing their potentiality, rather than being cured of it.

Despite rejection by many professionals, Laing provided inspiration to the service-user movement, which felt his ideas resonated with their own experiences (Crossley, 1998). Chadwick (1997) also emphasised the non-pathological nature of schizophrenia, making reference to studies which have evidenced the positive aspects of schizophrenia. These included providing a deeper meaning to life as well as spiritual

and mystical enlightenment (e.g. Buckley, 1981); enhanced creative performance (e.g. Keefe and Magaro, 1980), and a protective function of some delusions to enhance self-esteem and purpose in life (e.g. Roberts, 1991).

Social Constructionism. Current social constructionist models continue to advocate that schizophrenia is a social construct defined by societal norms and the dominant cultural narratives about mental illness. The social constructionist model (Gergen, 1977) argues that society and individuals create reality through language and labels. As a result, there can be many 'truths', all socially constructed by discourse between one or more people. However, dominant social constructs can arise and marginalise others. Burr (1995) noted that since knowledge is socially constructed, it is historically and culturally bound, and therefore is not an enduring or absolute 'truth'. She encourages the need to take a critical stance and to challenge assumptions and perception.

Dominant socially constructed truths and labels can be internalised by individuals, and cause distress. According to Young (2009) *"the social construction of mental illness is internalised by someone, who then expresses that construction in symptoms, which are interpreted by another social construction of terms, which affects the symptomatic experience the person has"* (p54). The focus of change in 'treatment' is therefore on the process of interaction and creating new meanings with language. Young talks of resisting the dominant cultural narrative and helping the person to construct rich alternative preferred narratives about their identity, and Burr spoke about the positioning of oneself in environments that favour more accepting and preferred discourses.

Questioning the Validity of Schizophrenia

Boyle (1990) argued that from the very beginning of the conceptualisation of 'schizophrenia' as an illness, there has been disagreement on the reliability and validity of the diagnosis. Bentall (1990) cites numerous studies which show that there is variable agreement on psychiatrists' diagnoses of schizophrenia (e.g. Beck, Ward, Medelson, Mock and Erbaugh, 1962; Blashfield, 1973). Furthermore Barham and

Hayward (1990) discussed how there was wide variability in outcome for those with schizophrenia, citing evidence from three sources (Ciompi and Muller, 1976; Manfred Bleuler, 1972; and WHO, 1979) which show that schizophrenia is not a uniform progressive disease process. Together, these studies give support to the argument that schizophrenia is perhaps not the most reliable, valid, or useful concept. Instead, the focus of research and interventions has shifted towards specific symptoms and experiences of psychosis, which are thought to have much greater clinical utility (e.g. Bentall, 1990).

Auditory Hallucinations

As noted earlier in the chapter, auditory hallucinations are a symptom of schizophrenia, which often occur in the form of hearing voices which are perceived as distinct from one's own thoughts, and which no one else can hear. As one of the symptoms of schizophrenia, auditory hallucinations are broadly explained by some of the above theories of schizophrenia. However, more specific explanations relating to hearing voices are explored in the following section.

Trauma. There are many studies that report a strong association between childhood trauma and the positive symptoms of psychosis, particularly auditory hallucinations (e.g. Read, Goodman, Morrison, Ross and Aderhold; 2004). Read and Argyle (1999) found auditory hallucinations in 52% of inpatients who had experienced childhood sexual abuse, 58% of those who had experienced childhood physical abuse, and 71% of those who had experienced both types of abuse. The authors found the content of many of these auditory hallucinations to be clearly associated with the abuse in some latent or more overt form.

Longden, Madill and Waterman (2012) concluded that voices can represent dissociated parts of the person or previous relationships that have been associated with past traumatic events. The authors consequently suggest that therapy should help people integrate and understand how such dissociated trauma may have triggered and maintain their voices. Furthermore, older adults whose symptoms are related to underlying trauma, may have received a number of diagnostic labels throughout their life time,

including schizophrenia and a variety of personality disorders, to explain their symptoms (Herman, 1992). It is therefore conceivable that this may have led to confusion in their sense making of their symptoms, further supporting the need for helping this cohort of people integrate and understand their experiences.

Read *et al.* (2004) note that the severity and frequency of childhood abuse, and later re-traumatisation, are significant risk factors for the development of psychotic symptoms. This is disturbing in light of the fact that many of those who have experienced trauma become subject to re-enactments of powerless experiences in the mental health system (Herman, 1992). This may be especially so for older adults who may have experienced some of the earlier theory-driven models of care, particularly institutionalisation and sedation, that were in use when they were going through treatment. Again, this supports the need to gain a rich understanding of their lifespan experiences.

Cognitive Theories of Voice Hearing. The cognitive behavioural therapy (CBT) model, based in part on cognitive theory, provides a further explanation of auditory hallucinations. According to cognitive theory, internal thoughts are misattributed as being 'voices', due to a number of cognitive reasoning biases such as externalisation and jumping to conclusions (e.g. Garety, Kuipers, Fowler, Freeman and Bebbington, 2001). These voices act as activating events to which the person attributes meaning, and then experiences particular emotional and behavioural responses (Chadwick, Birchwood and Trower, 1996). The origins of some of these beliefs and appraisals may relate back to the person's social relationships generally. For example, Birchwood, Meaden, Trower, Gilbert and Plaistow (2000) found that the perceived omnipotence and power of the voice in relation to the disempowered individual, often reflected the person's perception of their own social rank in other relationships. Specific beliefs that Chadwick *et al.* (1996) have found to be important relate to the voice's identity, purpose, malevolence or benevolence, omnipotence, and the associated consequences of obedience or disobedience. The authors have found that it is these beliefs that predict distress, and behaviours of either engagement or resistance, rather than the content of

the voices *per se*. Therefore the unique meanings people ascribe to their voices are of paramount importance in relation to their distress and the impact on daily functioning.

Theories of Relating to Voices. The relationships people have with their voices have been the subject of much research, as illustrated by Hayward, Berry and Ashton's (2011) review of studies exploring interpersonal theories of voice hearing. They noted three main theories that have emerged from the literature, which are thought to underpin voice hearers' relationships to their voices; structural analysis of social behaviour (SASB), social rank theory, and relating theory.

SASB (Benjamin, 1989) postulates that interactions between two people in a relationship are interdependent and complementary, for example, reciprocal hostility or submission in response to control. Thomas, McLeod and Brewin (2009) found that in response to a hostile controlling voice, hostile reciprocity from the voice hearer was common, whereas submission was not. Submission was, however, a more evident response after a longer duration of voice hearing, perhaps owing to the relentlessness of the experience. Benjamin (1989) concluded that voice hearers had *"integrated, interpersonally coherent relationships with their voices"* (p291), where the *"richness of social interaction can be found in the internal world represented by the voice"* (p308). Some studies have even found that such rich relationships with voices can serve an adaptive function for those who live in an otherwise socially impoverished world (e.g. Beavan, 2011).

Social rank theory (Gilbert, 1989, cited in Hayward *et al.,* 2011) assumes that in social environments there is competition for power and control, where one will attempt to exert power and control in order to subordinate another. Gilbert, Birchwood, Gilbert, Trower, Hay *et al.* (2001) found that voice hearers will either defend or submit to a hostile, dominant voice. As noted above, Birchwood *et al.* (2000) found that social rank differentials usually favoured the voice, which was often reminiscent of the hearer's wider social relationships. Indeed it was the hearers' appraisals of themselves in their wider social network that then predicted their appraisal of their relationship with their voice (Birchwood, Gilbert, Gilbert, Trower, Meaden *et al.* 2004), highlighting a key

aetiological role for prior social subordination in the later experience of distressing voices.

Relating theory (Birtchnell, 1996, 2002, cited in Hayward *et al.* 2011) was the third theory reviewed, which postulates two axes of relating; one of proximity (ranging from close to distant) and one of power (range from being of high power to low power). Voice hearers who have had negative or impoverished social relationships will often occupy a limited number of usually negative positions on the axes; often relating from a position of distance in response to a powerful voice. These relational positions were found to be associated with distress, and subsequently therapy has aimed to educate hearers about these axes and help develop ways of relating to their voices that give the hearer more control. Active engagement with voices (rather than distance) can actually increase a hearer's sense of control and power in the relationship (e.g. Jackson, Hayward and Cooke, 2011). It has been hypothesised that the distancing strategy so often used by voice hearers, might be perceived by them as a way of showing that they can cope with the voice. It could perhaps also be an established relating pattern that developed as a way of coping with earlier socially adverse relationships, and later issues of stigma and expressed emotion, which the person may have tried to distance themselves from.

Attachment theory has also been implicated in aiding understanding about relationships with voices. Berry, Wearden, Barrowclough, Oakland and Bradley (2012) found that the presence of an established insecure avoidant attachment style, was higher in those voice hearers who heard critical, rejecting, or threatening voices. This may link to trauma theories of having experienced a critical, rejecting or threatening other, who is later echoed in their voices. It may also link to the distancing strategy of how the voice hearer may then relate to their voices.

Approaches to Voice Hearing as a Normal Human Experience

According to a recent review (Bevan, Read and Cartwright, 2011), spanning over a century of studies, 13.2% of people in the general population were found to hear voices (overall reported range of 0.6% to 84%). This indicates that the experience of

voice hearing lies on a continuum in the general population. In turn, this suggests that the experience of hearing voices *per se* is not necessarily pathological or problematic. Indeed, as the cognitive model posits, it may be the beliefs and meanings made of the voices that lead to distress, debilitation and referral into services.

As noted above, the many models of psychosis suggest different ways of 'treating' psychosis and its symptoms, the most commonly recommended approaches being the use of antipsychotic medications and cognitive behavioural therapy (NICE, 2009). Whilst these have their place, there are other approaches available whose origins have been more service-user led, such as hearing voices groups and person-centred work on exploring the experience and its meaning for the individual (as discussed below). Such approaches can involve taking the view that hearing voices is not necessarily pathological, and can sometimes be seen as an enriching human experience – similar to the ideas of the 'antipsychiatry' movement of the 1960's.

Currently, the focus of services seems to be shifting away from attempts to eradicate or dampen the 'symptoms' of psychosis, towards understanding the context and idiosyncratic meaning of such experiences (e.g. Romme and Escher, 2012). Recovery, from this perspective, involves accepting and living alongside voices, whilst minimising distress and the disruption to functioning that can be caused by those voices experienced as problematic to the individual.

A hopeful service-user led approach to recovery was starting to be developed from the1990s onwards, and was endorsed by the National Institute of Mental Health in England (NIMHE) in 2005. The 'recovery model' approach is based on the principle that optimism, empowerment, and collaboration, can help people recover more quickly from mental health difficulties. It works towards reducing stigma, valuing individual differences and taking a strengths-based holistic approach to care, with service-user run initiatives at the centre (NIMHE, 2005). In summary, subjective and idiosyncratic understandings of mental health difficulties, are important in enabling recovery. The principle of empowerment may be particularly pertinent for individuals, particularly those from an earlier cohort, who have been socialised to disempowering medical labels and stigmatising narratives.

Another service-user led approach has been the Hearing Voices Network (HVN), which was founded in 1988.   The HVN is a charity which aims to support people who hear voices, from a service-user led stance, giving them an opportunity to talk openly about their experiences, and promoting awareness of the non-pathological understanding of hearing voices. One way of achieving this has been through the organisation of self-help groups, which have grown to include over 180 groups in the UK (Dillon and Longden, 2012). These groups aim to help people make meaning from their experiences, often with an added therapeutic value of sharing an open dialogue about experiences which may have previously been thought of as unspeakable. Escher (1993) claims such groups allow people to identify patterns in their voice hearing, reduce the isolation of their experience, and facilitate acceptance and normalisation. Escher also notes that such meaning making may give people new perspectives on their voices, enabling and empowering them to negotiate more helpful relationships with their voices.

Lee, Hannan, Bosch, Williams and Mouratoglou (2002), reported on a hearing voices group they facilitated for older people. Both distressing and positive experiences of hearing voices were shared by participants in the group. Outcomes of the group were mostly positive, in that people reported feeling a sense of inclusion, some value in sharing their experiences and being able to give advice to, and learn new coping strategies from, others.

The focus of these therapeutic approaches is to help individuals make meaning out of their experiences, with their own perspectives being at the centre. Taking an active and central role in constructing meaning from their experiences, may help build a sense of control and empowerment.

Subjective Meaning-Making of Hearing Voices

It can be seen that there are many different models of schizophrenia and hearing voices, which can be broadly divided into biological, psychological and social domains, as well as the more alternative, anti-psychiatric perspectives. People with the symptoms

of psychosis may therefore have a number of frameworks available to them for making sense of their symptoms, perhaps more so now than 50 years ago.

In recent years, there has been a growing interest in individuals' own unique interpretations and the meanings made of, their symptoms and experiences. Hoffman (2011) argued against the reductionist medical models, including their use of technical terms such as 'auditory hallucinations', noting that these convey the message that the experiences are not real and therefore not worthy of exploration. Many researchers in the field have noted that historically, particularly with the dominance of the medical model, there has been a lack of attention to the content, meaning and experience of hearing voices (e.g. Beavan and Read, 2010; Coffey and Hewitt, 2008). However, today there is growing emphasis on formulating rich understandings of hearing voices, through the links between voices and historical life events, psychological trauma and defences against difficult feelings, and the metaphorical meanings of voices (Romme and Escher, 2000).

Romme and Escher (1989) interviewed twenty people who heard voices and described themselves as able to cope well. Demographics were not reported, but the sample was selected from a group of respondents to a television appeal. They identified three phases of responses to hearing voices. The first stage the authors proposed was the 'startling' phase at onset, which was well remembered by participants. The majority of this sample linked the onset to a traumatic event, and the voices were either experienced as helpful and a source of strength, or hostile and negative. The second 'organisation' phase was characterised by attempts at coping, with the use of maladaptive strategies such as expressing anger at the voices, trying to ignore them, or acceptance strategies that resulted in positive growth. The final phase of 'stabilisation' was associated with people accepting and integrating the voices into their identity as part of life, often resulting in a positive relationship with the voices, and the person feeling in control. The researchers noted the unique and varied frames of reference which people used to interpret their voices, including psychological, cultural, spiritual, biological, and mystical frameworks, and highlighted that these are important in guiding individual coping strategies.

A Q-methodology study by Jones, Guy and Ormrod (2003), showed that in a sample of voices hearers (including both mental health service-users and non-service users), a number of different frameworks for understanding the voice-hearing experience were used by participants. These included: spiritual communication, spiritual possession, traumatic life experiences, stress, genetics, brain dysfunction, neurochemical imbalance, and an overall medical diagnostic framework. The authors noted that participants used multiple frames of reference, and did not fully adhere to all of the biomedical concepts, despite the dominance of the model in many Western services. Elements of a psychological perspective featured in all participants' meaning-making. Jones *et al.* suggested that understanding people's multi-faceted frameworks for understanding their voices, can help guide interventions that are best suited to their idiosyncratic understanding.

All too often in services the focus on subjective experience and meaning of hearing voices is neglected. Coffey and Hewitt (2008) interviewed both service-users who hear voices, and staff involved in their care, to explore their views on staff responses to service-users who were hearing voices. Results indicated that people who hear voices would really value talking about the content of their voices. However, some staff in the study did not believe a person's voices had any links to past experiences, and one nurse commented that her training (22 years ago from the date of the study) had not advocated exploring the content of a person's voices, and so limited her in doing so currently. This is a troubling finding, not least because the beliefs and meanings about the voices and their content have been found to be the strongest predictor of emotional reaction to the experience (e.g. Chadwick *et al.,* 1996), often have strong personal relevance to unresolved past experiences (e.g. Read and Argyle, 1999), and guide coping efforts (Romme and Escher, 1989). Coffey and Hewitt (2008) conclude that there is a need for professionals to explore and understand a person's unique voice hearing experience; not doing so is invalidating, damaging to therapeutic rapport, and limits recovery.

Calton, Cheetham, D'Silva and Glazebrook (2009) reviewed 9,284 abstracts presented between 1988 and 2004 at prominent international schizophrenia research

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fora. They found that only 2% of abstracts addressed patient-centred, subjective experiences, whereas 74% of abstracts were classified as biologically focussed. This indicates there is still a paucity of research into subjective experiences of psychosis. However, the review also indicated that research on this has significantly increased, doubling between 1988 and 2004. This is an important area of study to ensure patient-centred approaches are successfully adopted in practice (Calton *et al.*, 2009).

As interest continues to grow, there has been an increase in qualitative research designed to explore the subjective experience of voice hearing. In a detailed interpretative phenomenological analysis of two case studies, Knudson and Coyle (2002) found the two participants had constructed valuable meanings and conceptualisations of their voices. Participants linked their voices to dissociated parts of themselves, unexpressed anger, adverse life events, drug use, genetics and divine retribution, which in turn guided their coping efforts. For example, one participant believed his voices represented dissociated aspects of himself, such as anger, and in turn he coped by recognising and accepting his anger, to reduce its manifestation as a voice. Another participant had numerous and uncertain explanations for her voices, which was reflected in her varied 'trial and error' coping strategies.

Beavan (2011) conducted a thematic analysis on semi-structured interviews conducted with fifty voice-hearers in the general population. Results showed that the content of voices was personally meaningful, related to concerns about the past, present and future; and the identity of the voices indicated the person's beliefs and attitudes toward themselves, others and the world. She also found that people had meaningful relationships with their voices, which remained stable for some and changed over time for others. Furthermore, the experiences had a significant impact on individuals' lives, varying from being enriching and positive, to frightening, negative and stigmatising.

Another qualitative study, by Fenekou and Georgaca (2010), on the experience of hearing voices, again shows the importance of subjective understanding of the origin, function and impact of hearing voices. Some people in their study evidenced Romme and Escher's (1989) proposed stage of stabilisation, where the voices were experienced as integrated into their lives, familiar and not disturbing. From this, Fenekou and

Georgaca (2010) concluded that clinicians need to work with voice hearers' subjective and complex understandings of their experiences, so they can find ways of coping effectively with the voices.

Older People's Subjective Meaning-Making of Hearing Voices

Although there is a growing literature on the subjective experiences of voice hearing in the working-adult population, there is still a paucity of such literature relating to the older adult population. A literature search was conducted through database searches including PsychINFO, Embase, and Ovid MEDLINE. Combinations of different key search terms were used including 'psychosis', 'schizophrenia', 'hearing voices', 'auditory hallucinations', 'older people', 'older adults', 'elderly', 'subjective experience', 'subjective understanding', 'personal meaning' and 'meaning-making'. A copy of the search can be found in Appendix A. Results of the search yielded four studies as shown in Table 2 below:

Table 2. Studies identified by the literature search

Authors (date)	Title	Overview
Charazac (1998)	The psychopathology of dependence in the elderly	This study looked at physical and psychological dependence in older adulthood. The full text of this study was unavailable to view in English, and is therefore not discussed further in the proceeding section.
Quin, Clare, Ryan and Jackson (2009)	'Not of this world': The subjective experience of late-onset psychosis	This was an interpretative phenomenological analysis of seven older adults with late-onset psychosis. Themes found included: the experience of social isolation, a solitary coping style, experience of self as different, and an attempt to find meaning. This study was noted to be the first attempt at exploring subjective experience of late-onset psychosis.

Shahar (2012)	"I don't want to be here": Projectuality versus eventuality in the life, symptoms and treatment of Ms.T.	This study was a psychotherapeutic case-study of an older lady with mental health difficulties, whose subjective experience was of 'life as not worth living'. The paper focussed on the diagnosis of depressive personality disorder, rather than any subjective experience of hearing voices across the lifespan. Therefore this study has not been discussed in the following section.
Solano and Whitbourne (2001)	Coping with schizophrenia: Patterns in later adulthood	This qualitative study looked at the coping strategies used by fifteen older adults who had experienced schizophrenia from an earlier age. The study found that they used similar coping strategies to younger populations, but that the efficacy of their coping had improved and they had accepted their illness.

The Quin *et al.* (2009) study and the Solano and Whitbourne (2001) study are of particular relevance to the current thesis.

Quin *et al.* (2009) conducted an interpretative phenomenological analysis on interviews with seven older adults about their subjective experience of late-onset psychosis. The four main themes found were, 'the heaviness of being alone', 'I'm not of this world', 'I would get on with it myself' and 'Why me?' This latter theme focussed on the diverse meanings participants made of their psychotic experiences. For some participants, symptoms were experienced positively, by providing relief, esteem, company and allowing them to relive previous valued roles. For others, symptoms were experienced negatively, being related to loss, ageing and regrets about the past. The authors noted that there were clear continuities between earlier life experiences and the content of current psychotic symptoms, particularly in relation to the first three themes which encapsulated difficulties with social relationships, isolation, rejection and coping

alone. The authors concluded that psychotic symptoms can have an important psychological function or meaning, which can sometimes be positive, for example as a form of company and interest, and sometimes be negative, such as acting as reminders of unresolved difficult past experiences. An exploration of such functions may help normalise psychotic experiences as an understandable reaction to adverse life experiences, rather than a pathological illness process.

The above study was, however, concerning late-onset psychosis, and focussed more on the psychotic symptom of delusions as a whole, rather than auditory hallucinations specifically, although two of the seven participants did experience auditory hallucinations. Older people who have had an early-onset psychosis, and lived with psychotic phenomena throughout their lives, may have had different experiences than those with later-onset psychosis; firstly because the clinical features of early and late onset psychosis can be different (e.g. Reeves and Brister, 2008; Harvey, 2005), and also due to the changing nature of the course of schizophrenia over the lifespan (e.g. Shepherd *et al.* 2010).

Solano and Whitbourne (2001) was the only study that was identified that looked at older adults who had experienced an early-onset psychosis. Again this study was not solely focussed on hearing voices, but rather the experience of schizophrenia more generally. Fifteen adults between the ages of 50 and 62, with a diagnosis of schizophrenia, were recruited from community centres that support people with mental health difficulties. The authors used semi-structured interviews to look at whether the experience of being 'mentally ill' changed across the lifespan and the variables that affected their coping, and also used a 'yes/no' self-report scale to identify which of a list of 22 coping strategies they used. The authors categorised responses according to whether they referred to cognitive or behavioural coping strategies. Results showed that participants used an average of ten coping strategies, most often these were behavioural such as watching television. From the data, the authors suggested that as participants grew older, they were better able to recognise and more effectively use their coping strategies to manage their symptoms, compared to earlier in their lives. The authors concluded that a process of learning, being able to better recognise symptoms, and

coming to an acceptance of their 'illness', accounted for participants' increased efficacy in coping. However, there was no specific, formal qualitative methodology or analysis of the subjective experience of being 'mentally ill' throughout the lifespan. Since the method of qualitative analysis is unclear, it makes it difficult to assess the quality of the findings.

Summary and Aims of my Thesis

There have been significant shifts in understanding schizophrenia and the symptoms of psychosis over the last century. Some theories and models have emphasised the pathological nature of psychosis (e.g. medical/biological models; the 'schizophrenogenic mother' hypothesis) and have been criticised for their stigmatising stance (e.g. Hoffman, 2011; Parker, 1982). More recently, there has been a growing interest in understanding the subjective experience of specific symptoms of psychosis, such as hearing voices (e.g. Calton *et al*., 2009). Research into this field has highlighted the importance of peoples' unique meaning-making in regard to the content of, and beliefs about, their voices. Studies have suggested this has implications for how people cope with hearing voices, and how people come to integrate their voices as meaningful in the context of their life experiences.

For the most part, research into the subjective experiences of hearing voices has focussed on the working-age adult population, and little attention has been paid to the older adult population. This is especially so for those who have experienced an early-onset schizrenia for most of their lives. This cohort will have negotiated a lifespan of developmental challenges, alongside the course of their symptoms of psychosis. Their understanding and sense making of their experience of psychosis and hearing voices, may also have been influenced by different theoretical explanations and treatments of schizophrenia that were developing in parallel. The evidence suggests that there is a variable course and outcome for those with schizophrenia; with a minority experiencing a deteriorating course, another minority experiencing an improving course, and the majority experiencing a fluctuating or stable course (e.g. Bleuler, 1972; Ciompi and Muller, 1976 (both cited in Barham and Hayward, 1990); Huber, 1997). Subjective

functional outcomes have also been shown to range from hopelessness and resignation, to acceptance and optimism (e.g. Shepherd *et al.,* 2010).

Understanding older people's subjective experiences of hearing voices throughout their lives is worthy of further exploration for a number of reasons. Firstly, it would be useful to understand more about older adults' experiences of their course of hearing voices, whether this be an improvement, deterioration or stabilisation of symptoms, and how their understanding of hearing voices has developed over time. Secondly, with the older adult population increasing in number, and services having come under criticism for age discrimination in mental health care provision, such services will need improve their understanding of, and adapt to meet, the specific needs of this population. To reiterate, Age Concern (2007) estimate that by 2021, 91,000 older people in the UK may be experiencing psychosis, of whom 75% (68,250) will have experienced it from an early-onset. Thirdly, this population may provide a valuable insight into the impact of the changing and emerging theoretical perspectives over time on their frameworks for understanding their experience of hearing voices. The research may help to inform current service approaches and therapeutic initiatives regarding subjective understandings of hearing voices. It may also inform local initiatives currently in Leeds Older Adult Services, such as the development of a hearing voices group.

Research Question and Aims

The broad research aim of the thesis is to gain insight into the lived experience of older adults who have heard voices throughout their lives, following early-onset psychosis. More specifically this includes the following questions:

- How do older adults make sense of hearing voices – what is the essence of this experience as understood by older adults?
- How have older adults' experience and understanding of hearing voices changed over the lifespan?

Chapter Two

METHOD

Methodological Approach

Interpretative phenomenological analysis (IPA) was the chosen methodological approach for this study. The first part of the following section outlines why other qualitative methodologies of grounded theory and discourse analysis were considered and then discounted, and then goes on to present the main tenets of IPA.

Alternative Approaches Considered

Grounded Theory (Glaser and Strauss, 1967) is an approach that involves analysing emerging categories of meaning from data, and using these to generate general conclusions or theories of the phenomenon under study. Similar to IPA, the process aims to move from the raw data, to higher and higher levels of conceptual coding and interpretation, and makes use of memos and reiterative cycles of analysis to remain open to the continual development of the analysis (e.g. Strauss and Corbin, 1990). However, grounded theory aims to reach an overall macro-level theoretical conceptualisation about a phenomenon based on a larger sample, compared to IPA which is more focussed on the micro-level nuances of smaller samples. In regards to this thesis, a large body of theory about auditory hallucinations and hearing voices already exists, and the aims were not to elicit or build on these theories further. Rather, my aim was to gain an in depth insight into what the long-term lived experience of hearing voices has been like for the individuals of a very specific group of people. Therefore, an IPA, rather than a grounded theory approach, was thought to be a more appropriate form of analysis to answer the research questions.

Discourse Analysis (Potter and Wetherell, 1987) is a qualitative approach that is interested in how people purposively use language to construct and understand social realities. The particular social context and discourses that people are surrounded by can

influence their experience and understanding of a phenomenon. This approach can either focus on how people use discourses, or on what discourses are available to them and the impact of these. Smith, Flowers and Larkin (2009) noted that meaning-making about an experience is inevitably embedded in culture and language, and so elements of social constructionism are implicitly present in an IPA approach, however not as strongly or critically as in a discourse analysis.

Discourse analysis was of some relevance here, given that older adults will have been exposed to certain theories of hearing voices and related discourses specific to their cohort over time, which they may have used to construct an understanding of their experience. However, the primary aim of my thesis was to gain a detailed insight into what it has been like for older people to have lived with, and understood, the phenomenon of hearing voices over a number of years. Although their experience and understanding will have been influenced by different discourses, I did not want to limit my analytical stance to the impact of discourse only, and so an IPA approach seemed better suited.

Thematic analysis. Braun and Clarke (2006) describe thematic analysis as the *"foundational method for qualitative analysis"* (p78), since its primary concern is to extrapolate themes from data. The authors argue its strengths as being a theoretically flexible and accessible method of analysis. However, thematic analysis has been criticised for its lack of theoretical underpinnings and being more of a general tool of the analysis process that is common to all other qualitative approaches. This method was discounted due to its lack of primary theoretical focus on the interpretation and phenomenology of lived experience.

Interpretative Phenomenological Analysis

Interpretative phenomenological Analysis (IPA) (Smith, 1996) is a form of research that seeks to understand individuals and their subjective world view on a particular phenomenon. It is specifically concerned with how people understand and interpret their lived world and make meaning of their experiences in their personal context. It is therefore a highly subjective and idiographic form of research. Analysis

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aims to capture the thematic essences of peoples' experiences through bringing psychological interpretation to their understandings. IPA is based on the theoretical frameworks of hermeneutics and phenomenology. Hermeneutics is the theory of interpretation, and posits that people are continually making sense of their experiences (e.g. Heidegger, 1962/1927, cited in Smith, Flowers and Larkin, 2009). Phenomenology is the intentional perception of a phenomenon as embedded in the world and experienced by a person (e.g. Husserl, 1927, cited in Smith, Flowers and Larkin, 2009). The way a person perceives a phenomenon is unique to the context and mental framework of that person and a phenomenon therefore only becomes meaningful through its perception by a person (e.g. Smith, Flowers and Larkin, 2009). IPA therefore seemed to fit well with my research questions which sought to understand what the experience of hearing voices has been like in the personal context of older people who have experienced the phenomenon throughout their lives.

Method of Data Collection in IPA

Semi-structured interviews are the method of choice when looking at participant's sense making of their experiences (Smith, 2005), as they provide a useful guide to facilitating an in-depth conversation on participants' meaning making, but are open enough to allow for them to recount their experiences as they have understood them.

However, Potter and Hepburn (2005) summarise a number of criticisms levied at the dominance of the semi-structured interviewing method in qualitative research. These criticisms include neglecting information about the interactional features of the interview process; neglecting information about the interview set-up; and the investments and biases of the interviewee and interviewer, to name a few. However Smith (2005) notes that different qualitative approaches attend to different features of the interview, and for IPA it is the analysis of sense making that participants engage in when reflecting on their experiences. Furthermore, reflecting on and attempting to bracket off researcher biases, as well as constructing pen portraits of participants and making field notes about the impressions and experience of the interview, may go some way to remedy some of Potter and Hepburn's criticisms.

Reflexivity in IPA

In IPA research, the first level of interpretation of the phenomenon is by the participant themselves, through their lived experience of it in the world. The second level of interpretation is the researcher's interpretation of this participant data. This is known as the double hermeneutic (Smith and Osborn, 2003). The researcher is therefore an integral part of the analysis process and will influence the final themes that emerge as answers to the research questions. This contrasts with other approaches such as grounded theory which strive towards a more objective and positivist approach, where their biases are thought to be removable from the analysis.

Although IPA does not seek to remove the researcher's subjective position, it does emphasise the need for researcher reflexivity and open-mindedness, in order not to limit the collection and interpretation of data through the influence of the researcher's own preconceptions and biases, or 'forestructures'. This can be helped by keeping memos to capture, and develop insight into, the researcher's preconceptions as they arise during the research, and allows transparency of how themes may have been influenced by the researcher's subjective interpretative stance. Before beginning data collection, I reflected upon my interest in, and position on, the phenomenon of hearing voices, to explore some of my forestructures (presented below). I also kept memos during the data analysis stage, and wrote a further reflexive statement after the analysis (presented later in the chapter).

Initial Reflexive Statement

Most of my clinical work before starting Doctoral training was in secure mental health settings, where I had a lot of contact with people who experienced psychosis. To begin with, as a nursing assistant, I was probably influenced a great deal by the dominant medical model of 'schizophrenia' on these wards where there was very little psychological input. Later moving into more psychological roles, I was exposed to mostly CBT models of psychosis. Although I saw the value of both the medical and CBT models, I still felt there were additional ways to conceptualise and understand psychosis, such as the protective function of voices and their relation to trauma, and that

did not seem to filter through to clinical practice. Psychosis and 'auditory hallucinations' were very much seen as dysfunctional symptoms of an illness to be eradicated. It was not until starting the doctorate that I became familiar with the more social-constructionist models and trauma models of psychosis, which for me seemed to fit my earlier experiences of working with people with psychosis, and sparked my interests and reading in this area. This also orientated me to a more optimistic view of hearing voices as a coping mechanism, as a positive and enriching experience, which has real meaning in the context of a person's life. My third doctorate placement was in an early intervention for psychosis service, which also utilised more psychological and optimistic models of hearing voices. Here I learnt to formulate experiences of psychosis in the context of what the voices represented, what the function of them might be in relation to past and current experiences, and how they fitted with a person's existing beliefs and frameworks.

It was these latter theories of voice hearing that attracted me to conduct my thesis research in this area. I am strongly aligned with the importance of understanding what are rich and meaningful 'symptoms', in the context of a person's past and present lived experience. It may therefore be that I am biased towards an anti-psychiatry stance, and prioritise ways of formulating voices in the context of earlier personal meaning and exploring the function of voices.

Although my clinical background before the Doctoral training had never brought me into contact with older adults, I really enjoyed my older adult placement. It gave me an appreciation of the psychological life challenges older people have negotiated, and how such experience can contribute to our understanding of younger populations. It has also highlighted the need for, and value of, tailored psychological intervention for this population. I have also worked in an early intervention for psychosis service, a new initiative from the 1990s, offering high intensity input for the younger generation, with a more optimistic and psychological understanding of the experience of hearing voices. This has left me feeling uneasy about the current older adult population whose generation has been through services in what I perceive as a more pessimistic time in comparison.

Design

The study employed a qualitative design, where five people were interviewed. These interviews were transcribed and interpretative phenomenological analysis (IPA) was applied to the data.

Participants

Sampling

In accordance with IPA principles, the sample was purposively selected to be homogenous in relation to offering a perspective on the specific phenomenon of hearing voices throughout the lifespan, as a reflection from the life-stage of old age. As the goal of IPA is to gain a rich and detailed analysis of each participant's perspective, and not to make nomothetic generalisations, only a small sample was necessary. Smith, Flowers and Larkin (2009) recommend between 4 and 10 interviews for a doctorate level project. This study therefore sought a sample of between 6 to 8 older adults between the age of 65 and 80 who had experienced hearing voices throughout their lives following earlier onset psychosis, with the following specific criteria:

Inclusion Criteria

- Under the care of Leeds and York NHS Partnership Foundation Trust (LYPFT) CMHT. This was to ensure an assessment of risk was available, and that management of any issues that the interview might bring up, would be supported by the CMHNs' on-going regular care. Four participants were recruited under these criteria. However, due to difficulties recruiting participants for the study, this inclusion criterion was extended to also include those who had been under the care of LYPFT CMHT within the last 12 months. One participant was recruited under the extension to this inclusion criterion.
- Experience of hearing voices over the lifespan, either constant or intermittent, including one or more voices, and with an onset prior to age 40 (this is the age limit in most literature for classifying "early onset" psychosis, and the lower limit for

"late onset"). All participants recruited for the study were verified by their CMHN to have heard voices from an early onset.

- Between age of 65 and 80. The lower limit was chosen to fit with current service classification of an 'older adult', and the upper limit was to ensure a more homogenous sample of cohort experiences, but with enough scope that recruitment of the desired number of participants would be possible.

- English as first language. IPA relies on very detailed interpretation of the language participants use. It was thought that understanding the richness and nuance in expression would be best facilitated if the researcher shared the same first language as the participants.

- Capacity to consent (as assessed by CMHNs involved in their care).

Exclusion Criteria

- Co-morbid diagnosis of dementia (including Lewy Body dementia) or significant cognitive problems, as this could have reduced ability to engage in a 45-75 minute interview that relies on the recollection of memories.

- Late onset psychosis as this would have limited the lifespan perspective of hearing voices.

- Current experience of floridly psychotic symptoms, which might be too acutely distressing to talk about, and could affect engagement in the interview process.

- An elevated risk of distress from engaging in an interview about the experiences of hearing voices. This was assessed by the CMHNs involved in the service-users' care, based on their clinical judgement and the service-user's FACE (Functional Assessment of Care Environments) risk assessment.

Recruitment

Recruitment began in August 2012. Participants were identified via the LYPFT CMHT. This was facilitated by my field supervisor Dr Louise Bergin, with the support of senior management, consultant psychiatrists and community mental health nurse (CMHN) leads. The study was communicated to professionals face-to-face in staff

meetings, through telephone contact, email contact, and written format (see staff information sheet: Appendix B).

The initial recruitment strategy involved these professionals then identifying service-users on their caseload that fit the inclusion and exclusion criteria. Unfortunately the service underwent considerable organisational change during the summer of 2012 when recruitment for this study began. The result of this change meant firstly that staff had fewer older adults with psychosis on their caseloads, and secondly many staff reported being under increased workload pressure. This impacted upon their capacity to give their time in identifying potential participants. A second identification strategy was introduced in February 2013 following ethical approval of the major amendment. This involved my field supervisor identifying potential participants via the electronic patient database that the service uses. Once identified, Dr Bergin directly contacted the allocated care-coordinator to ask them to approach to service-user and introduce the study.

Brief recruitment leaflets (see Appendix C) about the study were given to staff to give to the potential participants who met the inclusion and exclusion criteria. The rationale for initial contact being made by CMHNs was twofold. Firstly it was to protect confidentiality up to the point of the service-user consenting to take part. Secondly, it was thought these professionals would have regular contact with the potential pool of participants, which would both aid participant identification and ensure follow-up support if necessary.

Service-users who expressed an interest in the recruitment leaflet, were then given a full participant information sheet (see Appendix D) and consent form (see Appendix E) by their CMHN. Consent forms of those who wished to take part were collected by CMHNs and passed to the researcher to arrange the interview.

Final Sample

The final recruited sample included five participants. A flowchart of participant numbers identified and recruited, along with reasons for those not recruited, is presented in Figure 4.

Strategy 1 – Care-coordinators / mental health professionals, identifying participants on caseload

Identified = 6

Not recruited = 2
Reasons:
- Professionals unable to introduce study (off-sick, caseload pressures)
- Service-user uninterested in study

Recruited into study = 4

Strategy 2 – Dr Bergin identifying participants via database (including those discharged within 12 months) who heard voices

Identified = 6

Not recruited = 5
Reasons:
- Care-coordinator confirmed unsuitable by incl./excl. criteria
- Service-user uninterested in study
- Service user did not agree that she experienced 'psychosis', therefore felt she didn't fit study criteria

Recruited into study = 1

Figure 4. Flowchart of participant recruitment

The final sample demographics and characteristics of the sample are detailed below in Table 3. The specific details regarding the sample that are reported throughout this write-up are from participant self-report. To have collected information from staff involved in their care would have breached confidentiality and ethical approval. The only disclosure pertaining to participant information, provided by involved staff, was definitive confirmation (yes or no) that participants fit the inclusion and exclusion criteria, as already ethically approved as part of the recruitment procedure. This confirmation was necessary to revisit following the interviews since some of the participants spoke more of delusional beliefs than auditory hallucinations, or reported a late onset of voice hearing. More detailed information about participants, including their

involvement with services throughout their lifespan, is provided in pen portraits in the Results chapter.

Table 3. Sample demographics and characteristics

Pseudonym	Age	Gender	Ethnicity	Age at voice(s) onset	Current diagnosis
Alice	71	Female	White British	Uncertain	Schizophrenia
Albert	72	Male	White British	29	Schizophrenia
June	68	Female	White British	Early 20s	Psychosis
Tony	68	Male	White British	13	PTSD
Frances	75	Female	White British	Late 30s	Schizophrenia

Semi-Structured Interview

Interview Guide

The interview guide for the study was influenced by a narrative approach of encouraging participants to tell their personal stories of hearing voices throughout their lives. Crossley (2000) noted that people continually construct personal narratives as an inherent way of making sense of, and organising, their lives into a coherent whole. Prompts were used to deepen and explore the stories which participants brought, however the course of the interview was open to the influence of the participant, in regards to talking about what was important and meaningful to them in their voice hearing experience.

The interview opened very broadly to ask about the person's experience of "psychosis". This approach was taken because "hearing voices" may not be a construct older people use to conceptualise their experience. Liaison with ward staff about the development of a "hearing voices group" at a local mental health hospital for older adults, highlighted that service-users felt the term did not resonate with them. Service-users chose to rename it the "psychosis" group – a term they all understood, accepted and were comfortable with.

Once participants began to talk about experiences of psychosis akin to hearing voices, I used their specific language and terms to explore the phenomenon further. Two participants referred to "hearing voices", one to "spirits" and the other two spoke more generally of a wider delusional belief that included an auditory hallucinatory element. Where necessary, I clarified what term the participant wanted me to use to refer to their experience. The interview protocol was modified as appropriate during the interview to allow for idiosyncratic exploration of the stories as they arose. A copy of the standard protocol can be found in Appendix F.

I took note of demographic data as and when it arose through the interview in order to help me construct pen portraits. At the end of each interview I collected any information from participants that had not naturally arisen during the interview.

Pilot

Prior to finalising the interview protocol ready for ethics submission, a pilot interview was conducted with the staff member who facilitates the older adults' psychosis group on one of the wards at a local mental health hospital for older adults. For the purpose of the pilot interview, the staff member took on the role of an older adult who hears voices, based on his experience of working with this population. The interview was observed by my field supervisor. After the pilot interview, we discussed which prompts were helpful and which less so, with regard to eliciting information and story-telling. It also allowed us to anticipate possible difficulties such as repetitive story-telling, poor memory of earlier life, not understanding certain questions, going off-topic etc. Solutions to these difficulties included the rephrasing of questions, taking

a more directive approach to move the interview on, and directly clarifying the significance of participants' voices in relation to any seemingly off-topic stories.

Interview Procedure

Participants were invited to participate in one interview that would last around an hour. Three participants' interviews lasted 60 minutes, and two participants' interviews lasted 75 minutes. Additional time during interviews was offered for breaks when participants felt distressed or wanted to take time out to use their coping strategies for active voice hearing during the interview. Two participants had brief breaks of a few minutes due to voice hearing.

Participants were given the choice of having the interviews at an NHS centre near to them, so that support would be available from staff if participants were to become distressed. Interviews were also offered in participants' homes, for those who preferred not to go to an NHS base. Of the five interviews, one was conducted at the CMHT base, three were conducted in participants' own homes (private residences), and one in a participant's nursing home. The rooms ensured confidentiality for the participants, and were generally quiet and free from distractions. One participant wanted her carer to sit with her for the first fifteen minutes of the interview, and two other participants had family or partners who were in the house and occasionally entered the room briefly, but did not input into the interview. For these participants, it was explained beforehand that the interview was about gaining their perspective only, and that any direct influence of other people's perspectives during the interview hour, would affect my being able to use the interview to answer my research questions. I also put forward the possibility that the presence of others may sometimes affect what participants do and do not talk about.

The interviews were audio recorded and then transcribed (three by myself and three by a transcriber). The transcriber was university approved and had signed a confidentiality statement. All material containing participant identifying information passed between me and the transcriber was deleted or destroyed once anonymised transcription was complete. All identifiable information was removed and names were

replaced with pseudonyms. I reviewed all transcriptions, in order to add non-verbal responses and check for accuracy.

Ethical Considerations

Wellbeing of Participants and Researcher

Participants: It was acknowledged in the Participant Information Sheet, that talking in depth about personal experiences of psychosis and hearing voices can be distressing, particularly for those people who may have experienced stigma and negative aspects of voice hearing. For this reason I limited the inclusion criteria to include only people who were under the care of LYPFT CMHT (or had been within the last twelve months) so that there would be a trusted mental health professional involved (or recently involved) who could be called upon for follow-up support if participants were to become distressed. The exclusion criteria also attempted to eliminate people who were at higher risk of becoming distressed, as judged clinically by the most recent CMHT risk assessment and professional involved. Furthermore, as a Clinical Psychologist in Training, I was able to use my own skills in supporting participants if I felt they were becoming distressed. In two interviews, participants were actively hearing voices and at those points in the interview I deviated from the interview schedule to support them in giving them time-out and validating their experiences in the moment. Both of these participants chose to continue with the interviews. At the end, I spoke with participants about their interview experience and asked them about any distress they were feeling. Although none of the participants reported distress, I ensured they had contact details of their care-coordinators to contact if necessary. Care-coordinators were informed of the interview time and the possibility of later telephone contact.

Researcher: As a researcher I was aware that I may be exposed to distressing and/or traumatic experiences recounted by participants in their interviews. I noted and reflected upon my reactions in my memos and field notes of the interview immediately afterwards. I also had the opportunity to talk with my field supervisor directly following the interview over the phone, and at a later date with my academic supervisor in our supervision meetings. The LYPFT Home Visiting Protocol was also adhered to for

researcher safety, whereby I made contact with my field supervisor before and after every interview.

Consent

Participants were given an Information Sheet, the reading and explanation of which was supported by the care-coordinator making contact with the participant. My own and my supervisors contact details were available if the participant wished to ask further questions, and it was made clear on the Information Sheet that they could discuss their decision further with others. For those who wished to take part, written consent was then recorded by the member of staff. I also revisited the information sheet and consent form with participants immediately before the interviews. Participants were judged to have the capacity to consent by their care-coordinator, and again immediately prior to the interview, based on their ability to understand, retain and weigh up the information given to them.

Confidentiality

Participants' data was kept confidential by ensuring all audio recordings were deleted once transcribed, and transcripts were anonymised. Participants were informed that if I became concerned about any risk to themselves or others, I would have to disclose those concerns to relevant professionals, but this would be discussed with participants first. The Information Sheet also highlighted who my field supervisor was and her role within LYPFT in case she was involved in their care presently, in the past, or in the future. This was explained to participants, none of whom reported this to be a problem.

Payment

Participants were offered a £10 'love-to-shop' voucher following the interview as a gesture of goodwill to thank them for their time participating. This amount was decided based on guidelines from the MHRN Service Users and Carers Payments Policy (2012). To avoid the potential for the voucher to have a coercive influence, it was not referred to during recruitment stages, and only offered after the interview.

Ethical Approval

Ethical approval for the study was awarded (see Appendix G) on 29th June 2012 by the National Research Ethics Service (The Committee for Yorkshire and the Humber - Leeds West). LYPFT Research and Innovation Department approval was granted on August 16th 2012. Due to difficulties recruiting numbers of participants for the study, several amendments were put forward during the recruitment stage:

1. Unfavorable outcome on 23.01.13: To offer staff vouchers to encourage and compensate them for giving their time to identifying and approaching potential participants.

2. Favorable outcome on 19.02.13: To request that my supervisor be allowed to search the electronic patient database, to identify potential participants who fit the inclusion and exclusion criteria.

3. Favourable outcome on 05.04.13: To request that one of the inclusion criteria was extended to include people who had been under the care of LYPFT CMHT within the last 12 months

The ethics amendment letters and the R&I approval letter are included in the extra appendices on the CD ROM.

Analysis

Smith, Flowers and Larkin (2009) outline a series of steps for the analysis process. Using their guidance and additional input from an IPA workshop I attended, I followed the process shown in Table 4, to analyse the data.

Table 4. Steps in the IPA process

Step	Process	Description	Example
1	Reading and re-reading	• Familiarising myself with the data. • Making an initial summary of the interview – the content and process.	An example of an interview summary can be found in Appendix H

2	Initial exploratory noting	• Making descriptive comments about the voices, relationships, time periods, language, social context. E.g. what the participant is describing; what their key concerns are.	An example of the exploratory noting can be found in Appendix I (left-hand column on the transcript).
		• Making conceptual/interpretative notes about these descriptive comments. E.g. inferring the possible meaning participants are making; inferring possible meanings based on my interpretations.	
3	Developing emergent themes	• Noting the relationships and patterns between the initial exploratory comments/notes.	An example of the identification of emergent themes can be found in Appendix I (right-hand column on the transcript).
		• Developing themes capturing the essence of the experience. E.g. thinking about what is crucial in particular comments.	
		• Looking at the detailed parts whilst being influenced by the whole and vice versa.	
4	Searching for connections across emergent themes	• Mapping how the emergent themes link together	See Appendix J for scanned photograph of example clustering of themes
		• Forming clusters of themes – e.g. those which are similar in some way, those which represent oppositional relationships, those which have a contextual link, or a	

		functional link	
		• Emergent themes were typed up onto index cards in red text, with example quotes beneath in black text. These cards were then clustered and re-clustered according to potential patterns and links	
5	Moving to the next case	• Repeating the above steps for the other interviews	
6	Looking for patterns across cases	• Noting any links between participants • Clustering across participants themes according to higher-order influences and concepts	This was done in the same away as seen on the photographs in Appendix J

Quality Checks

Although qualitative research cannot be subject to the same reliability and validity checks as quantitative research, there are still principles and guidelines that can be adhered to in order to demonstrate validity. Yardley (2000) outlined four such principles: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. The first two can be ensured by thorough background research to show the appropriateness of using IPA for the research questions; appropriateness and viability of the sample; and well conducted interviews that empathically balance any interactional difficulties, with a schedule that opens up rich stories about the person's experience of the phenomenon.

Further towards fulfilling the principle of 'commitment and rigour', I attended the qualitative research support group set up and attended by third year colleagues in the Leeds DClin programme, and I also met separately with two other peers in my year

group who were specifically using IPA methodology. These opportunities enabled me to discuss concerns and difficulties that I encountered with the methodology, and to gain feedback and discussion on my transcripts and themes. For example, my peers did some initial noting and emergent theme identification on a number of blank transcript pages. This allowed me to confirm and validate the themes they noted which matched my own, as well as see new themes and discuss rationales and biases behind these.

I also had access to regular supervision, and both my supervisors had experience in IPA, and supported me in the analysis. During the analysis stage I met jointly with my supervisors on average every two weeks and additionally with my academic supervisor on a regular basis. My supervisors provided valuable checks on whether their overall impression of the transcripts matched my themes, as well as more detailed checks on my line-by-line analysis of the transcripts, and my naming of themes and illustrative quotes. My supervisors also gave me different perspectives on ways of clustering themes. These discussions enabled me to reflect on, and recognise, some of my biases and how they may be influencing my analysis, highlighting the need to revisit the noting, theme development, and clustering again. For example, my supervisors helped recognise how my clustering was initially biased towards a similarity principle, and instead helped me think more widely about clustering based on difference, continuums, and transitions. Supervision discussions also helped me move between looking at overarching patterns, to the detailed individual themes and back again, each time developing ideas and themes further.

Some qualitative methodologies suggest the possibility of taking themes back to the participants to gain their feedback as a validity check. Due to the in-depth interpretative process of IPA methodology, the final group-level themes were far removed from the individual original accounts, therefore it would have been inappropriate to gain participant feedback.

Yardley's (2000) third principle of 'transparency and coherence' can be demonstrated by clearly laying out the stages of analysis and how the researcher's interpretations were reached. My stages of analysis have been outlined above in Table 4, and extracts can be found in the appendix. I also kept detailed memos of each step of

the analysis and interpretation, which has informed my results write-up. Furthermore, memos to capture arising fore-structures and influential discussions and decisions throughout the process, also helped ensure transparency and coherence, and extracts of these are presented for the reader in Appendix K.

Writing memos gave me the opportunity to notice any biases and explore how my forestructures may have affected the interpretation of the data. For example, I recognised after my first interview that my forestructures about the nature of 'hearing voices' were limiting me from interpreting the wider phenomena it was embedded in for my first participant (i.e. part of a bigger delusional belief system).

There will remain some biases and forestructures that I have not recognised, however by using memos and supervisory discussion regularly, I hope to have captured those which did arise. Further notes on these will be provided in the Results chapter.

With regard to Yardley's (2000) final principle of 'impact and importance', I hope to have demonstrated this throughout my thesis write up, but particularly in my final Discussion chapter.

Chapter Three

RESULTS

The following chapter will outline my interpretative phenomenological analysis of the lived experience of older adults who have heard voices throughout their lives, following early-onset psychosis. I will firstly present the pen portraits of the five participants, followed by a diagrammatic representation of the themes, which will then each be outlined in detail. A table of the various developments in theories of psychosis and hearing voices over the last century will also be presented alongside participant timelines to contextualise their experience. Finally, I will present my reflections on the research process.

Pen Portraits

Alice

Alice was a 71 year old lady who reported the involvement of a man (who it becomes clear throughout the interview is the phenomenon under study) in her life since age 16, however she reported only 'hearing his voice' specifically since a hospitalisation in 1990. She noted that she first saw a psychiatrist at age 23 although cannot remember what this was for. She recalled being diagnosed with 'schizophrenia' in her 50s, although again she was uncertain about the accuracy of her recall of this timeframe.

Alice's story was one of a very negative experience of the man/voice, who she perceived had wanted to cause serious harm to her, wished her dead, and had sabotaged many of the happy times she had throughout her life. He seemed intensely relentless, surreptitious and interfering, leaving Alice powerless and vulnerable in response. His presence kept the early significant loss of her mother at the forefront of her mind, since Alice believed he had a crucial role in her mother's death. Over the past ten years, however, Alice seemed to have come to understand more about the man/voice, which

had perhaps given her more of a sense of control and power. Her story appeared to reflect a shift to a greater ability to cope and an increased self-agency and hope.

It seemed difficult to use my conceptualisation of 'hearing voices' when talking about Alice's experience, since for Alice the psychotic phenomenon was conceptualised as a whole person with a detailed identity that was deeply inter-woven as part of a wider persecutory delusional construct. My interview with Alice made me question whether isolating the phenomenon of a 'voice' is even possible for some people. At points in her story, it was hard to tell if the man had indeed been real at some time, and at what point he may then have become a psychotic phenomenon. At times there were clear indications that Alice understood the voice as being of an internal origin. At other times, however, she spoke of the voice as an external phenomenon.

Alice recounted her experiences in an open, confident and factual manner. I wondered at first if she was emotionally detached from the experiences she spoke of, but I also considered that it may have reflected an acceptance and integration of her experiences. There was clearly an impact of fading memory which limited detailed reflection on the earlier years of her experiences with the man/voice that her story centred around. I thought about possible reasons for her difficulty in accessing earlier memories: an unconscious defensive strategy; more recent experiences being more relevant and important to her; a fading of memories with age and time; or a factor of rapport and trust in me as a researcher.

Albert

Albert was a 72 year old gentleman who reported hearing voices since age 29. Earlier in his life, around age 16, he received ECT and had a brief admission to a psychiatric hospital. This seemed to be linked to an experience of being bullied, and he reported being diagnosed with 'nerves' at that time. In relation to hearing voices, he reported that his diagnosis was 'schizophrenia', but that around age 60 he believed it to have been temporarily changed by a psychiatrist to 'depression'.

From age 16 until the onset of hearing voices, Albert worked in the coal mines, which was a valued role for him. He had a sense of pride in helping his family and

keeping fit. Albert also married around this time. From the onset of hearing voices at age 29, many of his valued roles seemed to suddenly disappear and Albert described the rest of his life as alternating between isolating himself in his home (which he shares with his wife) and a number of admissions to psychiatric hospitals.

Religion was a central theme of Albert's story. After turning to religion for protection from his early experience of bullying and psychiatric treatment, he then later became resentful of it after the negative experience of hearing voices. The voices Albert began to hear when he was 29 were 'spirits' with religious links to the bible. After initially believing the spirits were offering him hope, the experiences became frightening and distressing for Albert. He and his family sought religious and spiritual cures for the voices, however these did not work, and on reflection, he felt they made him worse. Albert felt as though the voices worsened over time and his experience of people trying to help him, both from the spiritual field and the mental health field, was of being let down and making him feel worse.

My response to Albert's story was one of empathy and sadness for the all-consuming losses he seemed to have experienced – of his former self, his potential, and his hope for things to ever get better. His story was difficult to make sense of, particularly when he jumped between events or tenses; this made it difficult to understand whether he was recounting past thoughts and feelings, or current reflections, and what specifically they referred to. Compared with his more recent experiences of what the voices had been like or how he coped, the initial onset and search for cures elicited the richest stories. I wondered if this reflected his complete loss of hope and perceived ability to cope, and was perhaps a coping strategy that helped him to avoid dwelling on his experiences.

June

June was a 68 year old lady who reported hearing voices since her early 20s. She remembered vaguely having had a number of periodic hospital admissions throughout her life, however could not remember the details of these or her earlier voice hearing experiences. At the time of the interview June had recently been discharged from a 12

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month psychiatric hospital admission, before which she reported being well for approximately 15 years. Much of her interview account centred on her recent experience. June was unsure if she had been given a diagnosis, but thought maybe a psychiatrist had said recently it was a 'psychosis depression'. She reported taking tablets, but again she did not know what these were for, other than to help her 'condition'.

June had four children, and lived with her son. Her stories relied heavily on her children's narratives of her episodes of hearing voices and being hospitalised, as she reported a loss of memory when acutely unwell. She was married for 20 years earlier in her life, and also worked when she was younger.

The voice hearing experience which June reported, appeared to be part of a wider paranoid delusional belief about her neighbours talking about her and plotting to harm her. When unwell she said that she could hear her neighbours talking about her. June couldn't give much detail about what this had felt like or what happened at these times, since she said she didn't remember and again was relying on what her son retrospectively had told her. Many times during the interview when asked specifically about her experiences of hearing the voices, June would respond to say that she now knows they aren't real and that it is part of an 'illness'. Her responses at these times seemed to echo the narratives of her son and her doctors, and I wondered if this had affected the development of a narrative about her own subjective experience and feelings about the voices.

June spoke more widely about the 'illness' in which her voice hearing experience and beliefs about the neighbours was embedded, and then more specifically about being hospitalised and her current recovery process. I wondered if this focus was a reflection of the current conversations that she was used to having with mental health professionals. For example, her recollections reflected views mostly from a place of wellness, where she assured me the voices weren't real and how she was coping well. This may have affected her capacity or willingness to think more about the difficult times, perhaps in order to maintain her current state of wellness, and assure those around her of this. Her focus on her recent hospitalisation, could also have reflected

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poor memory of early experiences and the increased relevance of recent experiences, particularly as it seemed she was still trying to make sense of why she had become unwell so unexpectedly after a stable period in her life.

At the time of the interview, June presented as well dressed, softly spoken and apprehensive. Her account seemed to stay at a surface level with little reflection on her emotions or thoughts about the experience, which I felt might partly reflect a protective defensive function of her current stage of recovery, but could also be a function of the depth of rapport with me meeting her for the first time, as a researcher. I found it hard to get an impression of any real felt emotion about her experience. I wondered if deeper exploration might only emerge in the context of a strong therapeutic relationship.

Tony

Tony was a 68 year old gentleman who had heard a male voice since age 13 when he was being bullied at school. Tony said the voice made him strong and encouraged him to fight back, however he said that this was against his intentions and character. The voice went away, but returned temporarily when Tony got married at age 20. The voice came back again when he was 25 and had been present in his life ever since. Tony also heard the voice of his mother since her death when he was age 38. He found his mother's voice supportive, calming, and counteractive to the negative male voice. Up until age 50, Tony kept the voice hearing experience to himself as he was frightened of being locked up due to the stigma surrounding mental health at that time. Tony worried that he had schizophrenia, having read this in leaflets and known of an uncle with it. Tony worked in a hospital maintenance team for a number of years, which he enjoyed, but found difficult to manage alongside hearing voices, and he had what he described as a 'breakdown' at work. This was the first time Tony began to tell people about his voice hearing experience and he was taken into hospital on four occasions during his 50s and 60s. Some of these admissions coincided with the deaths of close family and friends. Tony's current diagnosis was Post Traumatic Stress Syndrome, which he links to these deaths.

Tony's experience of hearing voices appeared to have been one of great difficulty, which he struggled with over the years. He seemed to have battled and fought to gain control over the voices' intentions to make him do destructive things to himself and others. Tony did this through an internal dialogue with the voice, which appeared to have brought about a deepening relationship with the voice over time, which allowed him to cope better with the voice. However, at times Tony became overwhelmed and felt desperate for the external containment and support of hospital and staff, which later in life he was able to ask for. His experience, on the whole, seemed to be one that transitioned from him feeling isolated and fearful, to feeling more included and understood since sharing his experience with others over the last 18 years. These changes seemed to have come from learning to cope with the voice, as well as perhaps changing societal attitudes and mental health services that have allowed him to share his experiences with less fear, and gain a true sense of support and understanding.

I found Tony to be reflective and insightful, and he told his story coherently and with evident emotion. He heard the voices during the interview and asked to take small breaks, where he conversed with his mother's voice and followed her instructions to take deep breaths. Tony appeared troubled and ashamed when he recounted how the voice had told him to kill people; he did not understand why, and he had to fight back to say no. I was moved by his resilience and self-efficacy to have managed this for so many years, at times without any support or awareness from others, when clearly he struggled.

Frances

Frances was a 75 year old lady who reported having heard voices since her late thirties. She said she had a diagnosis of schizophrenia, although was confused about the timeframe of when this was given, ranging from two weeks ago, to 14 years ago. Her voice hearing experience seemed to have varied over the years, with her most recent experience being of two unknown voices, and her early experiences being related to her neighbour. The content of what Frances heard was sometimes derogatory and persecutory, and at other times benign. Her response to the voices seemed to have been one of ignoring and blocking-off from them, and as a result they have generally 'not

bothered' her. Frances also reported experiences that related to at least one psychiatric admission.

Frances lived in a nursing home at the time of the interview, where she had lived for about 5 years. She was born and lived in Glasgow for a significant period, however it was difficult to ascertain when she moved to England. She worked as a cleaner earlier in her life, and had a son and daughter from a marriage that has now ended.

A main focus for Frances was on her neighbour, by whom Frances felt targeted and persecuted. It was difficult to tell whether Frances's stories about her neighbour were based wholly in 'reality', or if they may have been delusional with an auditory hallucinatory element. There were aspects which could be argued as fitting the DSM-IV-TR definition of a delusion, and at one point in the interview Frances referred to her neighbour as being an early voice hearing experience. However, Frances's interview account of her early experiences were generally contradictory and confused; in places she said that she first heard voices in her thirties, at other times saying she never heard voices before her current experiences.

Frances's account was difficult to follow in the interview, as she would appear to change the subject soon after starting to answer some of the questions. There were also a number of contradictions throughout the interview, and there seemed to be limited depth in many of her responses. I wondered if Frances also found it difficult to understand and make sense of her voice hearing experience. Perhaps her ability to recollect her experiences, and her confusion in her sense of time, had been influenced by the effects of medication and ageing on her memory. It could also be that employing a strategy of blocking-off the experience would then make any depth in dialogue about it during interview understandably limited. I also wondered whether she had a coherent understanding of her experience, but that I struggled to understand her communication of it. Upon reflection, I also think that my confusion may have impacted upon my ability to explore and deepen her account at the time of the interview.

Timeline of Theories and Models in Relation to Participants' Experiences

The following section is presented in order to set the context of participants' experiences alongside the developing and changing models of psychosis and hearing voices over the years. Table 5 illustrates an approximate timeline of the introduction of the different service developments over the previous century, as outlined in the introduction, alongside participants' reported timelines of their lives. From this, the possible impact of the different theories and models of psychosis on participants' experience of hearing voices can be considered. Particular elements which emerged in participants' accounts included their changing conceptualision of the experience, the legacy of stigma and the changing approaches to care.

Alice's conceptualisation of "hearing voices" only since 1990, despite confirmation from recruiting staff that she has heard voices from an early onset, led me to wonder what impact service understandings, and the language used, may have had on her understanding of the experience over time. Similarly this could have been the case for Frances and June.

Tony's experience of heavy sedation from antipsychotics and a lack of 'talking therapies' 18 years ago, compared to his more recent experiences of professionals and other service users who talk with him about his voices, was a particularly evident shift in his account. The stigma experienced by most participants, but particularly by Tony who kept his voices a secret for over 25 years, made me wonder how the legacy of stigmatising models of hearing voices may have impacted on participants' experiences. I wondered how different Tony's experience might have been if he had been around more accepting and helpful narratives, similar to the ones he values today, and whether he still would have endured such a chronic and difficult course of psychosis.

Table 5. Timeline of participants' lives and the introductions of the various theory / service developments

Theories and Treatments	Year	Alice	Albert	June	Tony	Frances
	2013	More efficacious coping	Feelings of hopelessness	Engaging in social activities to cope / Difficult 12 month hospital admission / Diagnosis of 'psychosis depression'	Wanting to share his experience of voices / Attending centre with other voice hearers / Dialogue with the voices	Hears two unknown voices saying names of relatives – not bothered / Given diagnosis of schizophrenia? / Moved to nursing home to get away from neighbour
Increasing qualitative research into subjective experiences psychosis and its symptoms / Recovery model / NICE guidelines recommend CBT and antipsychotics for schizophrenia	2010	Periodic admissions to hospital – voice relentless and surreptitious in her life			Periodic admissions	Admission to hospital / Given diagnosis of schizophrenia?
Research into trauma theories / Rise of CBT for psychosis / Final asylum closures / 'Atypical' antipsychotics introduced	2000		Admitted to hospital "It all came back" / Medication and diagnosis changed	Long period of wellness / Periodic hospital admissions, but no memory of these	PTSD diagnosis / Family deaths / Admissions to hospital, sedated on medication / 'Breakdown' at work / Told a doctor about hearing voices	
Rise of the symptom approach / Questioning validity of diagnosis label / Hearing Voices Network began	1990	Schizophrenia diagnosis / 1st admission to hospital	Stable on regular depot medication	Divorced		At some point in her life she moved to England, and was again employed as a cleaner. She was unable to specify when, and referred to hearing her neighbour both in Glasgow and in England.
Stress vulnerability model / Expressed emotion theories	1980	"[the voice] Comes and goes, comes and goes"	Admissions? / Search for religious cures	Periodic hospital admissions, but no memory of these	Mother died. Since this heard his mothers' calming voice / Enjoyed working in a hospital	Began hearing voices - her neighbour?
	1970	Settled in idyllic life until the voice came and hypnotised her, which made her ill	Started hearing spirits	Worked / Had four children / Started hearing voices / Married	Fear of stigma / Voices returned and stayed. Became a very negative experience / Had children in his 20s / Voices briefly returned / Married / Voices went away / First heard voices – they gave him strength to fight back to bullies	
Antipsychiatry movement / Plans for asylum closures / Rise of family and social theories e.g. 'schizophrenogenic mother' / 'Typical' antipsychotics introduced	1960	First saw psychiatrist / First met the man who is her voice	Worked in coal mines / Married / ECT and hospital for depression / Bullied at age 16			Married and had a son and daughter in her earlier life. This marriage ended but unknown as to when / Worked as a cleaner
Legacy and continuation of asylum care	1950			June born	Tony born	
WWII holocaust / Legacy of earlier ideas e.g. genetics, brain chemistry, psychodynamic	1940	Mother died (Alice blames the man who is her voice) / Alice born	Albert born			Frances born (Glasgow)

Nb. Use of blue and black text is to aid clarity of reading separate points

Group Analysis Results

A group analysis was conducted to explore participants' experiences of hearing voices over their lifespan. The results of the group analysis comprised four master themes and eleven superordinate themes, which are shown in Figure 5, and the frequencies with the eleven superordinate themes, in terms of which participants evidenced each theme are shown in Table 6. Each theme will be described in more detail following these figures, with illustrative quotes from participants. Summary tables for those themes with multiple detailed elements, along with extra quotes, are provided in Appendix L. The following symbols have been used in the quotations:

…   indicates the omission of text

[ ]   indicates text which has been inserted or replaced (for understanding or

          confidentiality)
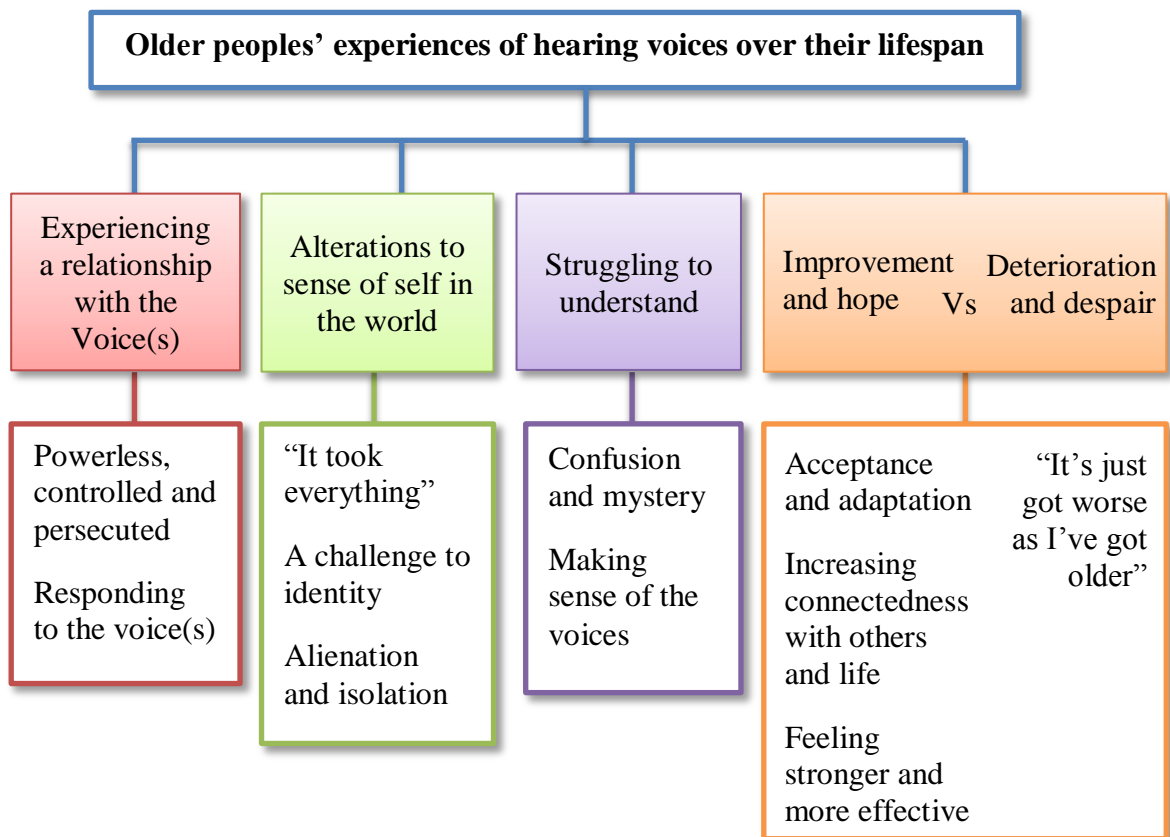
Figure 5. Thematic map of the group analysis

Table 6. Frequency of themes evidenced by participants

Master Theme	Superordinate Theme	Alice	Albert	June	Tony	Frances
Experiencing a Relationship with the Voice(s)	Powerless, Controlled and Persecuted	✓	✓	✓	✓	✓
	Responding to the Voice(s)	✓	✓	✓	✓	✓
Alterations to Sense of Self in the World	"It took everything"	✗	✓	✓	✓	✗
	A Challenge to Identity	✓	✓	✓	✓	✓
	Alienation and Isolation	✓	✓	✓	✓	✓
Struggling to Understand	Confusion and Mystery	✓	✓	✓	✓	✓
	Making Sense of the Voices	✓	✓	✓	✓	✓
Improvement and Hope	Acceptance and Adaptation	✓	✗	✓	✗	✓
Vs	Increasing Connectedness with Others and Life	✓	✗	✓	✓	✓
	Feeling Stronger and More Effective	✓	✗	✓	✓	✓
Deterioration and Despair	"It's just got worse as I've got older"	✓	✓	✓	✓	✓

Experiencing a Relationship with the Voice(s)

This master theme conceptualises the experience of having a relationship with voices, and encompasses the two superordinate themes which comprise the perception of the power and control of the voice, and participants' emotional and behavioural responses to the voices, including fear, anger, blocking-off and engaging with the voices. Some participants had mixed responses that were a function of a transition over time.

Powerless, Controlled and Persecuted

All five participants perceived some of their voices to have predominantly negative characteristics that transmitted a sense of power, control and persecution. One such characteristic was the voice's malicious intent to cause harm to the hearer. Frances said: *"The voices told me to… tie a rope around my neck and go to the river and jump in and drown myself"*. For Tony, some of his voices made commands to cause harm not only to himself, but to others: *"The voices were telling me to kill my wife"*.

The controlling nature of the voices was also evident in most participants' accounts. At times participants spoke of being put in a position of unawareness, powerlessness and vulnerability by the controlling powerful force of their voices. For example, Alice believed the voice hypnotised her which allowed him to control and ultimately harm her: *"He winked at me with dark glasses on, and I was like passed out, and I had a slight stroke"*.

Furthermore, the voices were often described as interfering, relentless and intrusive, instilling a sense of hopelessness. For some, the voices were thought to have been making attempts to sabotage the participants' lives, particularly with relationships and work: *"Everything was happy. Just got a new house, new relationship, everything, it were lovely... Then I were ill, he came up and hypnotised me" (Alice)*.

The power of Albert and Alice's voices came from the voices' higher status. Albert believed his voices could have been God or the Devil, and Alice identified her voice as a doctor, who would therefore have had a higher and more powerful social

status when comparing to Alice's role as a 'patient', as well as Alice's access to education and other social resources. She also stated that the man whose voice she heard, had looked down on her family in the past: *"He knew my mother when she were young, didn't think she were good enough cos she worked in the mill"*.

For one participant, the power of the voice was explicitly likened to power differentials in a prior 'real' relationship with a teacher: *"I used to put my hand up in class and he used to go 'put it down!'. I were right at the back of the class where the dunces used to sit… I used to shout out 'I'm not an effing dunce!' I knew what were coming then, slipper or belt. Anyway I used to get belted by him regular. But I suffer from dyslexia"* (Tony). Similarly, other participants had experienced bullying or persecution earlier in their lives, and made reference to their voices calling them derogatory names, but did not make an explicit link themselves.

Contrary to this theme, for two participants, there were also neutral and positive experiences of hearing voices. For example, Tony spoke of hearing a positive voice; that of his mother, who had died earlier in his life: *"She were calming and relaxed and she'd say 'he's not worth it. He's a piece of shit'. So I used to say right, I'll take notice of what my mum says. Cos it was my mum's voice I could hear. I still hear her today trying to calm me down when he, when he gets on to me again"*. This positive familiar parental voice may represent a coping strategy to ameliorate the power and control of the negative voice. It may also reconnect Tony to the comfort and support of a positive past relationship that was lost through death, but has endured in this other important way.

Responding to the Voice(s)

Participants responded to their voices in a variety of ways, including a range of emotional reactions from fear, through worry, shame and anger, to neutrality. The following is a quote illustrating June's worry about her voices: *"It was, 'oh heck I hope it doesn't start again', you know worrying about it… And then I'd think 'oh no' and then I'd sit down and think 'oh if I hear voi- anything, oh no its starting again'"*, and Tony illustrates the strength of the emotional impact in the following quote: *"I felt as*

though I was scum of the earth", "I just wanted the earth to swallow me up and let me go that way".

Frances and June appeared to have a neutral or absent emotional response to their voices, which could perhaps be related to a blocking-off coping response, or a result of an under-developed emotional narrative about their experience. The next quote is one of a number of examples where June appeared to dismiss any feeling she had: *"Researcher: "How did they make you feel, those voices and what they said?" June: "Well I know that they're not real. And you know, things. I can carry on".*

Another element to the theme of responding to the voices, related to participants' behavioural responses. Some participants blocked off from the voices, whereas others engaged with them. Blocking-off and distancing appeared to be Alice's, June's, and Frances's predominant response to their voices: *"I don't pass the time of day with him. I'm not delving into his life. I don't want to know... I don't want to know anything about him".* Despite blocking-off being their predominant response, these three participants also spoke of times they engaged with the voices, for example: *"Researcher: 'So you did talk back to them previously?' Frances: 'Oh aye. Because it got out of hand, it was just getting annoying... but I don't bother now, I just go to sleep'".*

Tony and Albert were the participants who most engaged with their voices. This appeared to have led to a relationship for Tony, but a destructive negative experience for Albert. Tony was able to battle, negotiate and even trick his voices: *"I'll promise him owt, just to leave me alone... But I don't do it with him... I tell fibs".* The relationship with his voice was something that developed over time, which proved beneficial in being able to manage them: *"Researcher: "Why do you think they listen to you?" Tony: "Cos I got to know them".* When Albert first heard the spirits, his response was to comply with them, since he thought the experience was going to be positive. However, later in his life he turned against the spirits as the experience became destructive: *"I took it to heart, because it didn't come true. It said that when I prayed this prayer, it would be the last time in hospital".*

Wider social relational frameworks could have been utilised by participants to help conceptualise and respond to their voices. Most participants personified their voices, and in this way responded to them as a whole person, in ways that had qualities of social relationships in the wider world generally.

Alterations to Sense of Self in the World

This cluster of themes represented participants' experience of an alteration to their sense of the self in the world as a result of hearing voices. Participants felt a sense of loss and emptiness, as their voices negatively challenged and altered their identity, character and valued roles. Participants felt disconnected from the world; stigmatised and disbelieved by others who invalidated the realness of their voices, leading them to feel alone and isolated in their experience.

"It took everything"

This theme related to the all-encompassing loss that participants had experienced due to their voices, in terms of the desolation, emptiness and stagnation of life. This was explicitly talked about by three participants. Albert was 29 when the voices started: *"I'm 72 now. I've been sat in this chair looking out of that window for 43 years"*. Similarly, Tony said of the consequences of taking medication for his voices: *"I didn't have a life at all. I just used to sit here, stare at the television"*. June also stated *"It just felt as though, you know as it were black, there were nothing here"*.

This small but important theme sets the scene for the following superordinate themes, relating to the challenges to participants' identities, and the alienation and isolation that the experience of hearing voices brought about.

A Challenge to Identity

This theme encapsulates how the experience of hearing voices challenged participants' identities and roles in life. Participants described how the voices transformed and altered their character and sense of self. For example, Albert

commented that: *"I used to be jolly and laughing and all that with them, I were liked. Aye. But I'm not the same man now"*.

For Albert, Tony and Alice, the voices presented a challenge to their working role. Albert had to give up his job working in the pit when his voices began at age 29, and Tony and Alice spoke of how their voices tried to sabotage their jobs: *"I were a right good nurse, and I couldn't get a job. He stopped me. Cos he didn't want me nursing, he didn't want me to have a career or a nice life"*.

Furthermore, participants' roles as parents were challenged by their voice hearing experiences, leading to feelings of guilt. Tony said: *"I was so nasty and I was getting so irritable. I wasn't a very nice man to live with. My wife would say, 'what's up with you? What are you so nasty with kids for? I'm saying 'I'm not nasty with kids. I love kids to bits'. I just wanted the earth to swallow me up"*. Conversely, the following quote from Frances's interview suggested that her parental and working roles were not challenged or altered by the voices, but rather her parental and work responsibilities took over the significance of voice hearing experience instead: *"I never noticed it so much because I was too busy working and earning a living to keep my children"*.

Both male participants spoke of a challenge to, and loss of, masculinity that the voices brought about. They both spoke of how the voices altered their identity and role in their marital relationships; for example Tony spoke about the internal conflict that the voices caused regarding his relationship with his wife: *"[speaking as the voice:] 'Why don't you end your wife! Get rid of your wife!' [speaking as himself:] 'But I don't want to get rid of her! I wouldn't be here now if it weren't for her'"*. The experience of hearing voices also brought about a loss of both Albert's and Tony's sexual relationships with their wives: *"After that proverb, I haven't made love to my wife for 43 years, since I was 29" (Albert)*. Albert's voices perhaps also mirrored insecurities he may have had about his sexual relationship with his wife: *"they [the voices/spirits] call me puff and allsorts"*.

Finally, encompassed by this theme was the challenge and alteration to Albert's religious beliefs. Prior to, and at the beginning of his voice hearing experiences, Albert

invested considerable hope in religion. As the experience progressed, he began to feel let down by the spirits he heard and the cures he sought, and turned against religion: *"I went to church and came out worse than I went in"*, *"I won't watch it on television, not songs of praise or nothing"*.

Alienation and Isolation

This superordinate theme captures participants' sense that they felt alien in the world, that they were different to others through their experience of hearing voices, and also different to their former selves (as shown in the previous superordinate theme). June spoke of her general sense of not belonging and disconnectedness: *"It were awful because, even though I'd a loving family you know, it was as though I didn't belong there"*, and Tony spoke of the alienating impact of the effects of medication for the voices: *"I used to have that many tablets I didn't know what, if I was on fullers earth or my own. You know just spaced out"*.

While voices were conceptualised as real, participants often commented on their sense that others perceived their experiences as not real, not visible and not believable, leaving participants perhaps feeling invalidated and alone in the experience: *"To me, it feels real… well it seems real to me, but it isn't to them [her children]… I always try to explain that to me it was real, but then I get told 'It's all in your mind'"* (June). Both Tony and Frances made comparisons between the hearing voices and a broken leg, to illustrate the invisibility of their experience to others. Phrases that participants often used during the interviews suggested that they perceived their experiences of the voices to not be believed by others, such as: *"You might find it unbelievable but…"* (Alice).

As a result of this conceptualision of their experiences by others as not real and unbelievable, there was a strong sense in the data that participants felt stigmatised, alone, isolated, and hopeless to being helped by others: *"I couldn't tell anybody about it, cos I thought they'd think I were going loopy. I were frightened I'd get locked up, you know. I kept it to myself, I struggled for about 20 year with it, till I were about 50, not telling anyone about it"* (Tony). When talking about the stigma of hearing voices, June spoke of her wish to not be treated differently: *"You want to be treated like other*

people, as though, you are just a neighbour… or you're a, you know, just want to be treated the same".

The loneliness and isolation that stemmed from their voice hearing experience was also evident in the loss of relationships that Alice, Albert and Frances described: *"I've lost friends through it, I haven't a friend now"* (Frances). June appeared to isolate herself as a coping strategy to avoid stigma or becoming paranoid, whereas Alice's loss of relationships stemmed from the direct sabotage of her voice: *"Yeh [he / the voice] ruined them. Two or three. Two were marriages. He were noseying... He were saying stuff to them"* (Alice).

Tony gave the greatest sense that the alienation, isolation and invisibility of the experience, led to a hopelessness about being helped by others. There was also a sense that what Tony would have valued most was to talk about and share his experiences, but this was not how nurses responded to him in the past: *"I used to say 'Will you just talk to me!?', they couldn't be bothered, just couldn't be bothered. 'Just go on, we'll give you your tablet later on', that's what they used to say. 'I don't want a bleedin' tablet… Talk to me please!'"*

Struggling to Understand

This cluster of themes relates to participants' attempts and difficulties to understand and create meaning out of their experiences of hearing voices. These struggles were characterised by not only finding varied frameworks to conceptualise some of their voice hearing experiences, but also with confusion around what they perceived to be unexplainable and mysterious elements of the experience.

Confusion and Mystery

All participants spoke about some elements of the voice hearing experience being unexplainable, both to others and also to themselves, having noted a number of unknowns and uncertainties about the experience. For some participants it seemed as though they were still seeking to make sense of the unexplainable elements of their voice hearing experience.

Regarding the emotional impact of the confusion, Tony spoke of the distress and struggles of not understanding the wishes of his voice which conflicted so strongly with his own: *"Tony: 'It's been telling me… to kill my wife. She's done nought wrong, so why should I kill her?' Researcher: 'Why do you think he says that?' Tony: 'I don't know, honest to God I don't know. Cos she's done nought to me. She hasn't hurt me in any way'"*.

For a number of participants, the course of the experience of hearing voices appeared to be unpredictable which participants found difficult to understand. June said: *"I couldn't understand why I'd gone so long. We'd moved [house] and then had a year of in and out [of hospital]. When I'd not done before, I've been in, and been out a few years. And nothing's happened you know"*.

Memory decline could have been integral to participants' confusion and un-explainability, particularly regarding the onset of the voices: *"Oh I can't remember, its going back a long time"* (Frances). Difficulties with memory were also evident in many participants' interviews, illustrated by the vagueness with which participants talked about onset: *"It just happened. Yeh but it wore off"* (Alice). Tony and Albert were exceptions to the fading memory of onset, instead having a much more detailed narrative. However, there were still elements of the onset that were unexplainable to them at the time: *"I didn't know what were happening. I just knew this voice were coming into my head, but I didn't know where it were from"* (Tony).

June described periods of memory loss which occurred whilst she was acutely unwell. Her recollections of these times were therefore limited and relied on what others had told her retrospectively: *"I can't really tell you much… sometimes I don't even remember being in, and family's told me you know that 'well you spent so and so in hospital'"*. This may have made the acute phases of hearing voices difficult for June to understand and make sense of.

Making Sense of the Voices

Despite the confusion noted above, participants did have some frameworks that they used to understand their voice hearing experience. Some participants used more than one framework, and all but one participant (Alice) made reference to the use of the medical model, often using the diagnostic label of 'schizophrenia', to explain their experiences.

For most participants, their medical conceptualisation appeared to be a result of the medical response and treatment from professionals. This seemed particularly evident in June's account: *"Like I say they [neighbours / voices] were talking about me and they were going to hurt me, but then I realised and I got told, you know, 'that's part of your illness'".* It was unclear if the medical conceptualisation was helpful for June, but considering her limited emotional narrative about the experience of hearing voices, it could be possible the medical framework had invalidated such a narrative. Conversely, having an externalised medical explanation may have served to reduce her distress.

In contrast to June whose meaning-making was guided by others, Tony kept his voice hearing experience to himself and had to try to make sense of this alone: *"Life's… got little passageways off it that you've got to go down and make sense of. That's what I've been doing all my life".* Tony came to use a combination of medical and genetic frameworks. The consequences of a genetic framework, however, brought about feelings of guilt and worry for Tony: *"I hope to God they never have to go through what I've gone through. That's what I was frightened of… Kids getting it off me, getting gene off me".* Tony was the only participant who explicitly referred to a trauma framework to understand why he might hear voices, but this only became available to him once in mental health services.

Albert was the only participant who used a spiritual / religious framework, as he believed the voices he was hearing were spirits. This conceptualisation appeared to be influenced by his prior affiliation with religion: *"Researcher: 'Did you understand what was happening at the time when you were getting these messages from the spirits?' Albert: 'Yes I understood what it all meant. I mean I went to school, that were my topic*

were the holy bible'". Albert's religious conceptualisation of the experience then guided his attempts at 'curing' it, with faith healers, exorcisms, and church confessions.

The experience of hearing voices was inextricably embedded in a wider delusional framework work for Frances and Alice, and it was this wider framework that was used to make sense of the voices. Frances was guided by her persecutory delusion about her neighbour: *"It was her [the neighbour] that got me them in the first place, to hear voices… She used an electric machine".* Similarly, Alice came up with a number of explanations for her voice hearing experience, that were embedded in the wider delusion about the voice's interest in her and her family: *"[My mother] had this little girl, and he [the voice] killed her, he killed this little baby… I got it into my head a bit back, that he thought I were that baby reborn".*

In summary, despite having some frameworks for understanding, making sense of the voices still appeared to be a struggle; some participants utilised more than one framework (e.g. Albert), some of which had potentially negative impacts (e.g. guilt for Tony) . Furthermore, for Albert, there was a transition from being let down by his religious framework and feeling regret at not taking up the medical framework sooner: *"I should have left it to the doctor, I'd have been better off, because they know best".*

Improvement and Hope Vs. Deterioration and Despair

This cluster of themes captures a conflict between participants' improvement and deterioration over time. In the stage of older adulthood, some participants evidenced an acceptance of their voice hearing experiences, became more able to share their experiences and engage in life, and displayed a development of an inner strength and internal locus of control for managing the voices more effectively. However, despite these improvements, participants also spoke about how their voice hearing experiences currently in older adulthood, were the worst they had ever been.

Acceptance and Adaptation

This theme relates to participants at a later stage of life, having heard voices for a considerable number of years over their lifespan, and coming to an acceptance of their voice hearing experience. This was evident for Alice, June and Frances.

Alice spoke of her transition from finding the experience difficult when she was younger, to an acceptance or adaptation over the years which has led to an improved state now in older age: *"Well I've got used to it. Just over the years. He hurt me that much when I were younger. But I'm a bit older now… I'm a lot better now".*

June spoke of an acceptance of the past and a focus on the future: *"I mean even now I don't think about them, it's just something that's happened, and it's like everything else, you put it behind you. You know I think of, say like tomorrow or Saturday".*

Frances explicitly noted the importance of acceptance, however this had the quality of being a forced acceptance in the absence of any other way of managing the experience: *"It's just an illness and it's happened and I must accept it", "When they [the voices] come I must accept them… There was nothing else I could do about them".*

The acceptance and adaptation to the voice hearing experience may relate to the following themes of reconnecting with the world and feeling stronger and more effective.

Increasing Connectedness with Others and Life

It seemed that after some of participants' earlier years of the voice hearing experience being characterised by alienation and isolation, their experiences became more sharable and they appeared to reconnect with the social world in ways that were beneficial for them. This represents a considerable contrast to the earlier theme of isolation and alienation.

When talking about the past, Alice said: *"I kept it to myself. I used to cry and that"* and compared it to how she now seeks support from staff: *"I get it off my chest*

now to somebody". The process of engaging with staff and being supported by them had important benefits for Alice, gaining new understandings about her voice hearing experiences: *"I didn't know that, until I met the doctor, and he made me see a bit of sense"*.

Earlier in Tony's hospital experiences, he spoke of staff not talking with him about his voices. However, recollecting his more recent hospitalisation, he spoke of talking more with nurses and how helpful this was for him: *"It's a place you can talk to a nurse anytime you want. And they understand you. They understand where you're coming from"* and he compared it to his past hospitalisations: *"I feel staff on that ward can understand you, whereas when I was in [previous old hospital] they just didn't want to know"*. It is largely unclear from the data if this transition to increasing connectedness with staff represents a function of changes in mental health services and staff approach, changes in participants' readiness to share, or a combination of both.

The benefits of increasing connectedness with other people who also heard voices, was evident in participant accounts. In the following quote, Tony is speaking about a day centre he attended, which seemed to offer him vicarious hope and an opportunity to learn about other people's coping strategies: *"Some of them have been through the same as me. And they've come through it… There's one lass up there, she says 'I hear voices Tony, when they come, I just go to bed and cover my head up and they go away'. I says I wish I could do that. And we have a conversation down that line"*. A sense of normalisation of the experience through recognising others also shared the experience was also evident, not only for Tony but Alice and Frances.

June and Tony both spoke of reconnecting with life generally. Tony spoke of how despite the voices, he was going to fulfil a life-long dream this year by visiting Rome, and Alice mentioned reconnecting with a past relationship that her voice had previously tried to ruin, but was now going well. June spoke of engaging more in social activities and going to church: *"If you do art and craft or knitting or whatever you want to do, and like Wednesday we have like a service and everything. You know, like hymns and things, but that helps a lot"*, *"Now instead of being in the house all the time, I go out"*.

Albert was the only participant whose voice hearing experience shifted away from an initial hope and positivity about the experience, and towards a sense of despair and hopelessness. The same shift occurred in relation to his connectedness with, and trust in, professionals. Albert began with seeking out cures from various professionals but then felt increasingly let down: *"She took me off all my tablets did psychiatrist, and I was in a hell of a state".*

Feeling Stronger and More Effective

This theme relates to participants feeling a greater sense of strength and self-agency in being able to stand up to the voices and cope with them. The theme illustrates the discovery and use of an internal locus of control, enabling participants to cope more effectively by taking back some of the power and control that the voices had over them.

For some this was about finding their own inner voice, and using it to challenge and be active, by arguing back to the voice, disagreeing with, or ridiculing it: *"The voices told me to go jump in the river and drown myself... I thought 'I'm not dying for the likes of yous'"* (Frances). For June, her inner voice appeared to take the form of positive self-talk directed at herself rather than at the voices: *"Well I'm better, it's going to stay that way".*

Participants spoke about having learnt how to cope more effectively. Tony illustrated that it has been a long process of learning to be effective over a number of years: *"I used to say 'Go away and leave me alone. I don't want to be bothered with you now. Come back later'. That's a skill that I've learnt over the years"* (Tony). Both he and June also showed that it took the development of an inner strength to become effective: *"It's having my own courage to do it, stand up and say 'enough is enough, leave me be' and it seems to be working"* (Tony).

June's account indicated that her life-stage and demands, particularly around parenting, may have had an impact on her ability to cope: *"Everything's changed because I've got four children. They're all grown up and I've got grandchildren, and things have altered over the years so it's not too bad. I can cope with it... I try to plan*

things… look forward to something whereas before I didn't. Everything had to be done in one day".

Linked to this theme of feeling stronger and more effective, seemed to be an increased understanding and awareness. From this position of greater knowledge, participants were perhaps empowered to cope more effectively: *"He [the voice] hasn't ruined this [relationship]… he tried it, telling him lies about me… [but] I've got too much sense this time. I didn't know what were going on [before], telling lies"* (Alice).

"It's just got worse as I've got older"

Despite the improvement in the voice hearing experience evidenced by participants' acceptance, increasing connectedness with life, and internal strength to take back control over the voices, there were also notable indications of deterioration and despair about the voice hearing experience in older adulthood. A number of participants spoke about how their most recent episodes of voice hearing had been their worst, particularly in terms of the intensity: *"It's just got worse as I've got older, I get them every night and day. I'm getting them when I talk to you"* (Frances).

Now at a life-stage of older adulthood, thoughts about the meaning of death in relation to the voice hearing experiences were evident for some participants. Tony spoke about welcoming death as an end to the voices: *"Soon I won't be able to breathe at all… Then my life's over. I think I'll be glad when it's all over, I will… I'd be happy as a pig in muck if he left me alone but he won't… He will when I'm dead. That's about the only time he'd leave me alone".* Albert also alluded to an anxiety about not knowing how things might end up, which could perhaps be linked to concerns about death and the conceptualisation of his voices being spirits in the afterlife. Alice worried about the potential that even death may not be the end of the relentless experience of hearing voices: *"He wants me to die, to dig me up".*

Finally, what was evident for Albert was a sense of regret and self-blame as he looked back over his life, noting how his experience of hearing voices came about and how he managed it: *"It's my own fault. I invited them [spirits] into my own house. Yes*

it's my fault", "I tried everything. But I shouldn't have done, I should have left it to the doctor. I'd have been better off. They know best".

Reflexivity

During the data collection and analysis period, I kept a reflective journal of my thoughts about the experience of the interviews and analysis of the data. Some of these reflections were present in the pen portraits, however I would like to share more of my reflective journal in the following section. I hope this will provide transparency in how any biases may have influenced my final themes, to ensure the quality of my analysis.

After the first two interviews I started to reflect on the emergence of an acute anxiety about getting my full sample of participants, since recruitment was proving difficult. This anxiety increased further as the months went on, and I think a fundamental negativity and hopelessness set in, and during each precious interview that I had managed to recruit, I wondered if this negativity was hindering the interview process as well as the on-going data analysis. However, after talking this through with my supervisors, tolerating the anxiety, and persevering to do justice to my participants' stories, I rediscovered my enthusiasm, clarity and positivity, particularly when cohesive themes began to emerge in the group analysis.

Part of the process of regaining this clarity and positivity, was about deepening my understanding of what I was struggling with and why. For example, at times I struggled with my hopelessness that some participants weren't talking about their voices specifically. However, I reflected on how this might have been due to my narrow conceptualisation of what hearing voices means, and my lack of realisation that for those who experience this phenomenon first hand, it may be too difficult to separate it from the wider experiences it is embedded in (e.g., delusions, illness, and hospitalisations). Similarly, the difficulty in some interviews, of eliciting a detailed narrative about emotional reactions or what happened at onset, was initially frustrating, but on deeper reflection told me a great detail about participants' experiences.

Through the analysis process I also found I had to reflect a lot on the meaning of the language and concepts that I was using. For example, using terms such as 'reality'

and 'not in this world', and defining elements of a participant's account as 'delusional', didn't feel comfortable. I struggled with these terms since they felt biased and judgemental coming from my perception of the world as a non-voice hearer. I used DSM-IV-TR definitions, and sought staff members' assurances about participant histories, to define delusional elements of participant's accounts. However, I was still uncomfortable with these concepts, particularly when engaging with the themes about participants not feeling they were believed by others and feeling isolated and invalidated as a result. Yet at the same time, the use of some of these concepts to describe my interpretations of the data felt necessary. I found myself continually returning to the data to ground myself in what participants were describing, remembering my role as interpreter, which inevitably was inseparable from my stance as a non-voice hearer who is also member of staff in mental health services.

A final reflection is on recognising I had a bias to find positivity and improvement in the voice hearing experience over time. At first, my final theme of 'improvement and hope' did not contain the 'versus deterioration and despair' element. With supervisory discussion and reiteration of engaging with the transcripts, the conflictual theme of 'deterioration and despair' of the worsening of the experience, emerged clearly. This was an important to process to have gone through, since it prompted me to readdress all my themes in this manner.

My propensity to want to gain clarity and coherence efficiently, was also challenged throughout the IPA process, and brought learning both about myself and about the experience of hearing voices; the first-hand experience of a phenomenon as complex as hearing voices is far from clear or coherent, and my need to find such clarity and coherence in people's experiences can be a hindrance to truly understanding them.

Chapter Four

DISCUSSION

The following chapter will summarise the main findings of the study, which was designed to answer the following research questions:

- How do older adults make sense of hearing voices – what is the essence of this experience as understood by older adults?
- How have older adults' experience and understanding of hearing voices changed over the lifespan?

I will firstly relate the findings to the wider literature, and then provide a critical evaluation of the study, and make recommendations for clinical practice and future research.

Synthesis of the Main Research Findings

The interpretative phenomenological analysis of the five semi-structured interviews, yielded four master themes and eleven superordinate themes, which will be discussed in turn below.

Experiencing a Relationship with the Voice

Overall, participants could be seen to have a rich relationship with their voices, evidenced by their perception and interaction with them. Participants generally experienced a negative relationship with their voices, often feeling powerless, controlled and persecuted by them. In turn they evidenced a variety of emotional and behavioural responses, from blocking-off from the voices, to engaging with them. For most participants their voices were personified, in some cases elaborated social identities, and in other cases possessing similar characteristics to previous relationships. For some participants, this relationship remained stable and for others it changed over time,

similar to findings of other qualitative studies regarding relationships with voices (e.g. Beavan, 2011).

Chadwick *et al.* (1996) showed that it was a person's beliefs about their voices that was the key factor in predicting distress. In the current study, participants' mostly negative perception of their voices (i.e. of being subjugating, persecuting, sabotaging, and controlling) may therefore have influenced their experience of fear and anger. Also consistent with this hypothesis, was Tony's positive experience of his mother's voice as calming and reassuring, and also Frances's perception of her neutral voices which did not cause her distress.

Furthermore, Chadwick *et al.* (1996) showed that a person's perception of their voice's identity, purpose, malevolence / benevolence, and power, can have consequential effects on the person's emotional and behavioural responses. The authors postulated that those who perceive their voices to be benevolent are more likely to submit to them, compared to malevolent voices which are more likely to be resisted. This appeared to fit for the participants in the current study who heard malevolent voices and tried to withstand their influence. These research findings also fit for Albert who initially submitted to the spirits he heard because he thought they were going to be a positive influence.

Participants' perception of their voices' power and omnipotence may have reflected participants' own social rank in relationships generally (Gilbert, 1989 (cited in Hayward *et al.,* 2011); Birchwood *et al.,* 2000). For example, Tony and Albert's voices were perceived as powerful and they both noted how they were bullied earlier in their lives. Similarly, Alice spoke about her family being perceived as working class and 'not good enough' and her voice was experienced as powerful and higher in social rank than herself. Social rank theory (Gilbert, 1989 (cited in Hayward *et al.,* 2011)) predicts that people will respond to a powerful voice by either defending or submitting. Participants in the current study utilised both responses at different times, depending on additional factors such as perceived consequences of their responses, and perceived benevolence or malevolence of the voices. For example, Tony submitted to the voice's power

initially when it was helping him against bullies, but defended when it threatened to harm those he loved.

Benjamin's (1989) social analysis of behaviour (SASB), predicts that people may respond to their voices with complementary reciprocity. This appeared to be the case for Tony, in that he mostly responded with hostility and battled against his hostile persecutory controlling voice. Similarly, Alice responded with hostility towards her persecutory voice, however this seemed to have developed over time. SASB theory postulates that submission is a less common response to a hostile voice, but becomes a more evident response as the duration of voice hearing increases. The findings of the current study contradict this however, with Tony and Albert instead showing increasing resistance to their hostile voices over time. This implies that in some contexts, submission may decrease over the duration of hearing voices, particularly if a person develops a stronger and more effective sense of control over the voices (see later in discussion).

Birchnell's (1996, 2002, cited in Hayward *et al.*, 2011) relating theory could help to understand why some participants (Frances, June and Alice) related to their voices from a position of distance. Relating theory suggests that in response to a powerful voice, voice-hearers may believe that the best response is to distance and block-off from the voice, possibly to show others that they can cope with their voice, but also as a habitual pattern of avoidant relating. Research suggests that this may be due to an avoidant attachment style developed in response to critical, rejecting or threatening others, evident in voice-hearers' lives generally (Berry *et al.*, 2012). Relating theory notes that active engagement increases voice-hearers' power and control (e.g. Jackson, Hayward and Cooke, 2011), which in view of Birchwood's research, would lessen distress. This appeared to be the case for Tony, and Alice later in her life.

It is worth noting that relating mostly from a position of distance and having a neutral emotional reaction to the voices at times, was a theme evidenced predominantly by the female participants. Conversely it was the male participants who engaged most with their voices. Much of the literature on gender differences in psychosis is quantitative research on symptomatology and age of onset (e.g. Eranti, MacCabe,

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Bundy, and Murray, 2013), rather than gender differences in coping over the course of psychosis, or for different cohorts. It may be that socio-political gendered beliefs and stereotypes of this cohort may have impacted on such differences, and may be worthy of further investigation.

As noted in chapter one, the medical view postulates that hearing voices is one symptom of the wider diagnosis of schizophrenia (APA, 2000). Other symptoms of schizophrenia include thought disorder, delusions, and 'negative' symptoms such as decreased emotional experience and withdrawal. The blocking responses to the voices could perhaps reflect elements of these negative symptoms of schizophrenia. They could also be an indication of a 'sealing over' coping style (McGlashan, 1987), with participants separating-off and disengaging from the experience as much as possible.

Alterations to Sense of Self in the World

The present study found that participants experienced an alteration to their sense of self in the world; feeling that the voice hearing experience resulted in an overall sense of loss, emptiness and stagnation. This was evident through the challenge that the voices presented to participants' identities, roles, and social connections, leading them to feel alienated and isolated in the world.

Bringing together the humanistic theory of development (Maslow, 1962), with the antipsychiatry and social constructionist perspectives of psychosis, it could be argued that society and cultural norms had supressed participants' inner drives to self-actualise and explore their human potentiality, which could include hearing voices as a 'normal' experience. Instead, the legacy of the stigmatising theories of schizophrenia that these older adults will have lived through, may have led to their feelings of alienation, isolation and negative alteration to their sense of self in the world. This cluster of themes highlights the lack of fulfilment of some of the basic humanistic needs of belongingness and self-esteem, caused by the isolation and alterations to identity resulting from the voice-hearing experience. Without fulfilment of these earlier stages, the humanistic model would suggest that further development may be blocked (Maslow, 1962).

According to Erikson (1959), there would have been earlier times in participants' lives where they were negotiating stages of 'identity versus confusion', 'intimacy versus isolation' and 'generativity versus stagnation'. Erikson postulated that without a coherent sense of identity, it can be difficult to achieve a sense of intimacy in the next stage, and ultimately the person can instead become isolated. The findings of the current study showed that the voice hearing experience significantly impacted upon participants' sense of self and identity, and later their feelings of isolation, which is consistent with Erikson's hypothesis. The impact of hearing voices may also have blocked participants from achieving generativity, instead resulting in stagnation. However, it seemed some participants were able to contribute to caring for the next generation, with three participants having brought up children, though two noted how this was difficult and overwhelming at times. This perhaps links to Hendry and Kloep's (2002) model of lifespan development, in terms of the mediating effect of a person's unique resource pool on their development. According to this model, the experience of hearing voices could be seen as a non-normative challenge that participants had to contend with. For some participants, this challenge may have led to the depletion of their resource pool at a time they were also contending with other demands of working and parenting. This could have resulted in a sense of stagnation and alteration to their valued identities in relation to their work, parental and marital roles. For other participants, the voice hearing experience could have influenced the non-occurrence of expected life-events, such as having children, which might have been the case for Albert and his wife. Participants' experiences of alienation and isolation could then have further depleted the resource pool, because they missed out on opportunities to replenish and develop it.

The experiences of loss, emptiness and isolation could also have reflected the negative symptomatology of schizophrenia, as well as comorbid depression that is often experienced by people with schizophrenia (e.g. Buckley, Miller, Lehrer, and Castle, 2009). Indeed the theme of alterations to sense of self in the world may help explain why depression is a common comorbid mental health problem in schizophrenia. This cluster of themes could also refer to a coping strategy; June indicated how she isolated herself and withdrew to avoid becoming paranoid about what people might be saying

about her. Similarly, at times when the voices were goading Tony to harm his wife, he noted how he would lock himself away in his room. Furthermore, this cluster of themes could reflect a 'sealing over' coping strategy (McGlashan, 1987), whereby participants viewed their voices as having had a negative impact upon their lives, and may have isolated themselves and withdrawn from engaging in talking about their experience. Thompson *et al.* (2003) noted how coping styles can alter over time, depending on the available support and resilience a person feels they have. As noted above, it could be that in the earlier stages of their voice hearing experiences, participants felt they had limited and depleting resource pools. As a result they may have perceived a hopelessness about being helped by others, particularly since they did not feel believed or understood, exacerbating their reliance on a sealing over coping style.

The stigmatisation and treatments that this cohort of participants experienced, may also have affected their sense of stagnation and alienation. The institutionalisation of the earlier 20th century impacted on Tony's fear of the stigma of being locked up if he shared his experiences. The antipsychotic revolution from the 1950s onwards, also led to feelings of sedation and alienation for Tony. It is possible that this might have been the case for other participants who took the earlier 'typical' antipsychotics and experienced feelings of stagnation, such as Albert and June. Similarly the treatment approaches of the time which did not prioritise talking about, or understanding, the content of voices (cf. Coffey and Hewitt, 2008), may have led to further feelings of hopelessness and isolation for participants such as Tony.

The findings of the current study are similar to those of Quin *et al.* (2009) who investigated older adults' experience of late-onset psychosis, and found themes of 'the heaviness of being alone', 'I'm not of this world', and 'I would get on with it myself'. They portrayed a similar picture of an isolating and alienating experience that was coped with alone. Since their study focussed on late onset psychosis, it could be that this cluster of themes relates closely to enduring cohort attitudes and beliefs, for example, of stigmatising stances towards hearing voices, and more generally of showing stoicism, and keeping difficulties private. It could also reflect a characteristic of the earlier phases of first hearing voices, since in the current study most participants transitioned from this

cluster of themes, towards a more hopeful and accepting stance later into their experiences (see below).

Struggling to Understand

The findings of the present study indicated that participants found it difficult to understand and make meaning out of their voice hearing experience. Some of their experiences were perceived as unexplainable and mysterious, whilst other elements were understood within a number of different explanatory frameworks. Overall, this cluster of themes shows that participants sought to make meaning out of their experiences, akin to the theme of "why me?" found by Quin *et al.* (2009). However, the present study adds to this finding by describing the nature of seeking meanings as being a difficult struggle.

The use of varied frameworks of understanding has been found in a number of other qualitative studies (e.g. Jones *et al.,* 2003; Knudson and Coyle, 2002; Beavan, 2011). Similar to the current findings, spiritual communication and possession, traumatic life experiences, genetics and medical diagnostic frameworks, were utilised by participants in the study by Jones *et al.* (2003). The medical framework was subscribed to by nearly all participants in the current study, which could reflect the dominance of this model for this cohort of participants. Interestingly, some literature suggests that this model can be disempowering, invalidating, and lead to an under-emphasis on exploration of personal meaning making (e.g. Hoffman, 2011). Coffey and Hewitt (2008) found in their sample that nursing staff training around 1986 had not advocated exploring the content of a person's voices, yet service user perspectives illustrated that this is what they would have valued most. This was evident in Tony's experience of staff when he was hospitalised in the 1990s; not being able to share and be understood, increased his feelings of isolation and alienation, and perhaps limited his sense making of the experience.

Much of the literature suggests that frameworks used to understand the voice hearing experience then guides coping and allows for the tailoring of interventions to be best suited to people's unique understandings (e.g. Jones *et al.,* 2003; Knudson and

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Coyle, 2002). This literature, along with the current findings, emphasises the importance of understanding and exploring people's meaning-making. Coffey and Hewitt (2008) go as far as suggesting that not doing so limits recovery and is invalidating.

The confusion and mystery experienced by participants could have been influenced by the 'disorganisation dimension' of the positive symptoms of schizophrenia, particularly when considering most participants did not experience hearing voices in isolation, but as part of a wider psychosis or diagnosis of schizophrenia. DSM-IV-TR (APA, 2000) describes distorted language and thought as one such symptom, which could understandably have led participants to have some incoherent, distorted, and disorganised narratives or memories of their voice-hearing experience. Confusion could also have resulted from other factors that may have limited participants' memory and cognition, including the effects of taking antipsychotic medication (Terry and Mendick, 2007), as well as cognitive decline seen at onset of schizophrenia (Jeste *et al.,* 2011) and cognitive decline seen in 'normal' aging (Stuart-Hamilton, 2012).

A lack of dialogue to encourage personal meaning making, may have meant that participants were left with feelings of confusion, or limited choice in their sense making with such a dominant medical model. This may have been particularly so if they did not wholly subscribe to the medical narratives available to them, for example where this may have conflicted or invalidated their other explanations (e.g. delusional explanations or spiritual explanations). This cohort of participants may not have had access to the alternative approaches to the dominant medical model, which are now filtering through into the mainstream, but would have been in their infancy 20 years ago; for example, the hearing voices groups which have risen in number to 180 in the UK (at 2012), the main benefits of which are to facilitate new perspectives and meanings about voice hearing experiences (Dillon and Longden, 2012; Escher, 1993). Having access to different dialogues would allow more narratives and models to become available to participants to help them further develop their understandings about their experiences.

Improvement and Hope Vs. Deterioration and Despair

This master theme illustrated how participants came to an acceptance of their voices, experiencing a more hopeful connectedness with others and with life, and felt stronger and more effective in coping with their voices. However, this also co-existed with feeling despair and hopelessness due to the endurance of the voices. This master theme gives a reflection from participants in their later stage of life, which speaks to Erikson's (1980) conceptualisation of the stage of 'integrity versus despair'. According to Erikson, this stage can either result in disgust and despair about the past, or an acceptance of life as it has been.

The cluster of superordinate themes of improvement, corroborate much of the research that has shown there is increased acceptance and more efficacious coping in the later stages of the course of schizophrenia (e.g. Jeste *et al.,* 2011; Solano and Whitbourne, 2001), as well as improved insight, motivation to manage symptoms, and adaptations to social networks (e.g. Shepherd *et al.,* 2010). These fit well with the present themes of acceptance, increasing connectedness with others, and feeling more effective. Interestingly, Solano and Whitbourne's (2001) sample of 50-62 year olds will have been of a similar cohort as the sample in the current study of 68-75 year olds. It is therefore possible that cohort beliefs and attitudes influenced the similar themes of acceptance and improvement found in both studies. Additionally, since the date of Solano and Whitbourne's study, service changes (regarding approaches to psychosis, and also older adult mental health) may also have contributed to the current sample experiencing an improvement. Solano and Whitbourne suggested that it was better recognition of symptoms and acceptance that led to increased efficacy in coping; however the current findings suggest that increasing connectedness with others, particularly with professionals and others who hear voices, also contribute to the experience of improvement.

For most participants the experience of improvement and hopefulness appeared as a transition from the contrasting state of isolation and alienation that they experienced earlier in their lives. Later in their lives, participants began to talk more about their voices, connect with others, and become more involved in life, despite the

voices. June's account suggested her life stage, which now had fewer demands compared to middle adulthood, could have allowed for this transition. Tony's account suggested that changes in mental health services' approach had helped, since there was now more opportunity for dialogue and he was now involved in more service-user led initiatives. This element of the theme echoes the approach of the recovery model; optimism, empowerment, collaboration, and reducing stigma, with service-user run initiatives at the centre (NIMHE, 2005).

The transition to hopefulness, integration and efficacious coping, may also represent changes in the strategies adopted for goal attainment, as described by Brandtstadter and Rothermund (2002). At onset and the years immediately following, participants may have maintained the use of assimilative processes (where goals remain the same and strategies are developed to attain them) which are important in earlier life for the optimisation of development. However, if these goals become unattainable, perhaps due to the debilitating effects of hearing voices, depression and hopelessness can result. The shift to using more accommodative processes (altering the goals to become more feasible), may only have happened for participants later in life when more acceptance, understanding and experience had been gained. This thematic concept could also represent a transition to a more 'integrative' coping style, where participants were able to seek support and explore their voice hearing experience with others.

The development of a sense of feeling stronger and more effective in their coping efforts seems to fit with Davidson and Strauss's (1992) concept of an efficacious sense of self; characterised by a sense of an internal locus of control and being an active and responsible agent in coping and recovery. They note that the development of this efficacious sense of self can be a gradual, fluctuating process that is influenced by outcome and social support. Most participants in the current study evidenced a gradual development of becoming stronger and more effective in their coping. For some, this state appeared tentative and fragile, for others more established, and for Albert not present. The positive outcomes experienced by Alice and Tony, could perhaps have instilled hope, furthering the development of this sense of self. Conversely, for Albert, the failed outcomes from his efforts at coping using religious cures, may have damaged

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any developing sense of an efficacious self, resulting in his predominant feelings of hopelessness and despair. The factor of social support in the development of this sense of self is worth noting, particularly since increasing connectedness with others was also present in this cluster of themes. Perhaps a reciprocal positive effect of participants' increasing connectedness with others helped their efficacious sense of self to develop.

The superordinate theme of coming to an acceptance of the voice hearing experience was predominantly evidenced by the female participants. As noted earlier in the chapter, it may be that socio-political gendered beliefs and stereotypes of this cohort may have impacted on such differences, for example female participants believing they had no choice but to accept it and carry on, compared with the males perhaps refusing to resign themselves to the negative experience.

The present study showed that there was a significant paradox between improvement and deterioration, where participants also wanted to be rid of the relentless battle with the voices. Participants felt despairing and hopeless at the prospect that the voices may never go, and felt that their current experience of the voices was the worst it had ever been. This finding is at odds with the research which claims positive symptoms remit or are less severe in older age (Harvey, 2005), since the current study shows that not only are these symptoms present, but they are experienced as relentless. In light of Harvey's findings, caution should be issued to not to overlook the relentlessness of voices in later life. This deterioration could link to the challenges posed by the life stage of older age, such as deteriorations in health, cognitive abilities, as well as existential issues of loss, all of which could deplete resources pools and make it especially hard to cope with the voices. Overall then, age appears to have brought acceptance and a sense of strength in controlling the voices, but it appears to also feel harder and more effortful to keep going.

The mixed picture of both improvement and deterioration, is consistent with the research that has also evidenced a varied outcome in the course of schizophrenia. Numerous studies have shown some people either improve, deteriorate, or fluctuate (e.g. Blueuler, 1972 and Ciompi and Muller, 1976 – both cited in Barham and Hayward, 1990; Huber, 1997; Palmer *et al.,* 2001; Harding 2003). The majority of participants in

the current study evidenced an improving course in terms of coming to an acceptance and having a more efficacious sense of control over the experience, yet with elements of some deterioration. Albert, however, appeared to have experienced a fluctuating and deteriorating course only, and did not evidence the elements of improvement that the other participants showed. The heterogeneity in experience of outcomes is similar to the findings of Shepherd *et al.* (2010) who also found a mix of experiences of hopelessness, resignation, acceptance, hope and optimism.

Critical Evaluation of the Study

Limitations of the Study

Sample Size. I originally sought to recruit six to eight older adults; however due to a number of difficulties only five participants were recruited. LYPFT CMHT went through significant reorganisation soon after ethical approval for the study was granted. This appeared to significantly impact on staff capacity to recruit. A number of amendments (cf. method chapter) were made in order to ease the recruitment burden on staff; however after nine months of recruitment, the decision was taken to cease recruiting and begin group analysis.

Recruitment could also have been affected by the age limits set in the inclusion and exclusion criteria. Life expectancy for people with early onset schizophrenia is lower than that of the general population (Jeste *et al.,* 2011), and this may have limited the number of participants. However after careful consideration, the inclusion and exclusion criteria were thought to be important for homogeneity, quality, and ethical standards, and thus a higher priority than the gathering of more data.

Furthermore, previous negative experiences of engaging with services may have deterred some potential participants, as well as the influence of negative symptoms such as reduced motivation.

Sample Characteristics. It is important to acknowledge a number of characteristics about the final recruited sample, which may limit the generalisation of the findings to other populations. Firstly, the inclusion and exclusion criteria ensured

that participants were living in the community, and were not floridly psychotic or likely to become severely distressed by talking about their voice-hearing experiences in the interview. Therefore, it is likely that the participants recruited offered more of a positive perspective than perhaps an inpatient sample would have. The fact that the sample was recruited from an NHS service is another characteristic to consider. It is often argued that distress from voices is what typically differentiates those who come into mental health services and those who do not (e.g Chadwick *et al.,* 1996). Based on this principle, the sample in the current study will have been more likely to have experienced distress as part of their recent psychosis, compared to a sample of voice-hearers who had not come into contact with mental health services.

As noted earlier in the chapter, the age of participants and the fact they had endured a lengthy course of schizophrenia which involved treatment with antipsychotic medication, may have impacted significantly on their memory. Part of the interview process involved asking participants to access memories that spanned several decades, which was difficult for most participants, and precluded the detailed exploration of their earlier experiences of the voices. This was not thought to be problematic however, since the study was to gain an insight into participants' subjective experience of hearing voices over their life-span, from their perspective now in older age. Since poor memory was an element of their current subjective experience, it informed some of the themes identified in answering the research questions.

Similarly, some stories recollected by participants were at times seemingly incoherent and inconsistent, but again this could reflect similar issues of the cognitive sequelae of age and medication, as well as the nature of the psychotic experience being inherently disconnected and difficult to make sense of, particularly in the context of thought disorder and the 'disorganisation dimension' of the symptoms. Again, this was thought to reflect participants' subjective experience and it helped define certain themes, although at times it did make the data difficult to analyse.

Some participants spoke of their voices as part of a wider delusional system, such as Alice and Francis, and Jean spoke more of her experiences of the 'illness' as a whole in parts of her interview. Consequently, it was difficult to be certain that some of the

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themes were specific to the experience of hearing voices alone, and not the wider experience of delusions or psychosis. This is perhaps again not so much a difficulty, but more worth noting, in that participants may have been making sense of their voices in these wider contexts, and for them, the separation of the these interdependent experiences was not possible in their sense making. Despite the clinical utility of the symptom approach being favoured over the syndrome approach (e.g. Bentall, 1990), the current research suggests that focussing solely on one symptom without the consideration of its context within other symptoms, may not be optimal.

      Research Procedure. Defining the concept of interest in the interview was another difficulty that was encountered. The interview was designed to begin with asking generally about 'psychosis' in order to allow participants to introduce their own construct / label about 'voices', and I had planned to continue to use their terminology throughout the interview. This was done in order not to influence participants with my own construction of 'hearing voices', which may not be shared by participants. In the interviews, two participants referred explicitly to 'hearing voices', one to 'spirits' and the other two spoke more generally of a wider delusional belief that included an auditory element. For the latter two participants, making a timely judgement in the interview to know what experiences were 'voices' as defined by my constructs and understanding, was difficult. In order to aid the defining of the constructs of delusions and auditory hallucinations / voices that participants were referring to in the interviews, DSM-IV-TR definitions were used. This was a strategy used in other similar studies e.g. Quin *et al*. (2009). However, these definitions themselves introduce a bias from a psychiatric position / construction, and my judgement of these may have caused premature narrowing of the interview.

Upon reflection, the use of only one interview could be seen as a limitation of the present study. For at least two of the interviews, a second interview would have been beneficial to build up rapport, corroborate inconsistencies, and deepen participants' stories to clarify themes.

A final limitation of the study was of my position as a researcher who was a clinical psychologist in training. Participants were aware of my clinical position due to

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the nature of the study being a thesis piece of research for my qualification. These participants may have had certain views of mental health professionals and services, particularly considering some of their negative experiences of services at times, which could have biased what they were willing to share with me. This could have been true for June, where it felt as though she was trying to assure me of her wellness. The fact that interviews were mostly carried out at participants' homes, may have helped reduce the potential for me to be seen as a mental health professional, and thus lessen any such role enactments and resultant power imbalances.

Strengths of the Study

Hearing the Voices of a Hard-to-Reach Population. Firstly, this could be seen as giving a voice to a population that is typically perceived as difficult to engage in research (e.g. Owen, 2001; Humberstone, 2002). I personally at times found the nature of conducting and interpreting the interviews difficult and challenging, due to the interwoven nature of voices and delusions, and stories being recollected in a sometimes thought disordered narrative. Although it was difficult to interpret participants' sense making, upon deeper reflection I realised that my conceptualision of 'making sense' was initially restricted to doing this within my 'reality', yet the very nature of psychosis can mean that different realities are being explored and experienced by the person. It was a privilege to hear the stories of my participants' realities, and to have the opportunity to explore my own interpretations of these.

The main strength of the study is that for the first time, a lifespan perspective of the experience of hearing voices has been explored and formally analysed using IPA. Following the literature review, no studies previously existed on older peoples' subjective experience of hearing voices since an early onset psychosis. The current study showed that similar themes existed to the study by Quin *et al.* (2009) on older adults' subjective experience of late onset psychosis, such as the sense of isolation and loneliness, alienation and feeling different, and seeking understandings. However the current study added a further dimension, in that over time elements of a more hopeful improvement are gained, with a sense of acceptance and feeling connected with others and life, and being more effective in coping. This latter theme was also found in the

study by Solano and Whitbourne (2001) though their study referred to the experience of schizophrenia as a whole, rather than hearing voices specifically. The current study also found an added dimension of deterioration and despair that the Solano and Whitbourne study did not. This finding offers a caution for clinicians to be mindful that difficulties and clinical risk still exists. Finally, the current study also provided an insight into the novel finding regarding the lifespan perspective on the relationships people had with their voices and how this changed over time. It also provided an insight into the possible impact of this specific cohorts' context of mental health service models and theories of psychosis, such as the dominance of the medical model in their sense making and the absence of alternative narratives.

Overall Reliability and Validity of the Study

Revisiting Yardley's (2000) criteria for demonstrating the validity of qualitative data, I believe the current study meets the principles of: sensitivity to context (evidenced by the argument for it being an appropriate worthy area of research that was suited to the IPA methodology, sample and data collection procedures); commitment and rigour (evidenced in my analysis process in the method section and appendix); transparency and coherence (again evidenced in my analysis process in the method and appendix, and also through discussion of my reflections); and impact and importance (evidenced in the current discussion chapter). Sensitivity to context could perhaps have been improved if more than one interview had been used, as well as a longer period of recruitment in a more stable service. This might have improved validity by allowing more in-depth stories to emerge from a larger sample.

Clinical Implications and Future Research

Providing implications for older adult services is particularly important, considering the focus on improving such services over the past decade and years to come with the growing older adult population (e.g. DoH, 2005; Age Concern, 2007). However, the results have implications not only for older adults who have endured a chronic course since an early onset, but also for younger populations to whom we can apply the learning from the reflections of older adults upon their earlier stages of

hearing voices. As a cautionary note, this thesis research was conducted on a sample of five older adult service users who have heard voices from an early onset, with the goal of gaining an in-depth understanding of their idiosyncratic experiences. Therefore the following implications are given as a flavour of what could be useful for others, and where future research might be directed; but are not presented as evidenced based generalisable recommendations.

The findings regarding the negative beliefs that participants held about their voices, and the distress that these caused, highlight that exploring people's perceptions about their voice's identity, purpose, malevolence or benevolence, and power, is important. Therapy could then focus on helping people to re-appraise these beliefs about their voices, in order to reduce distress (e.g Chadwick and Birchwood, 1996). CBT has been shown to help people to challenge these perceptions, and research suggests this approach has beneficial outcomes in reducing distress (e.g. Trower, Birchwood, Meaden, Byrne, Nelson and Ross, 2004). The results of the present study suggest that useful conversations to have in such therapy would be around normalising, and making sense of, the experience of hearing voices and reducing the use of stigmatising terminology (e.g. Dudley and Turkington, 2011).

Participants' powerless relationships with their voices may have been representative of their positions in wider social relationships in their lives (e.g. Gilbert, 1989 (cited in Hayward et al., 2011); Birchwood *et al.,* 2000), or a more general insecure attachment style (e.g. Berry *et al.,* 2012), therefore therapeutic relational work may be clinically useful. Therapy to help people understand their problematic relational patterns, such as Cognitive Analytic Therapy (CAT) (e.g. Ryle and Kerr, 2002), might help them to consider other ways of relating that result in less distress, which may then have generalised effects on their relationships with their voices. CAT specifically for psychosis also has a growing evidence base, and particularly stresses the importance of building a meaningful narrative of peoples' experiences, and focussing primarily on interpersonal patterns and dialogue with the self and others (e.g. Kerr, Birkett and Chanen, 2003; Ryle and Kerr, 2002).

Birchnell's (1996) relating theory (cited in Hayward et al., 2011) suggests that relating to voices from a position of active engagement, rather than distancing, may help empower people and reduce distress. Participants in the current study generally appeared to develop a more active and challenging position towards their voices later in life. However, they also found the distancing responses helpful at times (e.g. for Frances), which highlights the need to gain a rich and detailed formulation of a person's relationship to collaboratively consider what would be most useful for the individual.

Jackson, Hayward and Cooke (2011) suggest that developing positive relationships with voices can not only be achieved through active engagement with voices, but also through connecting with people who accept voices, and developing a meaningful subjective understanding about voices. Opening up dialogue to explore and co-create meanings and understandings about voices, is another key therapeutic endeavour that the current research highlights. This is particularly so for an older adult population who may have missed out on such 'talking therapies' in the earlier approaches to 'schizophrenia' (as evidenced explicitly by Tony, and also in the Coffey and Hewitt (2008) study). Coffey and Hewitt stated that not exploring subjective experiences of voices can be invalidating and limiting to recovery. This was clearly evidenced in participants' experiences of alienation, isolation and loneliness experienced from feeling they were not believed, and so felt hopeless about others being able to help them.

Furthermore, exploring subjective experiences and opening up different narratives may help challenge some of the dominant negative social constructions and stigma. This is important given participants' experiences of stigma, being different, alienated, and disbelieved by others. Negative social constructions can suppress a person's inner drive to self-actualise and develop (Maslow, 1962), therefore exploring and challenging such social constructions could have important implications for development and wellbeing. Hearing voices groups are one such initiative, since such groups have been found to help open up different narratives, allow people to identify patterns in their voices, reduce isolation, increase normalisation, belongingness and acceptance (Escher, 1993). Lee *et al.* (2002) have also shown that similar benefits were experienced in a hearing

voices group for older adults, and participants in their study noted the positive outcomes from sharing advice and coping strategies. This fits well with the master theme in the current study about the value of increasing connectedness with others. Services should therefore encourage the development of such groups.

The findings generally stress the importance and value of exploring subjective understandings of the experience of hearing voices. Although most participants in the current study did not explicitly formulate their experiences in terms of understandable responses to difficulties; themes of bullying, subjugation, poverty and trauma could be seen to run through participants' lives and were echoed in their voices. It may be that without having had many opportunities to explore these ideas, participants had not considered such explanations. Since research has found that the content of people's voices can relate to unresolved past experiences (e.g. Read and Argyle, 1999), exploring and processing these experiences may be of clinical benefit. Garret and Turkington (2011) have suggested that CBT can be a useful initial therapy to help reappraise external experiences as internal, but could then importantly be followed by psychodynamic therapy to help understand and process the unconscious meanings behind the symptoms.

Furthermore, as people's unique understandings about their voices guides their coping efforts (e.g. Jones *et al.,* 2003; Romme and Escher, 1989), it is important that staff take the time to explore people's subjective understandings. This would allow for the idiosyncratic tailoring of interventions which people may be more likely to engage in when this fits their understandings (e.g. Jones *et al.,* 2003).

Participants' experiences of alterations to their sense of self, in terms of stagnation and loss of roles, highlights the need for services to encourage the development of positive identities and roles that are meaningful for people, and provide support in helping them to maintain roles they value. This may involve support in the reappraisal and accommodation of achievable and realistic goals that people can then successfully direct assimilative strategies towards. This study showed that participants benefited from reconnecting socially, and with valued pursuits in life, which multidisciplinary mental health services should consider encouraging and supporting. Furthermore, these

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endeavours could also be beneficial in the development of an efficacious sense of self (e.g. Davidson and Strauss, 1992).

Supporting people to reflect on their lives in older age may help them develop a more coherent narrative in place of what might have been a confusing, disordered and incomplete understanding. The importance of narrative therapy for such reasons has been highlighted by Roberts (2000), who cautioned against the impersonal mechanistic and dismissive approaches of the psychiatric model, and instead advocated for a focus on narrative therapeutic approaches. In the context of a supportive therapeutic relationship, a more coherent understanding and acceptance of the experience of hearing voices might be reached, in turn reducing distress.

The current research findings also highlight some fundamental principles for mental health services for psychosis, to keep in mind. Firstly, those who work with older adults that have heard voices from an early onset, should ensure they have a good awareness of this cohort's experiences of different models and treatments regarding psychosis and hearing voices (Laidlaw and Pachana, 2009). Secondly, staff should also be mindful of the mixed experiences of improvement and despair that might be seen in this population, in order to not solely hold pessimistic assumptions (as cautioned by Laidlaw *et al.,* 2007), but also not to underestimate the risk posed by underlying hopelessness. This paradox of despair and improvement needs important consideration by professionals, since after such a long duration of voices, people find the experience much harder. These feelings of despair need to be validated and supported by services, particularly for this cohort who, for the majority of their course of psychosis, have not felt the benefit of the more recent normalising and supportive approaches to care. Furthermore, staff need to be aware of the reciprocal effects and inter-dependence between the different symptoms of psychosis (such as negative symptoms, thought disorder, and hearing voices), when working with people with psychosis. Staff should also ensure that the treatment approaches they offer are holistic and based on a comprehensive formulation, as well as having the recovery model principles at the core.

Implications for future research include addressing some of the limitations of the current study that were noted earlier; for example to obtain a larger sample, and to

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conduct more than one interview to deepen rapport. This would help corroborate the findings of the current study. The analysis of participants' use of different discourses may also be of interest, to help further understand how they made meaning of their experiences over their lifespan depending on what discourses were available to them. Furthermore, a qualitative study to explore this cohort's experience of services and the different treatments they have received and what was and was not helpful for them, may be of interest. This would help services be mindful of what this cohort has endured prior to their current treatments, and how these experiences may currently impact in their engagement with services. In light of Coffey and Hewitt's (2008) study and the findings of the present study, it would also be useful to find out more about staff experiences of working with older adults who hear voices, to help services identify training needs for working with this population.

In the current research, a possible gender difference was found within the themes of responding to the voice (female participants having more distancing and neutral responses, compared with the male participants who engaged with the voices more), and coming to an acceptance of the voice hearing experience (more evident for the female participants). Further research to elucidate whether there is a gender difference, in coping with psychosis or in the socio-political and gendered beliefs of this cohort, would be interesting, particularly given the paucity of literature on these issues currently.

It would also be useful to further investigate the here-and-now experience of voice hearing in the interview. As noted in the pen portraits, a number of participants actively heard voices during their interviews. It would be interesting to explore where and when this happened in relation to what was being discussed at those points in the interview. A second researcher, whose role could be to observe the interaction between the participant and the interviewer, would enable process issues and relational elements to be elucidated.

It would also be useful to conduct further research into the use and benefit of some of the different clinical recommendations from the present study, for example, the use of hearing voices groups for older adults. Discourse analyses could be conducted at

an early phase of the group, followed by a later phase, to determine if new narratives are being co-created and shared by the group. Outcome measures on wellbeing and distress could also be taken, as well as qualitative interviews to understand participants' experience of the group.

The finding of the current study that increasing acceptance appeared to contribute to an improvement in the experience of hearing voices, raises the hypothesis about whether acceptance and commitment therapy (ACT) may be a useful intervention for psychosis. This research is beginning to be conducted, with some initial studies recently published (e.g. Bach, Hayes and Gallop, 2012). This could perhaps be further explored in relation to the current cohort of older adults who have endured the earlier models and treatments of psychosis that may have been disempowering and stigmatising. It could help understand in what contexts this type of therapy could be useful or not and what adaptations may be needed; perhaps there could be dangers in this cohort's acceptance of the stigmatising medical label that they have been subject to for the majority of their experience. Perhaps a context of normalisation and alternative discourses would need to be created first. Such questions could be elucidated in future ACT research. Similarly, the continued research on relational therapies for psychosis and particularly for hearing voices, such as CAT, would also be supported as a useful endeavour by the current study.

CONCLUSION

This thesis research explored older adults' experiences of hearing voices over their lifespan following an early onset of psychosis. The findings indicated that all participants experienced a relationship with their voices that encompassed beliefs about, and emotional and behavioural responses towards them. The research also showed that these developed over time; for some voice-hearers this changed for the better, for others it fluctuated, and for some it remained stable. The research also showed that the voice hearing experiences altered participants' sense of self in the world, where the voices brought about feelings of alienation and loss of valued identities and roles. Participants sought out frameworks to help them understand their voice hearing experiences, but found elements confusing and mysterious. At a time of reflecting upon their lifespan and the future, participants evidenced both an improvement in their voice hearing experience, but also deterioration and despair. Similar themes to previous studies emerged, however, the lifespan perspective on the subjective experience of hearing voices is unique to this study. This has highlighted how relationships with voices can develop and change over time, and that in some important ways there can be a transition from the experience of alienation and loss, to hopefulness, acceptance and more efficacious coping with the voices. It has also given an insight into this particular cohort's longitudinal experience, which has paralleled significant changes in theoretical models and mental-health service approaches to hearing voices.

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APPENDIX

*Some of the above listed documents have been reformatted and resized to fit thesis margins and page limit

Appendix A. Literature Search Results

Search No.	Term	Results
1	Schizophrenia	346644
2	auditory hallucinations	5495
3	hearing voices	507
4	Psychosis	162048
5	1 or 2 or 3 or 4	454446
6	older people	39614
7	older adult	95588
8	Elderly	457988
9	6 or 7 or 8	559326
10	subjective experience	8350
11	personal meaning	1566
12	subjective understanding	145
13	meaning*making	6
14	10 or 11 or 12 or 13	10051
15	5 and 9 and 14	8
16	remove duplicates from 15	4

Appendix B. Staff Information Sheet

CMHN Information Sheet

A project to explore the lived experience of older adults who have heard voices throughout their life span following early-onset psychosis

1. Who is conducting the study?
My name is Mary Hardacre and I am the main researcher on this project, which is part of my training course in Clinical Psychology at the University of Leeds. Dr Louise Bergin, Clinical Psychologist at The Mount, is also part of the research team involved in this project.

2. What is the reason for this study?
In recent years there has been increasing interest in people's unique and subjective experiences of hearing voices, however most of this research has focussed on the working-age adult population. This study is therefore designed to explore more about older adults' experiences of hearing voices, particularly from the perspective of those who have lived with voices throughout most of their lives. This would be valuable in helping services deepen their understanding of older adults who hear voices, perhaps informing more effective ways of being able to work with them. It may help inform local initiatives such as the "Psychosis Group" being developed on the wards at The Mount. It should also help to understand the experience of hearing voices at different stages and challenges throughout the lifespan, therefore having implications for services who care for younger adults who hear voices.

3. How will the study be conducted?
We hope to interview about eight people to enable us to understand the themes of service-users experiences of hearing voices. In particular they will be asked what these experiences meant to them and how they have personally made sense of them. This should help inform services what hearing voices is like, from the perspective of those who have heard voices for a considerable amount of time. Interviews will last for about an hour. The service-user will be asked to choose where they would like to have their interview: - either at The Mount, St Mary's, Asket Croft, or Aire Court. As a last resort, if recruitment is severely affected by difficulty in attending these locations, we could interview participants at their homes. Any travel expenses will be reimbursed.

4. Who can take part?
We would be really grateful if you could hand out the recruitment leaflets about the study to clients you currently see, who in your clinical judgement and knowledge fit the following criteria:

Inclusion criteria:
- Under the care of Leeds and York Partnership Foundation Trust CMHT
- Aged 65 or older

- Experience of hearing voices over their lifespan. This may either have been constant or intermittent, include hearing one or more voices, and with an onset prior to age 40
- English as first language
- Capacity to consent

Exclusion criteria:
- Co-morbid diagnosis of dementia (including Lewy Body dementia) or significant cognitive problems which would reduce ability to engage in a 45-60 minute interview that relies on the recollection of memories
- Late onset psychosis after the age of 40
- Current experience of floridly psychotic symptoms
- Risk of distress as assessed by your clinical judgement and use of current FACE risk assessment

Should clients express an interest in taking part, we would be grateful if you could send them / give them an information sheet and consent form for them to sign and post back to you. If after two weeks there was no response from service users, we would be grateful if you could briefly follow this up where appropriate. I will regularly stop by to collect any consent forms. Once eight people have consented and taken part, no further recruitment will be necessary. You will note that the leaflets and information sheets ask about people's experiences of 'psychosis', rather than 'hearing voices'. This is because we acknowledge that older adults may not use or be familiar with the term 'hearing voices' and that many are more familiar with the term 'psychosis'.

5. Safety
Of upmost importance is the safety and wellbeing of participants. We acknowledge that talking about personal experiences of psychosis and hearing voices may be upsetting. Should a participant become distressed during the interview, it would be terminated and I would offer immediate support. I will ensure that I inform you of the time of the interview and will contact you immediately if participants appear to be at risk of significant distress. With your already established therapeutic relationships with the service-users taking part, I would be grateful for your follow-up support to participants in a time period you feel is appropriate, in case of any delayed or undisclosed distress.

6. Contacts for further information:
Should you want further information or wish to speak to myself or the other research team members, our contact details are as follows:
Mary Hardacre (Psychologist in Clinical Training)
        Email: ummeh@leeds.ac.uk / Tel: 0113 3432732
Dr Louise Bergin (Clinical Psychologist, Leeds NHS Partnership Trust)
        Email: louise.bergin@nhs.net / Tel: 0113 3055587
Dr Sylvie Collins (Clinical Psychologist and Tutor at the University of Leeds)
        Email: S.C.Collins@leeds.ac.uk / Tel: 0113 3432732

Thank you for taking the time to read and consider this information.
I would be really grateful for your support.

Appendix C. Brief Recruitment Leaflet

Tell Your story

We are gathering stories of people's experiences of psychosis.

Would you be willing to share your story?

If you're interested, please speak to your nurse.

We want to improve care for people who have psychosis. To do this we want to understand your experience better.

You are being asked because your nurse identifies that you have experienced psychosis during your life.

To take part you would be asked to talk about what having psychosis has been like for you. This would take about an hour.

If you're interested in taking part, tell your nurse and they can send you more information.

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Appendix D. Participant Information Sheet

Participant Information Sheet

A project to explore what it is like for people over 65 to have had psychosis for a lot of their life

My name is Mary and I am the main person working on this project, which is part of my training to become a Clinical Psychologist at the University of Leeds.

You are being invited to take part in this project. Before you decide it is important for you to understand why the project is being done and what it will involve. Please take time to read the following information carefully, and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information.

Thank you for taking the time to read this.

What is the project's purpose?
There has been a lot of interest in people's personal experiences of psychosis. Most research has focussed on people under 65. We want to understand more about what it is like for people over 65 who have had psychosis for a long time. This would help health-care staff understand and care for people with psychosis better.

Why have I been chosen?
Your nurse identified you as someone who has experienced psychosis for a lot of your life, and so could give a personal insight into what having psychosis for a long time has been like.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. You will also be asked to sign a consent form. You can withdraw from the study at any time. You do not have to give a reason, and it will not affect your care in any way.

What would happen to me if I take part? What would I have to do?
You would be asked to talk with me for around an hour about what it has been like for you to have psychosis throughout your life. You can choose to do this either at The Mount, Aire Court, Asket Croft or St. Mary's – depending on which of these locations is most convenient for you. We will pay any travel expenses incurred.

What are the possible disadvantages and risks of taking part?
Sometimes talking about psychosis can be uncomfortable or upsetting. Your nurse will know the time and date of when we are meeting and we can arrange for them to talk to you afterwards if you have found it upsetting in any way.

What are the possible benefits of taking part?
Sometimes talking with someone about your experiences can be enjoyable and helpful. The findings of this research will also help health-care staff to understand and better care for people who experience psychosis.

Would I be recorded, and how would the recording be used?
Yes, what you say will be audio-recorded and then transcribed. The written transcripts will be analysed by me and I may use some quotes in the final reports. The University of Leeds keeps the transcripts securely for 3 years, but no other use will be made of them without your permission, and no one other than the research team (see below) will be allowed to see or use them.

Would my taking part in this project be kept confidential?
All the information we collect about you will be kept strictly confidential. Your name will not be linked with the research in any way and you will not be identified in the reports that result from the research. Any quotes that may be used from your interview in the final reports will be fully anonymised, with any identifying information removed.
We wish to make you aware that Dr Louise Bergin is part of the research team and also works as a Clinical Psychologist at The Mount, so she may be, or have been, involved in your care at some point. Louise will keep any information we collect about you during this research strictly confidential.
However, if Louise or I become concerned about any risks to you or others, we would need to share this information with your nurse and care team, however this would be discussed with you first.

What will happen to the results of the research project?
The results of this research will be written up as part of my training in Clinical Psychology. This will be available to read in the University of Leeds Library in 2014. The research may be published in an academic journal in the future. A short summary report of the results will also be given to you personally.

Contacts for further information:
Should you want further information please contact the research team:
Mary Hardacre (Psychologist in Clinical Training)
    Email: ummeh@leeds.ac.uk / Tel: 0113 3432732
Dr Louise Bergin (Clinical Psychologist, Leeds NHS Partnership Trust)
    Email: louise.bergin@nhs.net / Tel: 0113 3055587
Dr Sylvie Collins (Clinical Psychologist and Tutor at the University of Leeds)
    Email: S.C.Collins@leeds.ac.uk / Tel: 0113 3432732

Appendix E. Participant Consent Form

<div align="center">

Participant Consent Form

</div>

Research Project Title: A project to explore what it is like for people over 65 to have had psychosis for a lot of their life

Lead Researcher: Mary Hardacre (Psychologist in Clinical Training)

Thank you for agreeing to take part in this research project. Please initial each box on the right if you agree with the corresponding statement.

1   I have read and understand the information sheet dated 25/06/12 explaining the research project and I have had the opportunity to ask questions about the project.

2   I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without any negative consequences. If I do not wish to answer any particular questions, I am free not to do so.

3   I understand that my interview will be audio-taped.

4   I understand that my responses will be kept strictly confidential. I give permission for the research team to have access to my anonymised responses. I understand that my name will not be linked with the research, and I will not be identified in the reports that result from the research.

5   I agree to parts of my interview being quoted in reports of the research, providing details that might identify me are removed.

6   I understand that relevant sections of my data collected during the study, may be looked at by individuals from the University of Leeds and/or Leeds and York Partnership NHS Foundation Trust, who may audit the research. I give permission for these individuals to have access to my data.

7   I agree to take part in this research project and will inform the lead researcher should my contact details change.

_____   _____   _____
Name of participant   Date   Signature

_____   _____   _____
Person taking consent   Date   Signature
(*To be signed and dated in presence of the participant*)

Appendix F. Interview Protocol

Semi-structured Interview Guide

Can you tell me about when your psychosis first started?

What happened? What was your response? How did you feel about it? How did you make sense of it / how did you understand what it was? Why did you think it was happening? What impact did it have? What was going on for you in your life at the time / how old were you? What place did psychosis have in your life then?

Can you tell me about what [psychosis / participant's own language re hearing voices] was like for you a bit later on in your life?

What happened? What was your response? How did you feel about it? How did you make sense of it / how did you understand it? Why did you think it was happening? What impact did it have? What was going on for you in your life at the time / how old were you? What place did psychosis have in your life then? In what ways did this differ from earlier times in your life?

Can you tell me about your most recent experiences of [psychosis / participant's own language re hearing voices]?

What happened? What was your response? How did you feel about it? How did you make sense of it / how did you understand it? Why did you think it was happening? What impact has it had? What else is going on for you in your life at this time? What place does psychosis have in your life now? In what ways does this differ from earlier times in your life?

Looking back then, do you think [your psychosis / participant's own language re hearing voices] has changed over time? If so, can you describe in what ways?

Has the way you relate to [your psychosis / participant's own language re hearing voices] changed? Have your thoughts / feelings / responses / coping with [psychosis / participant's own language re hearing voices] changed? How? Why do you think that is?

Has your [psychosis / participant's own language re hearing voices] affected your relations with other people currently and in the past? If so, can you describe how?

Partner? Family? Friends? Work colleagues? What did that mean for you?

Has your [psychosis / participant's own language re hearing voices] changed the way you think and feel about yourself as a person? If so, can you describe how?

How would you describe yourself as a person? How does [psychosis / participant's own language re hearing voices] fit in with this? Has this changed over time?

Appendix G. Ethics Approval Letter

NHS

Health Research Authority
NRES Committee Yorkshire & The Humber - Leeds West

First Floor
Millside
Mill Pond Lane
Leeds
LS6 4RA

Telephone: 0113 3050122
Facsimile: 0113 8556191

13 June 2012

Miss Mary Hardacre
Psychologist in Clinical Training
The Leeds Teaching Hospitals NHS Trust
Leeds Institute of Health Sciences
Charles Thackrah Building
101 Clarendon Road, Leeds
LS2 9LJ

Dear Miss Hardacre

Study title:	**The lived experience of older adults who have heard voices throughout their life-span following early-onset psychosis: An interpretative phenomenological analysis**
REC reference:	**12/YH/0277**

The Research Ethics Committee reviewed the above application at the meeting held on 08 June 2012. Thank you for attending to discuss the study.

Ethical opinion

The Committee asked for clarification on your experience of qualitative research; you explained your supervisor is very experienced in Interpretative Phenomenological Analysis (IPA) and you have undertaken a training module in qualitative research that involved conducting a mock study. The mock study included conducting interviews and you eceived feedback on her performance of undertaking the research.

Further information was sought on the use of both 'hearing voices' and 'psychosis' in the supporting documents; you explained you intended psychosis to be the overall term but didn't wish to influence participants at the start of the research, when participants start using the term 'hearing voices' during their interview she would also. You confirmed you had intended to only use psychosis in the information sheet and advertisement.

The Committee queried if all people with psychosis will be approached or whether diagnosis is important; you explained you would not recruit those with dementia but otherwise the diagnosis is not a consideration.

Clarification was sought on the upper age limit of 80; you explained you wish to make the sample homogenous, 65 years reflects the departments definition of older patient. Members suggested that an age range of 65-80 may not guarantee a homogenous sample and chronological age is not always relevant.

A Research Ethics Committee established by the Health Research Authority

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The recruitment procedure was raised; you explained you have spoken to the CMHNs about the study and they have agreed to identify potential participants and give out the leaflets and information sheet.

The Committee expressed its concern regarding your safety if you undertake home visits for the interviews. You explained both the University and the department have a lone worker policy which you will follow; you also explained that home visits were decided upon to ensure the participants do not associate the research interview with their standard therapy. Members asked how you will deal with participants who become distressed; you confirmed you have been trained and are experienced in dealing with psychotic patients. Your first concern will be to de-escalate the situation and when you consider the participant is safe you will organise a follow up within the department. The Committee suggested it would be preferable to conduct all interviews at the Mount; you agreed this would ensure more support is available if required and if participants normally attend the Mount you will conduct the interviews there. You reminded the Committee that the CMHNs will have screened the potential participants.

The decision to exclude those whose first language is not English was raised; you explained that even if fluent in English they may hear voices in their mother tongue and would then have to explain to her in English, some of the descriptions may be very complex. Members pointed out that many older people may not speak English as their first language if they came to the UK several years ago.

An explanation was sought for the advertisement referring to telling stories; you explained you wish to encourage a narrative approach from participants.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

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For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

1   The language in the consent form regarding anonymisation is very clear and the same phrase should be used in the participant information sheet.

2   The upper age limit of 80 should be removed.

3   The Committee would prefer you to attempt to only recruit those who can be interviewed at the Mount, interviewing in people's homes should be a last resort if recruitment is severely affected by this request.

4   The consent form should have the mandatory section of access for regulatory authorities.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Evidence of insurance or indemnity		28 September 2011
Interview Schedules/Topic Guides	1.0	14 May 2012
Investigator CV		21 April 2012
Letter of invitation to participant	Advertisement 1.0	14 May 2012
Other: CV for Dr Collins		14 May 2012
Other: CMHN Information sheet	1.0	14 May 2012
Participant Consent Form	1.0	14 May 2012
Participant Information Sheet	1.0	14 May 2012
Protocol	1.0	14 May 2012
REC application		17 May 2012
Referees or other scientific critique report		14 May 2012

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

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Appendix G. Ethics Approval Letter (cont.)

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.
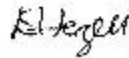
Further information is available at National Research Ethics Service website > After Review

12/YH/0277	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Elhazell

PP
Dr Rhona Bratt
Chair

Email: Elaine.hazell@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*
"After ethical review – guidance for researchers"

Copy to: *Faculty Research Ethics and Governance Administrator*
Mr James Hughes, Leeds and York Partnerships Foundation Trust

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Appendix G. Ethics Approval Letter (cont.)

NHS
Health Research Authority

NRES Committee Yorkshire & The Humber - Leeds West

First Floor
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Telephone: 0113 3050122
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29 June 2012

Miss Mary Hardacre
Psychologist in Clinical Training
The Leeds Teaching Hospitals NHS Trust
Leeds Institute of Health Sciences
Charles Thackrah Building
101 Clarendon Road, Leeds
LS2 9LJ

Dear Miss Hardacre

Full title of study: **The lived experience of older adults who have heard voices throughout their life-span following early-onset psychosis: An interpretative phenomenological analysis**

REC reference number: **12/YH/0277**

Thank you for your letter of 25 June 2012. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 08 June 2012. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	Version	Date
Covering Letter		25 June 2012
Participant Consent Form	2	25 June 2012
Participant Information Sheet: CMHN	2	25 June 2012
Participant Information Sheet	2	25 June 2012
Protocol	2	25 June 2012

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

12/YH/0277	Please quote this number on all correspondence

Yours sincerely

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Appendix H. Example Interview View Summary

Interview 3 – June: Field Notes

- It seemed as though June had experienced a difficult previous 12 months of hospitalisation and this was the main focus of her story in terms of time period and hospitalisation only. Therefore little was gained on earlier time periods or the specific experience of hearing voices. I felt as though I repeated myself a lot with trying to get information about earlier experiences and about what it was like to hear voices specifically, but these questions were nearly always answered about the recent past and about her experience of hospitalisation and being 'unwell' generally. I was unable to deepen much her narrative or gain any detailed reflection from her.
- I wonder if her current wellness (in comparison to what had been the 'most difficult' last 12 months), affected her capacity to get in touch with reflecting on the experience of being unwell – in order to maintain her current wellness?
- Her narrative seemed to reflect views from a place of wellness – i.e. that she knows the voices aren't real, but she cannot access in detail what she believes when unwell. It was almost as though she was trying to assure me that she was well and had insight (as perhaps she may be used to doing currently with her care team), and to admit to any beliefs and feelings about the voices that she has when unwell – i.e that they are real or any 'delusional' explanations about the experience at the time, would be counterintuitive in assuring wellness?
- She had a very poor memory for the onset of her psychosis. I wondered if this reflected a very gradual onset, of an experience that isn't too far removed from reality – i.e. hearing people talk about her Vs hearing spirits?
- I felt her story was very much a surface account and that any deep exploration might only come with the passage of time after this recent episode, and only when a strong enough therapeutic relationship develops. I felt as though she was 'self-managing', perhaps that she was a little apprehensive and her engagement, which made it hard to get close to her felt experiences.
- Summary of story:
    - As above – the focus was on recent hospitalisation
    - She hears other people talking about her but could not describe any content of what they say or her response to them
    - Her focus is on the consequence of hospitalisation
    - She feels that her coping has very recently improved (but is this just a reflection of the recovery stage of the recent episode?)
    - Importance of social support and activity was evident

Something by chance / external ceased the experience

The car cut out

Unawareness → realisation
Regret
Frightened at power of consequences of voice
External cause.

Regret when he realised what he'd done
Frightened.

Powerless to voice at times
Vulnerable to "It's" control
Frightened
Regret

Against his wishes

689 dozing off you know, with fumes… And it
690 must have cut out, engine. Choked up or what
691 … and summat cut it, stopped the engine…
692 and I was sat in front of steering wheel and
693 started to come round. "Ah what have I
694 fucking done? What have I done?" And I was
695 so frightened over what I'd tried to do…
696 M: Do you think it was you that tried to do
697 that or do you think it was the voice making
698 you do that?

699 T: It was voice making me do that.

700 M: So it wasn't something you wanted to do
701 yourself?

Powerless
Controlled
Against own intentions.

A disowned part of self?

Voice made him do it – he didn't want to kill himself

702 T: No. No. (pause) That's how its been, really
703 bad, in past over years, trying to reconcile
704 myself with voices and myself.

705 M: Can you tell me more about that?

706 T: Yes… Well… that's what I tried to do
707 over the years, to reconcile myself… So I
708 wouldn't go down way the voices were telling
709 me to go… I'd go my own separate way. And
710 if I went my own way, I'd know my wife
711 would be safe. I'd be safe… And that's how I
712 felt, you know?

713 M: Mm. So you thought of going your own
714 way? Your separate way?

Struggle for power over the voices

He wanted to seperate himself from the voices & go his own way – then he & his wife would be safe

Goal to protect his wife / others – prevent adverse consequences

Struggle / battle for power.

Isolated himself for control.

He wanted to be alone when voices were bad so he couldn't hurt anyone

715 T: Yes. I just wanted to be on my own, when
716 they're really bad, so I can't hurt anybody.
717 Cos once, I know once they start, they… my
718 body strength… it's so strong, makes me feel
719 like superman. I feel like superman
720 sometimes, and that's why I get worried.

Isolating self
Scared of his potential when taken over by voices
↳ transforms him.

Worries about his strength & potential to hurt

Voices increase his body strength. Feels like superman.

comes from voice (not him) – a disowned part of self?

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Appendix J. Analysis - Example Clustering of Themes

Neighbour as a causal factor for her isolation and loneliness (526-528, 1014-1017) "I spent 32 years in a house on my own with no television, no wireless, no radio, no nothing like that because of her up the stair"; "I spent 32 years in a house. Without any visitors. No one came to visit me whatsoever. Because of her up the stair"

Difficult relationship with neighbour – oppositional in values, beliefs and ethic (183, 600-615) (unfairness?) "My neighbour upstairs shouting down into my living room 'There's never been a Jesus Christ, never will be, never will come'"; "I had to go to work to keep them alive, you know, keep them in clothes and things like that. But they (neighbours) never did a pennyworth of work. wanted for nothing. Because they'd shout for cornfl my hoover. I leant them milk. I leant them this 'Can telephone?' I leant the whole lot to them. They never work in their life"

Externalisation [...] (406-407) "When I went [...] neighbour, there were nothing [...] wrong with me. It was my neigh[...]

EXTERNALISATION OF CAUSALITY

Neighbours unboundaried / unlimited intrusiveness (73[...] friend that was in the Mount at the same time and she [...] the rumour. When the rumour started going around, I t[...] God, she's even in here so's her friend, spreading the [...]

[...] as a causal factor for mental health difficulties (367-370, 401-404, 571) "M: Do you remember what had happened at those times that meant you needed to go to the Mount? F: Yes, my neighbour"; "They were saying their names (the neighbours). When I went to hospital, they told me it was my neighbour, there were nothing wrong with me"; "F: It was her that got me them in the first place, to hear voices. M: She? F: She used an electric machine. M: She used an electric machine to make you hear voices? F: Mmhm"

Victimisation, derogation and intrusion into pri[...] (69-, 106-, 233-239, 327-337, 551-553, 721-72[...] neighbour up above was the one that brought him to me. An[...] walk in, she pushed her way in. Well I was angry because I [...] know who she was"; "She had a house where all the window[...] what I mean, and windows were never shut, so she could tell [...] your house"; "Every penny I had in the bank she's get. Even [...] name she's still get it. She'd go into the bank and say she was [...] have the money in her hand and I'd be left without a penny"; "She used to play my business on a tape recorder... [so] she could spread it around, scheming, everybody could know your business"; "She used to sit and listen to everybody that came into my house and what their business was. Even my business"; "F: Around the Mount I was a dirty prostitute and everything so I was. M: Is that what the voices said? F: No that's what my neighbour put around the Mount"

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Appendix K. Example Extract from Memos / Reflexive Journal

29/12/12

My forestructures about the label of 'voice' is perhaps inadequate and limiting

- Alice's 'voice' is clearly a wider conceptualision of a person as a whole
- Hard to judge what is real and delusional – this needs thought with supervisors
    o Supposing Alice's 'voice' is from a real man?
    o Albert's contacting of spirits is a phenomenon believed by a large number of people in the 'normal' population

Difficulty of interview process

- Confusing / conflicting accounts within an interview
    o Hard to know what refers to what (e.g. in Albert's – where the religion comes in and out, and he's referring to the depression experience or the later psychotic experience)
- Difficult to elicit a coherent narrative
    o Should I expect this? – by the nature of their age, there is an awful lot of lived experience, as well as memory decline, impact of severe mental health on reflective capacity??
- Not understanding / hearing at the time of interview, only in transcription, and realising I've missed an opportunity to follow up something potentially quite meaningful.
- The wish to go back and ask more questions.

Difficulty of analysis process

- Feel as though I'm formulating and imposing my own hypothesising based on very limited information - feels almost unethical?
- Don't feel I'm getting at the *participants* understanding, just mine, and at best that seems like its just guessing
- Feel as though I'm doing it wrong – is formulating analysing? Yes and no. Formulating is relating assessment information to psychological theory, in order to come up with an understanding of a phenomenon. Isn't that what I am supposed to be doing in research analysis? The bit I'm stuck with is the participants' understanding of the phenomenon.
- I really don't feel I'm going to answer the research questions
- All this frustration with it might make me rush the analysis. I must try and remember the drive to do justice to my participants lived experiences, and to hold them in mind – that they have trusted me with their precious thoughts and feelings

Appendix L. Summary Tables of Theme Characteristics & Extra Quotes

SUPERORDINATE THEME: Powerless, controlled and persecuted	
Elements of the theme: Voice characteristics	**More example quotes:**
Intent to cause harm	*"I think they're just against us. Against me. Or they are trying to harm me" (June)* *"He were telling me to kill some of the staff"(Tony)*
Controlling	*"He came up to the house and hypnotised me"(Alice)* *"like something inside you, controlling you"(Albert)*
Relentless, interfering and intrusive	*"I've had it all the time since I've been 50 now. Every day. You just want to rip your hair out" (Tony)*

SUPERORDINATE THEME: Responding to the Voice(s)	
Elements of the theme: Responses	**More example quotes:**
Negative emotions – frightened, angry, upset, worried, ashamed	*"It were awful. Frightening. Frightening… It were too painful, it were too frightening"(Albert)* *"That's what I'm frightened of, [the voice] taking over me and doing what he wants me to do"(Tony)* *"It made me feel angry, really angry" (Tony)*
Blocked off / neutral feelings	*"Researcher: "How does that make you feel?" Frances: "Oh it doesn't bother me"*
Distancing from the voice(s)	*"I don't pass the time of day with him. I'm not delving into his life. I don't want to know… I don't want to know anything about him" (Alice)* *"You know if you don't think about your illness, you're ok" (June).* *"I just close my eyes and go to sleep, and I don't bother with whether the voices are there or whether they are not there. But they're going constantly the whole time… It doesn't bother me the same, I'm in a world of my own when I'm sleeping" (Frances).*
Engaging with the voice(s)	*"I were fighting the voices all the time I were in there"(Tony)* *"Go away, leave me alone… I don't want to be bothered with you now. Come back later"(Tony)*

SUPERORDINATE THEME: A Challenge to Identity	
Elements of the theme: Challenges	**More example quotes:**
Character	*"My son knows then to contact my daughter. You know, 'Mother's not herself'" (June)* *"That's what it feels like to me. I feel like another person. I know once they [the voices] start, my body strength, it's so strong, makes me feel like superman" (Tony)* *"I'm awful, supposed to be 'an effing basket'… [the voices] just said it there now" (Frances)*
Working role	*"'Leave gases alone they used to say… to hurt other people" (Tony)*
Parental role	*"It got to such a stage where I were just, I could have walked out… I just felt as though that were it… But I didn't, I mean how can you walk out on your family… It was just that I couldn't cope anymore" (June)*
Masculinity	*"I wasn't like this. I used to come home and do weight lifting and bodybuilding. It took all my strength away" (Albert)* *"Its changed the way Margaret thinks about me" (Albert)* *"If I went my own separate way, I'd know my wife would be safe" (Tony)* *"Oh my sex life has suffered. I haven't done ought like that since I was about 40" (Tony)*
Spiritual beliefs	*"I don't like Sundays"* *"I call him a Judas"*
SUPERORDINATE THEME: Alienation and Isolation	
Elements of the theme	**More example quotes:**
A sense of being in another world	*"It was just as though you were in another world and it weren't, you weren't sort of real, you know, in reality" (June)*
To others, the voices are invisible, not real, and not believed	*"It's a bit far-fetched like, but that's what I think" (Alice) "Believe it or believe it not…" (Albert)* *"My son knows then to contact my daughter, you know 'Mother's not herself, she's saying things that are not true'" (June)* *"Well if you've a broken leg, you could see it. This is something you can't see" (Frances)*

Stigmatised	*"There'll always be that stigma attached to you. No matter people don't know you, but there'll always be that" (June)* *"They might realise you're ill, but you're not ill. You're sound up here, intelligent up here" (Tony)*
Alone and isolated	*"I don't go out, it's stopped me going out. Never go out for a pint with the lads" (Albert)* *"I probably ignore 'em, if people say hello to me, I say hello back. Erm, and that's as far as it goes. I don't have a conversation with them" (June)*
Hopelessness to being helped by others	*"This psychiatrist what I see, she's alright, but its 'Hi Tony, you're looking well', and I'm feeling like shit" (Tony)* *"It were no good, I knew she [his wife] couldn't help me" (Tony)* *"I sit there, staring at the psychiatrist and I'm saying 'Christ I want help' 'Help me please!' and they're not helping me" (Tony)*

SUPERORDINATE THEME: Confusion and Mystery

Elements of the theme	**More example quotes:**
Unexplainable to self and others	*"What does he want with me? That's what I want to know" (Alice)* *"I don't know, I don't know how to explain it" (June)* *"That's what upsets you, you don't understand why it is happening to you" (Tony)* *"I don't know, I couldn't tell you. I wish I knew, I could use it now" (Tony)* *"I don't know, I don't know why" (Tony)* *"I can't explain it to you. It's so hard to explain" (Tony)* *"I've no idea… I've no idea" (Frances)*
Confusing unpredictable course	*"It's a mystery, it's a mystery" (Albert)*
Vague and fading memories	*"Don't know, can't remember, its that long since. I can remember now, this time" (Alice)* *"I can't really remember the first time. Its years, I mean years and years ago" (June)* *"[my son] said twice I go admitted, but I can't remember" (June)* *"Oh I can't remember, its going back a long time" (Frances)*

SUPERORDINATE THEME: Making Sense of the Voices

Elements of the theme:	**More example quotes:**

Frameworks	
Medical diagnosis	*"Schizophrenia, you hear things, you see things, you feel things. Aye. It makes you behave differently"* (Albert) *"I got told it were part of your illness, and that were it"* (June) *"I read it in a pamphlet, I saw these pamphlets and I thought 'oh hearing voices, schizophrenic'. And I thought 'God I'm not schizophrenic am I?'"* (Tony) *"It's what they call schizophrenia, hearing voices in your head"* (Frances)
Genetic inheritance	*"My uncle, he heard voices. You miss a generation and it comes up in somebody else"* (Tony)
Trauma	*"Tony: 'I lost three sisters and one brother. I get flashbacks of all of them... So that's why they say it's Traumatic Stress Syndrome. That's why they put me in that category.' Researcher: 'Do you hear voices in response to-' Tony: 'some of that, yes, what's going through my head'"*
Spiritual / religious	*"Well my mam and dad sent for vicar and he poured salt water over my head"* (Albert)
Delusional	*"He were jealous of our sex life"* (Alice) *"This fella who'd be causing my psychosis..."* (Alice) *"When I went to hospital, they told me it was my neighbour, there were nothing wrong with me"* (Frances)

SUPERORDINATE THEME: Increasing Connectedness with Others and life	
Elements of the theme	**More example quotes:**
Sharing with, and being understood by, mental health staff	*"They have a chat to me, tell me I haven't to worry"* (Alice) *"you could always go to a nurse and have a talk or anything, yes that's how I've got over it by talking, you know, to nurses or doctors"* (June) *"I'm not on my own, whereas before I've always been on my own with it"* (Tony)
Normalisation & belongingness of connecting with other voice hearers	*"There was a lady on here, she could hear voices. Winston Churchill could hear voices"* (Alice) *"It were reassuring... there's other people like me"* (Tony)
Engaging with life despite the voices	*"We just got friendly again... We got in touch again, and it's rekindled it all"* (Frances) *"I always wanted to see the Sistine chapel even when I was a little*

	kid. Seen pictures in books, but I always wanted to see how he painted it" (Tony)

SUPERORDINATE THEME: Feeling Stronger and More Effective

Elements of the theme	More example quotes:
Finding own inner voice to challenge with	*"He's stupid. A stupid man" (Alice)* *"He wants me to die. And I don't want to. I'm not going to take an overdose" (Alice)* *"I tell him off, 'Leave me alone!'" (Alice)* *"He's daft, there's something wrong with him" (Alice "[speaking as the voice:] 'Why don't you end your wife! Get rid of your wife!' [speaking as himself:] I don't want to get rid of her!" (Tony)*
Coping more effectively over time	*"I just feel that I can cope more with them. You know, it's not too bad, whereas before I couldn't do it" (June)*
Increased strength and courage	*"I think I'm stronger this time, than I was last time" (June)*
Increased knowledge and awareness	*"What I didn't realise though, was what he had done, until a bit back, a few month ago… I know what's happening now though. Not immediately, but not long after" (Alice)* *"Now I just think oh well, I know what to do, I know how to cope" (June)* *"I understand more than what I did twelve months ago" (June)*

SUPERORDINATE THEME: "It's just got worse as I've got older"

Elements of the theme	More example quotes:
Recent experience as the worst yet	*"It's going on forever, what does he want with me?" (Alice)* *"It's got more intense" (Alice)* *"The last twelve months have been more difficult that any" (June)* *"I've never had it this bad in my life, as what I have it today. I never knew what it was to hear voices, up until recently" (Frances)*
Welcome of death as an ending	*"It's more frightening now I'm older… I don't know how it's all going to end. How it's going to end up" (Albert)*