Service users' experience of voice hearing:

The interface between the service user

and the health care provider

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Abstract

There is an increasing body of literature to suggest that service users should be more involved in their care, and work more collaboratively with professionals within mental health services. One way of achieving this is for professionals to be more mindful of the experiences of voice hearers.

The aims of the present study were to gain insight into the subjective experience of voice hearing and in particular, to explore this in relation to interactions between professionals and voice hearers.

In depth interviews were conducted with six voice hearers. The resulting narratives were analysed using the qualitative methodology of grounded theory. A core category termed 'Reconstructing a sense of identity' was identified. This highlighted the different ways in which voice hearers attempted to assimilate the experience of hearing voices into their sense of identity. A process model was developed to describe the factors influencing the core category. Five main categories were identified in relation to this: 'being psychotic', 'disclosing information' 'receiving treatment' 'attempting to make sense of experience' and 'sense of self in relation to the psychiatric system'.

The core category and the process model are discussed in relation to existing literature in this area. It is suggested that clinicians should focus greater attention on accessing and working within voice hearers' frames of reference in order to maximise positive outcome. The implications of the present study in terms of clinical practice and policy development are discussed. Finally, methodological considerations are explored and reflections on the research process are provided.

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Chapter One

Introduction

1.1 Overview of Chapter

This chapter provides a summary of how the phenomenon of hearing voices has been perceived and managed by society over time. It seeks to demonstrate how contemporary western society has pathologised the experience and discuss how current psychiatric approaches regard an individual who hears voices as ill and in need of treatment. The merits of this medical model approach to understanding the experience are described along with some of the limitations. Psychological approaches to understanding and managing voice hearing are discussed, as is the increasing emphasis on seeking to understand the meaning of the voice hearing experience to individual voice hearers themselves. Emphasis is also given to considering relevant processes that facilitate understanding of the experience. In particular, the importance of the interaction between voice hearers and professionals charged with their care is explored. The development of user movements and an increasing desire within government legislation to involve users in the development of services is described. Finally, a rationale for the present study and the use of methodology adopted within it is also discussed.

1.2 Hearing Voices

Individuals who hear voices have historically represented dilemmas for society, which has explained and treated such individuals in different ways at different times. For example, in Europe in the Middle Ages hearing voices was often ascribed to supernatural causes such as the presence of demons. Treatment usually involved prayer or exorcism (Holmes, 1994). Whilst years later within the same societies, voice hearers were regarded as gifted visionaries (Leuder & Thomas, 2000a). In many present day African cultures individuals who hear voices are regarded as shamans and afforded high status with society.

The increasing reliance, within western society, on scientific insights to interpret difficult-to-explain phenomena has dominated the 20th century (Thomas, 1997). Society has increasingly looked to science to offer explanatory frameworks for phenomena like hearing voices. Medicine, and in particular psychiatry have become a dominant presence. As such, hearing voices has become pathologised and experiences that society cannot understand are regarded as indicative of insanity. Within this framework, contemporary psychiatry categorises voice hearing as a hallucinatory experience borne out of problems with an inability to objectively evaluate reality and therefore indicative of mental pathology (Leuder & Thomas, 2000b). Hearing voices is regarded as a defining symptom of a psychotic disorder. Other symptoms include delusions, serious deficits in judgment and insight, and cognitive difficulties (American Psychiatric Association, 1994).

Whilst not necessarily always distressing, the symptoms associated with psychosis can be complex and frightening (Garety & Hemsley, 1987). The majority of people who hear voices are likely to come into contact with the psychiatric system and receive a formal psychiatric diagnosis. The most common diagnostic category used to classify psychotic experience is 'schizophrenia'. Individuals may also receive a diagnosis of 'bipolar disorder' (manic depression) or 'schizo-affective disorder' (American Psychiatric Association, 1994). It is estimated that about one person in a hundred will be diagnosed with schizophrenia during their lifetime (Birchwood, Hallett & Preston, 1988). This means that between 100,000 and 500,000 people within the UK, are experiencing problems at any one time (British Psychological Society, 2000).

It is generally accepted that people diagnosed with psychiatric disorders form one of the most marginalized groups within society (British Psychological Society, 2000). Within this group, individuals who have psychotic experiences arguably encounter the greatest degree of marginalisation and social exclusion (Bracken & Thomas, 2001). The public perception of a typical individual who hears voices is heavily influenced by psychiatry's pathologising of the experience. Leuder and Thomas sum it up eloquently when they say, "In Britain today, the 'public knowledge' about voices is that they are bound to insanity, to violence or at best eccentricity...and the experience lacks any intrinsic meaning worth considering"

(Leuder & Thomas, 2000b, pp, 13). Such frameworks of understanding reflect a medical model approach, which regards hearing voices as a symptom of a disease. As such voice hearing has been regarded as a clearly abnormal entity, quite separate from 'normal' experience, thus setting those with these experiences apart from the rest of the population. This presents a very negative image of voice hearing and voice hearers, which is often maintained by the media.

1.3 The Role of Medication

Receiving a psychiatric diagnosis then, implies that the recipient is ill and in need of treatment. The goal of treatment within this medical conceptualisation of psychosis (which includes voice hearing) is to prevent the occurrence of these symptoms by use of medication. The most important medications prescribed for individuals experiencing psychosis are antipsychotic drugs (sometimes called neuroleptics or major tranquillisers). These have proven efficacy for some people, and have become the treatment of choice for psychosis. Such drugs can be taken during an acute phase of psychosis or used intermittently (when the individual feels unwell or distressed) (Herz, 1999, cited in British Psychological Society, 2000). They can also be taken as prophylactics in order to try to prevent relapse. Indeed for many people prophylactic treatment can help prevent hospital admissions (Jolley *et al*, 1990). It is clearly the case that for many people treatment with antipsychotic medication is effective in reducing the intensity and frequency of the voices (Cobb, 1993).

There are, however, concerns about the efficacy of medication in the treatment of psychosis. Firstly, a recent paper (Rabinowitz, Bromet & Davidson, 2003) questioned the evidence base supporting the use of antipsychotic medication. The evidence on efficacy comes mainly from controlled trials, which often have strict exclusion criteria and may not reflect the real life patient group that would be recipients of the drugs. In addition to this, it is important to acknowledge that taking antipsychotic medication does not help everyone. It cannot offer a 'cure' nor remove the problems completely (Awad & Hogan, 1994). Indeed, there are unpleasant and often potentially very serious, even fatal, side effects of such medication (Dukes,

1997 cited in British Psychological Society, 2000). For some people, these can be at least as troubling as the psychotic experiences themselves (Rogers, *et al* 1998).

A conservative estimate appears to be that around a third of people who receive a diagnosis of schizophrenia will continue to experience psychotic symptoms despite complying with medication (Fowler, Garety & Kuipers, 1995). Research has shown that people harbour a range of opinions about their drug treatment ranging from totally positive to unequivocally negative (Day & Bentall, 1996).

1.4 Difficulties with Psychiatric Diagnoses

Aside from the fact that there are limitations as to the effectiveness of antipsychotic medication, there are also serious concerns about the fundamental concept of diagnosis itself (Bentall, 1990). Diagnosis is usually a pre-requisite for treatment with antipsychotic medication. Yet, psychiatric diagnoses are essentially labels that describe certain types of behaviour and assign them to different categories (British Psychological Society, 2000). They do not yield information as to the nature or cause of the experience. There is growing recognition that the experience of psychosis is unique to each individual and to classify individuals in the same manner is to disregard the uniqueness of the experience and ignore opportunities to explore this further.

This awareness of the need to strive for greater understanding of psychotic phenomena has led to an argument for the development of theories that aim to explain individual *symptoms* rather than *syndromes* (Bentall, Jackson & Pilgrim, 1988; Boyle, 1990). Instead of treating specific disorders attention has shifted towards focusing on specific symptoms of psychosis such as hearing voices. This approach of trying to understand individual symptoms has pragmatic appeal and has proved crucial for the development of psychological interventions in this area (Wykes, Tarrier & Lewis, 1998).

This move from syndromes to symptoms in an attempt to increase understanding of the experience has been brought about by an increasing recognition

that psychosis, and within that hearing voices, can no longer be viewed as the product of a disease entity. For many years, theories regarding the causes of such symptoms were clearly rooted in biological and biochemical research and focused upon, for example, genetic endowment, or chemical imbalances in the brain. (See Pinel, 1993 for a review). Hallucinations and delusions therefore were considered irrelevant meaningless symptoms of biological dysfunction (Garety *et al*, 1998), to be treated using anti-psychotic medication. Psychotic phenomena were defined in terms of disordered individual experience, and the role of social and cultural factors in contributing to and maintaining symptoms was largely ignored. Until relatively recently, it was almost heretical to question this paradigm (Bracken & Thomas, 2001).

1.5 Vulnerability–Stress Models

Whilst there remains undoubtedly a biological basis to the development of psychotic symptoms, it is now accepted that psychological and social factors are also important, especially with regard to understanding individual symptoms and the course of disorders (Fowler *et al*, 1995). Interactions between biological, psychological and social factors have been summarised in 'Vulnerability–Stress' models (Nuechterlein, 1987, cited in Fowler *et al*, 1995; Strauss & Carpenter, 1981; Zubin, Stuart & Condray, 1992).

These models suggest that every individual has a different vulnerability to developing psychotic symptoms. People are more or less vulnerable depending on biological factors (e.g. genetic disposition), and psychological and environmental factors (e.g. being either sensitive or resilient to stress). This vulnerability results in the development of symptoms only when sufficient social or environmental stressors are present. These can be, for example, major life events or the use of illicit substances. If an individual's vulnerability is great then low levels of stress might be enough to cause symptoms. Whereas if vulnerability is low, the individual may be better able to cope and much higher levels of stress will be needed before symptoms appear.

These models are important as not only do they draw together factors contributing to predisposition, precipitation and perpetuation of symptoms, they stress the individual nature of psychotic experience and imply that it is possible to reduce the influence of adverse environmental factors using psychological techniques (Fowler *et al*, 1995).

A major advantage of 'Vulnerability–Stress' models over the medical model is that they offer scope for individual variation and seek to explain why some individuals develop symptoms whereas others do not, even when they experience similar life events. The implication therefore is that anyone can develop psychotic symptoms if exposed to sufficient stress (Hemsley, 1993), for example, following bereavement, as a consequence of childhood sexual abuse or in response to trauma (British Psychological Society, 2000). Rather than taking a categorical approach to psychotic symptoms it is much more useful to adopted a dimensional perspective (van Os *et al*, 1999), and that far from being an abnormal concept, psychotic experience lies on a continuum with 'normality' (Claridge, 1985). There is considerable evidence to support this notion. For example, one in ten people report hearing voices not associated with sleep states (Tien, 1991) and a large proportion of the population hold 'unusual beliefs' (Romme & Escher, 1993). Such ways of constructing hearing voices help to discredit the dichotomous view of sanity and insanity. They emphasise the need to adopt a holistic approach to understanding the phenomena and place considerable importance on understanding the meaning this has for the voice hearer.

1.6 Is Hearing Voices an Illness?

Whilst many people troubled by voices will see their voices as a consequence of a mental illness and look to medication as a potential solution, many others develop very different ways of understanding their experiences. The notion that psychotic experiences (like hearing voices) lie on a continuum with normality has led many professionals to question the construction of hearing voices as an illness (Bentall, 1990). Leuder (2001) goes further and suggests that hearing voices is not a

symptom of an illness nor is it particularly distressing in itself. It *becomes* distressing because of the way society explains it.

It has also been argued that mental illness may be a perfectly rational response to intolerable or adverse conditions (Thomas, 1997). Szasz, a psychiatrist by training but a fierce critic of his profession, goes further in suggesting that there is no such thing as mental illness. Rather psychiatry is society's 'tool' for controlling deviant individuals (Szasz, 1974). Although these views do not sit well within contemporary psychiatric thinking regarding hearing voices, they are important to consider as they bring a more diverse perspective to understanding the meaning of voice hearing.

1.7 Psychological Explanations

As has been demonstrated with the description of vulnerability-stress models above, the literature suggests that professionals working with voice hearers need to adopt a holistic approach regarding their conceptualisations of the experience, which must allow room to question the dominance of the medical model (Thomas, 1997). Psychological approaches with their intrinsic emphasis on helping individuals make sense of their experiences have a lot to offer (British Psychological Society, 2000).

Interest in psychological approaches towards informing the understanding and management of psychosis has grown considerably in recent years. Although still a relatively new field of enquiry, the focus of much of this work has been about voice hearing. Much of this research has focused on developing cognitive models to explain voice hearing (e.g., Garety *et al*, 2001; Morrison, 2001). Such models stress the cognitive process that may lead to the formation and maintenance of voice hearing. Such processes include cognitive deficits and biases (Frith, 1992) and attribution errors (Hemsley cited in Fowler *et al*, 1995).

Evidence suggests that attribution errors result from significant life events, which have resulted in the development of negative schematic models of the self and the world (Garety *et al*, 2001). Such core schemas lend themselves to cognitive

behavioural approaches towards intervention, and there is now a growing body of literature demonstrating the efficacy of cognitive behavioural therapy (CBT) as an intervention for voice hearing (Chadwick, Birchwood & Trower, 1996). Despite the increasing popularity of CBT, little research has focused on seeking to explore voice hearers' understanding and experiences of this approach. A notable exception is a recent qualitative study (Messari & Hallam, 2003), which highlighted the individual way in which voice hearers experienced treatment. This again emphasises the need for professionals to seek to understand voice hearers experiences and not make assumptions.

However, many of the cognitive behavioural models remain fundamentally rooted in the medical model approach in that they regard voice hearing as a product of disordered or dysfunctional thinking on the part of the voice hearer. They seek to develop theories as to what the voices *are*, not what they actually *mean* (Leuder & Thomas, 2000a). It could be argued that professionals could help voice hearers to a greater degree by seeking to determine what voice hearers themselves actually think about their experiences.

The basic premise of much of the psychological literature in this area stresses that each voice hearer has a different relationship with his or her voice(s). This has implications for the development of coping strategies. Much of the psychological literature on coping with voice hearing regards the individual as an active agent searching for meaning and control over their experiences (Birchwood *et al*, 1993). Individuals are perceived as searching for a framework with which to make sense of their experiences and coping has been shown to be enhanced once an individual has developed their own explanatory system and has a perceived sense of control over the experience (Romme and Escher, 1989). A person's ability to cope is linked to their appraisal of the experience of hearing voices. The importance of the exploration of the content and beliefs about the voices is stressed in order to develop an understanding of the experiences of clients. This in turn is a pre-requisite to successful intervention. This offers perhaps a more shared understanding and collaborative approach to intervention than the use of medication.

There is a relative lack of research concerned with psychological adaptation to voice hearing (Drayton, Birchwood & Trower, 1998). A dated but still relevant investigation into this area by McGlashan *et al*, (1975) proposed that voice hearers adopt one of two coping styles to help them cope with the experience: either 'integration' or 'sealing over'. An 'integrative' coping style is characterised by an individual's active attempts to make sense of the voice hearing experience and incorporate it into their sense of self. This is in contrast to individuals who adopt a 'sealing over' coping style. Such individuals tend to isolate the experience and view it as alien. They generally do not wish to explore, understand or incorporate the experience into their sense of self. Individuals who employ an 'integrative' coping style have been shown to have a better clinical outcome than those who 'seal over' (McGlashan, 1987: Thompson, McGorry & Harrigan, 2003).

The coping styles proposed by McGlashan *et al* (1975) are important in determining how voice hearers construct their identity in response to the presence of voices. They may choose to see themselves as ill and adopt an identity based around a sick role, or they may reject the medical model and construct their voice hearing differently (Davidson & Strauss, 1992). One might expect individuals who 'seal over' to accept an illness identity more readily than those who have sought to explore and integrate alternative explanations. (Taylor & Perkins, 1991). It is likely that a number of factors are important in the process of constructing identity. For example, individual differences in personality are important. The explanatory framework adopted by an individual is of paramount importance as is the process of interaction between the voice hearer and the psychiatric system.

1.8 The Search for Meaning

Perhaps the first meaningful attempt to understand what voice hearing means to individuals was by Marius Romme and Sandra Escher (1989), who have since gone on to be pioneers in this area of research. In this study Romme, a Dutch psychiatrist described his work with a voice hearer who was not helped by medication and who was becoming increasingly distressed and desperate. Romme's patient had described her theories regarding the meaning of the voices and Romme

felt that providing her with an opportunity to discuss these theories with other voice hearers might be beneficial. Adopting a somewhat innovative sampling strategy, Romme took part in a television programme where he invited other voice hearers to contact him. A research project of major importance followed in which Romme and Escher clearly demonstrated that the voices heard by respondents were meaningful and applicable to their daily lives.

A significant finding from this study was the fact that not only were voices experienced by those described as 'mentally ill' but also by individuals society regarded as 'well'. Romme (1989) put forward the idea that voices can be lived with and even if they are particularly distressing, trying to understand their meaning can promote effective coping (Baker, 2000).

Romme and Escher (1989) identified three distinct phases that voice hearers go through relevant to their coping: an initial 'startling' phase usually associated with the onset of voices which was experienced by most as particularly frightening. This was followed by a phase of 'organisation' whereby the voice hearer began to communicate with the voices. The third phase was one of 'stabilisation', characterised by the development of a more constant way of explaining and managing the voices. A search for meaning pervaded each phase. The study is open to criticism on methodological grounds, yet remains a seminal paper in this area.

It is becoming more widely accepted that it is not the experience of hearing voices in itself that is a problem for individuals; it is the distress caused by the voices that is important (British Psychological Society, 2000). It has been postulated that a mediating factor between voice hearing and distress is the belief a person has about their voices (Chadwick & Birchwood, 1994). Chadwick and Birchwood (1994) used cognitive models to help promote an understanding of both the content of the voices and the voice hearer's affective and behavioural responses to them. It was found that voice hearers interpreted the phenomena according to their beliefs about the voices, and their appraisal of the voices in relation to themselves (Close & Garety, 1998, pp, 175). As such, subsequent emotional responses and action were shown to be inextricably linked to the beliefs about the voices. From this work, they developed

the Beliefs about Voices Questionnaire (Chadwick & Birchwood, 1995) the first of its kind to specifically assess voice hearing experiences.

Chadwick and Birchwood's (1994) study was relatively innovative and they acknowledged that the methodology adopted was lacking demonstrable reliability. However, their findings have subsequently been supported by other studies (Close & Garety, 1998). This strongly suggests that the degree of distress associated with voice hearing is closely related to the subjective meaning of the experience. If professionals can understand voice hearers' beliefs about their voices, they can then hope to develop enhanced coping strategies for managing distress.

Romme and Escher have developed their ideas further, and explored the differences between voice hearers who are able to successfully manage their voices and those who continue to experience overwhelming distress in relation to their voices (Romme & Escher, 1993). Research suggests that those most successful in managing their distress were able to modify their beliefs and attitudes about their voices. They were then able to integrate the experience into their lives successfully. Interestingly, the literature suggests that many of those not able to integrate the experience into their lives are often the recipients of psychiatric services (Baker, 2000). It is important to consider why this might be the case.

1.9 Relationships Between Voice Hearers and Professionals

Explanations that regard voice hearing as an illness tend to dominate mental health services. This may be a major factor in understanding why voice hearers often find it difficult to change their beliefs about their voices. This exclusivity of medically orientated explanations often means that voice hearers have little or no access to alternative frameworks of understanding. This is generally regarded as problematic (Ritsher, Coursey & Farrell, 1997).

In addition, the now outdated and erroneous belief that professionals should not enter into discussions with voice hearers about their voices lest they be seen as colluding with them and as exacerbating their distress, is still prevalent in some areas

of the psychiatric system (Thomas, 1997). Indeed, all the evidence presented above would suggest quite the contrary and regard it as essential to enter into dialogues about the voices in order to enhance an individual's ability to cope.

Professionals often fail to hear aspects of the subjective experiences of voice hearers (Strauss, 1989). This could be for a number of reasons. For example, professionals may perceive it as too threatening to accommodate the experiences of voice hearers as they may conflict with their own experiences or call into question some aspects of their professional practice. At a wider level, it seems likely that the psychiatric system as it functions at the present time is poorly equipped to facilitate discussions of this nature between professionals and voice hearers as an integral part of their care (Beech, 1999).

Many first person accounts of voice hearers' contact with the psychiatric system that have been published speak of the problems within the system (Anonymous, 1989; May 2000). In particular, individuals who have had prolonged contact with mental health services cite three main sources of difficulty: their original mental health problems, the effects of the medication prescribed to manage these and also the effects of the legacy of care in which they often become deskilled and institutionalised (C. Stowers, personal communication, 18th June 2003). Whilst it is entirely possible that there may be publication biases in terms of prioritising critical accounts of services over more positive ones, it is vital that professionals heed the comments of users of services. Many voice hearers continue to regard professionals working within the psychiatric system as too quick to adopt a medical approach that reinforces the denial of the personal reality and meaning of hearing voices (Sayre, 2000). Rufus May, a clinical psychologist but also a voice hearer and recipient of treatment within the psychiatric system describes the experience of being in hospital as frightening and as a test of endurance (May, 2000). He also speaks of having to fight against a "disempowering general sense of being undervalued" (May, 2000, pp, 6).

A recent study suggested that users felt that many professionals were only perceived as helpful and supportive if they were able to talk to them 'on a level' and demonstrate a caring attitude (Corring, 2002). First person accounts from voice

hearers have stressed the importance of professionals being 'real'. This involves professionals being open and honest in interactions with them. The professional boundaries considered so important by professionals are often seen as barriers by voice hearers preventing them from accessing support (Anonymous, 1989). As a consequence many voice hearers do not feel contained or supported by the psychiatric system and often feel it simply confirms for them a sense of personal failure (Hatfield & Lefley, 1993). It is perhaps important for professionals to try to identify the processes that facilitate recovery and seek to incorporate them into practice (May, 2000).

1.10 Challenges for Professionals

Working with voice hearers requires a very different attitude to therapy than that usually promoted during the training of most mental health professionals. Romme and Escher (2000) have produced a comprehensive guide for professionals outlining ways of understanding and working effectively with voice hearers in order to maximise the subjective understanding of the experience. They advocate a collaborative approach and one that considers professionals as experts by profession but perhaps more importantly voice hearers as *experts by experience* (Baker, 2000). Voice hearers need to be seen as experts by virtue of their own experiences.

The recognition that voice hearers need to have access to a variety of different explanatory frameworks to explain their experiences has implications for the training of professionals. Whilst users of services have a role to play in facilitating training (Coleman & Smith, 1997) this is unusual, and an area in need of further development.

Perhaps more philosophically, it has been argued that in order to really understand the experiences of voice hearers, professionals must be aware of how their own beliefs and actions impact on interactions with voice hearers. The tendency for professionals to pathologise voice hearing still exists. Professionals need to be mindful of the fact that speaking in purely medical or psychological language carries with it the risk of excluding the voices of the voice hearers themselves (Thomas,

1997). For example, when individuals' explanations for their voice hearing are sought, it is often the case that these are reinterpreted into professional language so much so that the meaning gets lost along the way and voice hearers are denied the opportunity to be heard and understood correctly. This often results in an increased sense of marginalisation (Thomas, 1997). Individuals do make sense of their experiences in a way that is functional for them. The fact that this explanation may not "fit" with the perspectives of those treating them should not serve to alienate them from the very services designed to support them. Voice hearers who feel empowered enough to discuss their explanations with both professionals and other users, can significantly advance professionals levels of understanding, insight and empathy. They can also give professionals a good basis for supportive interventions that will be acceptable to the client and are therefore more likely to prove useful.

1.11 User Involvement

There is a growing service user movement in the UK ranging from small, locally based self help groups to larger organisations such as MIND or 'Rethink'. All share common aims, act as advocates, campaign for improved services and challenge assumptions and attempt to combat stigma surrounding mental illness (British Psychological Society, 2000). Members of such groups cite the opportunities for self help and peer support as essential to increasing a sense of well being (Chamberlin, Rogers & Ellison, 1996).

The aims of some user groups are to go beyond influencing service development and start challenging the professional dominance of the understanding of mental distress and therefore adjust the balance of power as it stands at the moment (Barnes & Wistow, 1994). This is closely related to the belief that user involvement should not be merely the icing on the cake, but rather the main ingredient (Perkins, 1996).

One such organisation is the Hearing Voices Network. This evolved largely out of the work of Romme and colleagues (Romme & Escher, 1993) described above and as the name suggests, is exclusively for voice hearers. The first UK based

Hearing Voices Group was set up in Manchester in 1988 and there are now over 40 groups running throughout the UK (Barker, 2000). The basic philosophy is to adopt a non-judgemental approach to voice hearing in which group members are accepted as equals and their explanations are accepted at face value and not imposed on them from external sources. Members can freely share their experiences of hearing voices with one another should they wish to do so but no expectations are placed on individuals to discuss their own experiences (Martin, 2000). Group members are able to speak from the experience of having 'been there' and as such can offer and benefit from sharing experiences and gaining insights that cannot be provided by the majority of professionals. The Hearing Voices Network offers a safe place for individuals to experience the full range of feelings often associated with hearing voices without feeling judged and free from recriminations. It has taken huge steps towards normalising the experience and has helped to promote awareness of the need to move away from thinking about hearing voices *per se* and more towards emphasising the relationship between voice hearers and the content of the voices.

However, the increasing number of user movements, self help groups and publications set up to support "survivors" of psychiatric services suggests that many users of such services are dissatisfied with their experiences of the psychiatric system. A cursory search on the Internet for related websites produces a surprisingly large number of sites set up for this purposes. For example, the websites set up by the Critical Psychiatry Network or organisations such as Mad Pride contain accounts of users of services regularly reporting that professionals emphasise their disabilities rather than their abilities. Many users also report dissatisfaction with their existing treatment plans, citing a lack of understanding of their experiences, by clinicians, as a major difficulty (Loewenthal, 1995). In addition a frequent complaint from users of services is that their views are dismissed if they do not agree with those in powerful positions, namely those professionals charged with their care (Williams & Lindley, 1996).

A way of addressing these problems is to employ voice hearers as providers of services. There is an argument that in doing so, services would become more relevant and acceptable to other users. It might also help promote feelings of hope for the future as well as benefiting those offering services in terms of increasing their

confidence and self-esteem. However, as yet, this remains somewhat an ideal rather than a norm. Indeed it has been demonstrated that the level of service user involvement with their own care often seems to be dependent on individual professionals (Peck, Gulliver & Towel, 2002). Others have questioned how far user involvement can be 'allowed' to go (Pilgrim & Waldron, 1998) and whether, in reality, it represents anything more than empty rhetoric (Perkins, 1996).

1.12 Rationale for the Present Study

This chapter has drawn attention to some of the main debates within psychiatry and psychology regarding the treatment of individuals who hear voices. Most notably the increasing recognition of the need for professionals of all disciplines to move away from concentrating only on the presence or absence of voices and towards much greater exploration of *content* i.e. what the voices are actually saying and linking this to previous experiences. By actively trying to understand the meaning of the voice hearing experience for an individual and working within their frame of reference, professionals have a much greater opportunity to help alleviate some of the distress associated with the experience. The findings of research in this area would serve to increase the psychological knowledge base regarding how voice hearers construct explanations for and make sense of their experiences. Whilst previous research has sought to obtain first person accounts of the experience of hearing voices (Anonymous, 1989) research focusing specifically on the interaction between voice hearers and the psychiatric system is scarce.

It is particularly important to increase professional understanding of the subjective experience of hearing voices, as there is evidence to suggest that between 25-40 per cent of individuals are likely to experience symptoms associated with depression (Johnstone *et al*, 1991) In addition, hearing voices is also associated with an increased risk of suicide (Briere *et al* 1998). Therefore clinicians need to address beliefs about voices in order to help alleviate associated distress and reduce risk of depression or suicide. The emphasis on the subjective understanding of voice hearing in relation to the psychiatric system and on user involvement is particularly salient in light of recent government legislation.

Mental health is now a priority within the National Service Framework produced by the Department of Health (Department of Health, 1999). This sets out national standards and identifies key strategies and targets for services to address. In particular it emphasises the importance of consulting with users of services. It also specifies that assessment and subsequent treatment of individuals with severe mental health problems should cover psychological and social factors as well as psychiatric functioning. Psychological interventions should be available to every service user and all mental health workers should be able to use psychological frameworks of understanding to inform their practice (British Psychological Society, 2000)

In addition the National Institute for Clinical Excellence in its most recent publication emphasises the need for professionals "to take the time to build supportive and empathic" relationships with users of services (National Institute for Clinical Excellence, 2002, pp, 6). It regards this as essential practice and vital to aiding the professionals' understandings. Whilst relying heavily on a medical model approach to constructing voice hearing, it does recommend that, where possible, service users should be active agents in regard to their own care and become engaged in the development and delivery of the service they receive. Investigating the extent to which voice hearers feel empowered, or otherwise, by health professionals, in relation to their voices, serves to highlight how well these targets are being met.

There is an increasing recognition of the importance of obtaining the views of voice hearers in relation to their experiences within the psychiatric system; and then to involve them in the development and delivery of services designed for their care. (Department of Health, 1999: 2000). Whilst research attention is being focused on the importance of involving service users, little is known about the extent to which users actually feel that they are being understood accurately and involved in planning their care. Research that can add to the growing body of literature in this area is needed. Insights gained into how users of rehabilitation services perceive the services available to them are important. Exploring the experiences of users can provide an indication of the degree to which users themselves would *like* to be involved, and compare this with the degree to which they *are* involved, in the planning and implementation of treatment strategies for the management of their voices.

The findings of such studies can provide an opportunity for developers of services at both a local and national level to consider how best to incorporate the experiences and views of voice hearers into current practice and future development of services.

Generally, user involvement takes the form of satisfaction studies, completed by users and analysed using quantitative research methods. Whilst these attempts to obtain the views of users of services are very important and informative, it is likely that some of the complexities and more subjective phenomena associated with being a user of services will not be tapped by such questionnaires that offer minimal scope for qualitative comments. Therefore, research that goes beyond this and attempts to explore the subjective experiences of being both a voice hearer and a recipient of psychiatric care offers perhaps a more meaningful attempt to involve users.

Research Question

The study focused on voice hearing, as it is the most common and most researched form of hallucinatory experience associated with psychoses. There were three broad aims to the study:

- _To gain insight into the subjective experience of hearing voices_

- _To explore voice hearers' experience of the interaction between themselves and professionals working within the psychiatric system in relation to hearing voices_

- _To consider ways in which the insights gained could impact on practice and help to improve mental health services for voice hearers_

1.13 Use of Qualitative Methodology

It was felt that the research questions would be addressed most appropriately using a qualitative methodology. A number of factors informed the decision to adopt such a methodology. Firstly, it has been demonstrated that qualitative methods are particularly important for exploring areas that have received little research interest (Turpin *et al*, 1997). Also areas of research that seek to uncover the meaning of specific phenomena to individuals are best researched using this methodology (Silverman, 2000). This method of analysis offers a way of generating considerable information exploring how individuals construct their reality. Analysis using this approach can provide researchers with "...alternative understandings of participants' beliefs and actions more so than those readily available in clinical settings" (Charmaz, 1990 pp. 1161). It is also a particularly useful means by which the relationship between an individual and the social environment can be explored (Humberstone, 2002). The suggestion that such an approach can allow the experiences of individuals to be explored (Parker, 1994) appealed to the researcher's interest in this area.

It was felt that researching the subjective experience of hearing voices was a potentially complicated area that would yield some complex accounts from participants. Indeed, despite the emphasis on understanding meaning, with the notable exceptions of Sayre (2000); Knudson & Coyle (2002) and Humberstone (2002), very little qualitative research has been undertaken. Qualitative methods of analysis offer a comprehensive and flexible means of allowing for considerable complexity and individual difference to be explored (Elliot, Fischer & Rennie, 1999). Adopting such an approach with individuals with persistent psychotic symptoms allows for a depth of information to be obtained, which may not be accessed using more quantitative research methods (Humberstone, 2002). Indeed it could be argued, that the open ended nature of data collection used in qualitative research offers a framework in which individuals who may have difficulty communicating effectively due to disturbance from the presence of voices, may have more opportunity to respond.

There are many approaches a researcher can adopt under the rubric of qualitative research. For the present study a Grounded Theory (Strauss and Corbin, 1998) methodology was adopted. Such an approach carries with it a mandate to develop a social theory that is grounded in the actual experiences of participants. Building of theory was considered important as research of this nature contributes greatly to developing fields of enquiry (Henwood & Pidgeon, 1992). Henwood and Pidgeon (1992) also state that a grounded theory analysis is particularly useful when theory relating to the topic of investigation is inappropriate, incomplete or absent. As has been discussed, it was felt that few studies had particularly addressed the interaction between voice hearers and professionals and as such the application of grounded theory was merited in this case.

A fuller description of qualitative research in general and more specifically grounded theory follows in the next chapter, along with the procedure involved in the present study.

Chapter Two
Method

2.1 Overview of Chapter

As discussed in chapter one, it was decided that in order to most effectively address the research questions, a qualitative methodology should be adopted, specifically grounded theory. This chapter discusses the nature of scientific enquiry and explores the key concepts within the qualitative research paradigm. It provides a brief examination of the epistemological position of qualitative research within the realm of scientific knowledge. The focus of this chapter is on grounded theory as a method of analysis, detailing its development, structure and application in psychological research. The rationale for adopting such an approach within the present study is further developed. The epistemological position of the researcher is discussed and information about using interviews as research tools is provided. Finally, this chapter documents the procedure adopted in the present study, highlighting the principles of grounded theory in practice.

2.2 The Nature of Scientific Enquiry

Within psychology, like the natural sciences, scientific enquiry has traditionally proceeded through the testing of pre-ordained hypotheses, in an attempt to discover laws of cause and effect that govern phenomena. Researchers conducted rigorous, often laboratory based, experiments designed to yield considerable amounts of quantifiable data that could be statistically analysed in order to provide objective, reliable and generalisable 'scientific truths'. This approach to science has become known as the 'quantitative paradigm' (Henwood & Nicolson, 1995). Whilst this positivistic model of science was most dominant in psychology in the 1950s and 1960s, it still has considerable influence today (Parker, 1994).

Such an approach, although clearly able to make invaluable contributions to the understanding of social and psychological processes across a range of disciplines, began to have its dominance questioned in the 1970s. The limitations of the paradigm were first voiced by sociologists and anthropologists and later those conducting research within psychology (Richardson, 1996). These commentators questioned whether too great an emphasis was being placed on the concepts of hypothesising and verification of *a priori* theories. It was felt that seeking to reduce human behaviour to a set of quantifiable variables and forcing people's experiences into pre-established categories resulted in an inability to access the complexity and range of meanings that people ascribe to their experiences (Strauss & Corbin, 1990). What has become known as the 'qualitative research paradigm' arose out of these concerns. There is much debate within psychological research as to the role and application of both quantitative and qualitative research methods. Those issues of direct relevance to the present study will be discussed later but see Gergen (1978) for a greater discussion of these issues.

2.3 Qualitative Research

Whilst the quantitative paradigm emphasises entities such as hypotheses testing, quantification and discovering knowledge, the qualitative paradigm places much more emphasis on accessing the stories or accounts of those taking part in the research. Researchers felt that positivist thinkers neglected meaning (Parker, 1994). As such, the defining characteristics of qualitative research revolve around giving the client a voice. Analysis of data that draws on qualitative methods is exploratory in nature (Henwood & Pidgeon, 1992). It focuses on the collection of data in much more naturalistic settings rather than laboratory based conditions. Such data are gathered from interviews, observations and transcripts, and the complexity of behaviour and language are analysed as opposed to frequencies and other discrete variables. Advocates of qualitative research methods put forward the argument that research that does not start with *a priori* hypotheses frees the researcher to consider multiple interpretations and meanings of the data. This is in contrast to quantitative research that seeks to test specific theories. As such, theory emerges from the data (Guba, 1981). The role of the researcher assumes greater importance in that they are

central to the analytic process (Parker, 1994). Qualitative methods of enquiry are essentially interpretative and constructionist in their approach in that they seek to understand the context in which phenomena occur (Henwood, 1996).

Traditionally, a tension between quantitative and qualitative paradigms has been noted, with many researchers perceiving them as being mutually exclusive and competing methods of enquiry (McLeod, 2001). In particular qualitative research has been perceived as of secondary importance to the more widely used quantitative methods. In this sense, qualitative methods of enquiry that seek to uncover the nature of experience are often used to promote an understanding of phenomena that have not previously been researched or where no existing theory exists (Strauss & Corbin, 1990). The use of such analysis is often seen as merely a preliminary method to open up new areas and provide pointers for further quantitative enquiry or to yield a novel insight into previously well researched areas (Richardson, 1996).

Whilst it is true that qualitative research often proceeds very satisfactorily in this way (McLeod, 2001) it is also the case that to restrict the use of qualitative methods to this limited role is to miss out on the full potential of the method of analysis (Charmaz, 1995). There is now a substantial argument that it is no longer appropriate to see qualitative and quantitative research as polar opposites within psychology (Silverman, 1992) as both methods have the same goal, i.e. greater understanding of psychological processes. Indeed, many studies adopt both approaches in the analyses of data to maximise the insights gained (Silverman, 1992; Todd, 1998). Qualitative research is increasingly being seen as a field of enquiry in its own right (Denzin and Lincoln, 1994) which has a distinctive role to play in the creation of a knowledge base to inform practice and policy (McLeod, 2001).

Qualitative research is not a unitary construct. Considerable variation can be applied both in the method of analysis adopted and the epistemological perspective applied to this. It is often regarded as useful to consider the methods of analysis within the paradigm as on a continuum ranging from the more empirical position adopted by content analysis (Krippendorf, 1980) in which the discovery of valid representations of reality is sought, through to the rather more constructionist approach adopted in discourse analysis (Potter & Wetherell, 1987) which, whilst still

evidenced based, is very interpretative and emphasises how language is used to construct the world. However, it is not always as simplistic as this as it is perhaps possible to conduct content analysis from an epistemological position rooted in social constructionism.

A method of analysis that is broadly speaking, somewhere between content analysis and discourse analysis in terms of its epistemological position is grounded theory (Glaser & Strauss, 1967). Grounded theory is epistemologically rooted in contextualism and places its emphasis on the construction of meaning. Much qualitative research within psychology has drawn upon grounded theory principles and techniques.

2.4 Grounded Theory

An Historical Perspective

Grounded theory as a methodological approach was first described by sociologists, Barney Glaser and Anselm Strauss in their book 'The Discovery of Grounded Theory' (Glaser & Strauss, 1967). At this time they were interested in understanding the processes involved in the institutional care of terminally ill patients. Their research focused on accessing the subjective experiences and meanings attributed to these by those involved.

A search for meaning and understanding of the experiences of individuals led them to develop a more "bottom up", inductively driven method of research, the aim of which was to develop a theory that was *grounded* in the accounts of research participants. This became known as grounded theory. A distinctive characteristic of this approach is the emphasis placed on understanding how people make sense of or construct their reality.

The inductive nature of enquiry dictates that a researcher begins the study with a general idea of the area they wish to explore, then allows the theory to emerge from the data collected (Strauss & Corbin, 1998). The notion that theory emerges or

is discovered from the data is itself quite positivistic and responses to this will be explored later. Glaser and Strauss (1967) believed that research conducted in this manner would represent the reality of a phenomenon more fully because the researcher has facilitated the emergence of theory as opposed to trying to force the data to fit an existing theory. Advocates of this approach argue that theory derived in this way promotes deeper understanding of and greater insights into the phenomena being explored and provides a meaningful guide to action (Strauss & Corbin, 1998).

Relevance to Psychology

Although Glaser and Strauss were sociologists, there is considerable literature to demonstrate that grounded theory has clear relevance to psychological enquiry (Henwood & Pidgeon, 1992: Rennie, Phillips & Quartaro, 1988). The methodology has been applied frequently to research carried out within health psychology (Charmaz, 1995) and social psychology (Currie, 1988). In addition, grounded theory has been used in psychotherapy process research (Rennie, 1994) and has been shown to be particularly sensitive in identifying psychological processes that are often impossible to access using alternative methods of analysis. This is likely to help increase clinicians' understanding of the internal worlds of their clients (Rennie et al, 1988). Developing insights into the internal worlds of clients is very important as obtaining a deeper understanding of clients' experiences is likely to be an important factor in improving clinical outcome.

Grounded Theory in Practice

Grounded theory analysis can be undertaken on any kind of qualitative data, for example, observations, interviews data or transcripts (Henwood & Pidgeon, 1995) and follows a systematic and rigorous procedure (Strauss & Corbin, 1998). As will be discussed later, researchers differ in the emphasis they place on different aspects of this procedure, but essentially analysis undertaken within a grounded theory approach proceeds in a similar fashion. Strauss and Corbin (1990; 1998) and Charmaz (1995) write in detail about how the process is undertaken.

Unlike quantitative research, data collection and analysis occur simultaneously. Data (usually the actual words spoken by participants) are broken down into small meaningful units and assigned a code that attempts to capture the essence of what is being said. Different codes that represent similar aspects of the same process are placed together to form categories. These are constantly compared to each other by a process known as the constant comparative method (Strauss & Corbin, 1990). This is effectively the backbone of the analysis and refers to a process of continually comparing and contrasting elements within the data. Similarities and differences between phenomena are identified and explored, as are the conditions under which the phenomena occur. This is an ongoing process that continues throughout the analysis (Pidgeon, 1996). The researcher keeps track of this process by means of memo writing (Charmaz, 1995) where links are made within and between different categories. These categories are then reassembled to form the basis of a theory. Gradually theories are developed to explain the behaviour and processes involved on the part of participants.

Sampling for subsequent data collection involves actively seeking participants who will add to the developing theory. This is known as theoretical sampling and is the process of recruiting specific individuals whose experiences are likely to increase understanding and development of theory. Data gathering is driven by concepts derived from the evolving theory and based on the notion of making comparisons between accounts (Strauss & Corbin, 1998). Events and incidents rather than people *per se* are being sampled. A method often used is negative or deviant case analysis (Strauss & Corbin, 1998) where a participant is recruited because some aspect of their experience does do not fit with the theory that has been developed thus far. In effect, analysis guides the subsequent data collection (Charmaz, 1995). Sampling should continue until theoretical saturation is reached (Richardson, 1996). This is the point at which further data collection adds nothing new conceptually to the developing theory.

The effective application of grounded theory requires 'theoretical sensitivity' on the part of the researcher (Henwood & Pidgeon, 1992). This is the common to all qualitative methods of analysis and is the ability of the researcher to be sensitised to the data, to be able to recognise salient aspects of it and to make coherent

associations as the research progresses. Researchers have to develop this by drawing on a number of sources, for example, personal and professional experience, referring to the literature (in the latter stages of the project) and through the process of interacting with the data itself.

2.5 The Role of the Researcher

It becomes evident from the above description of grounded theory analysis that, in order to make sense of the often vast amounts of data generated and begin to put it all together to form the basis of a coherent theory the researcher must be immersed in the data. Indeed, their role within the analytic process is very significant (Charmaz, 1990). The creativity of the researcher is paramount to the research process (Sandelowski, 1995 cited in Richardson, 1996). Yet as well as being creative, they must also be able to think critically and abstractly (Patton, 1990), for example, to be open to multiple ways of interpreting data and to exploring them all thoroughly, before deciding on one way that makes the most conceptual sense to themselves.

Consideration of the role of the researcher in this process has gained importance over time. Glaser and Strauss' (1967) original work made passing reference to the role of the researcher but perhaps did not fully consider the variety of ways researchers can influence the process. However, more recently there is increasing recognition that the researcher inherently "gives something of themselves" to the process, as analysis is the "...interplay between the researcher and the data" (Strauss and Corbin, 1998, pp. 12). The previous experiences, background and assumptions of the researcher will inevitably impact on analysis of this nature. Far from being problematic, this is desirable, providing these assumptions are made explicit at the start of the research process and that there is an ongoing attempt throughout the research process to examine the impact of these on the research process. In practice, many researchers will begin research without having consulted the pertinent literature in their area of study, in order not to unduely contaminate research with their pre-conceived assumptions as to the nature of the findings.

2.6 Considering Quality

Good quality research using grounded theory demonstrates a degree of theoretical sampling and shows that data have been analysed using the constant comparative method. The researcher must have a developed sense of theoretical sensitivity in order to see what is important in the data. Each of these concepts was described briefly previously and together are regarded as the cornerstones of quality (Strauss & Corbin, 1990).

It is generally accepted that the quality of qualitative analysis cannot be adequately judged by reference to the same criteria or standards adopted for assessing quantitative research. This is due to the very different methods and epistemological perspectives adopted by qualitative researchers (Henwood & Pidgeon, 1992). Concepts such as objectivity, reliability and generalisability are of little relevance to qualitative research, especially that drawing upon a constructionist or contextualist approach (Madill *et al*, 2000). Consequently an increasing number of psychologists have begun to explore appropriate ways of adequately assessing quality (Stiles, 1992). However, although several criteria have been put forward to date it appears that this is still an area under development (Richardson, 1996).

Although reliability, as understood by quantitative researchers, is not regarded as a useful concept in the evaluation of qualitative research (Marshall & Rossman, 1989), researchers still have a responsibility to demonstrate the 'trustworthiness' of their analysis (Lincoln & Guba, 1985). Therefore the concept of validity assumes great importance (Silverman, 2000). A form of this is internal coherence (Richardson, 1996). A good qualitative study will have a high level of internal coherence. It will demonstrate clearly that a coherent and consistent argument has been put forward by the researcher. Any contradictions in the analysis will have been identified and addressed. The researcher will have made the thought processes behind decision making transparent and clearly grounded ideas in the available data. Enough of the raw data should be woven into the analysis to allow the reader to understand why interpretations were made.

A further measure of quality is to pay considerable attention to deviant (or negative) case analysis (Silverman, 2000). This is essentially the process of identifying and focusing on aspects of the data where 'things go differently' (Perakyla, 1997). Attempting to integrate variation within the theory seeks to give it greater conceptual density and richness.

All of the data should be filed in such a way that someone else not involved in the project could follow the "data trail" that led to the final report (Yin, 1989). Transparency is such an important concept that some researchers have suggested conducting an independent audit and actually employing someone not involved in the project to actively try to follow the data trail from start to finish (Lincoln & Guba, 1985). It should be stressed that although this may sound similar to the quantitative notion of inter-rater reliability, it is not the same thing. In ground theory analysis, there is no "right" way to proceed and a different researcher repeating the same study would inevitably bring different experiences and interests to the collection and analysis of data and thus generate different findings. This is not of concern. What is important is that that person can follow the logic behind a given study. If so, this serves as a good indicator of quality (Rennie *et al*, 1988).

Constantly grounding the theory being generated in the original data ensures it remains true to the original accounts obtained. A further means of ensuring quality is to lay open the analysis to other researchers and to try to defend the interpretations made. If, after concerted attempts to challenge the decisions made, they retain a degree of conceptual sense, then this serves to strengthen the theory. Another means of assessing quality is to engage in a process of respondent validation (Silverman, 2000). This involves the researcher going back to participants once the analysis is complete and asking them whether the theory generated 'fits' with their experiences. There are a number of problems with the concept of respondent validation. These, along with criticisms of grounded theory will be presented below.

2.7 Criticisms of Grounded Theory

Grounded theory like all methods of analysis, be they qualitative or quantitative, has limitations and is open to criticism. These criticisms will be discussed and attempts to address them will be taken into account in the procedure of the present study. Broadly speaking, these criticisms can be split into those pertaining to pragmatic concerns and those of a more epistemological nature.

From a practical perspective, in terms of data collection, it can be argued that grounded theory researchers are often too quick to treat participants' accounts as reflections of reality. In fact, what is obtained is not only a product of the interaction between researcher and researched as described earlier, but is also only one account. It is impossible to ever fully know the reality of another's internal world. All researchers have is an account provided by a participant and participants may censor the accounts they offer for a range of reasons. For example, participants may feel shame or stigma and give only partial information. They may acquiesce or be aware of a power imbalance between themselves and the researcher.

These difficulties may equally apply to the process of respondent validation. In reality, whilst the process of asking participants to comment on the theory being generated is certainly appropriate, it is entirely possible that respondents again will acquiesce. In addition they simply may never have thought of their experiences in such abstract terms and not understand the theory presented to them. The researcher's role is to minimise this as much as possible by developing good rapport with participants in order to promote an environment of trust. It is also important to present information to them in language that they can identify with. As each individual participant provided only some of the data, it is possible that presentation of a complete and abstract theory may be difficult for them to interpret.

Grounded theory studies often do not end in the generation of an all-encompassing theory. This was a point of considerable debate for Glaser and Strauss who disagreed on the ultimate aim of analysis with Strauss arguing that complete theory was not automatically necessary (Richardson, 1996). Charmaz (1995) claims that not generating a complete theory at the end of analysis is not problematic, as

considerable conceptual description can be obtained that still provides the reader with insight and greater understanding, even in the absence of a complete theory.

However, some researchers note that often what is obtained is merely a re-description of the data or simply a content analysis (Stern, 1994) offering no new insights into the phenomena under investigation. To guard against this, researchers need to follow the procedures for conducting the analysis carefully and adopt a structured approach whilst at the same time think comparatively and abstractly to ensure the quality of the analysis. The researcher needs to be guided by the data but not stick too rigidly to it. Data should guide theorising not limit it (Layder, 1992). The resulting theory should be conceptual rather than simply descriptive in nature.

A further criticism of grounded theory is the very real danger that the results of the analysis may simply represent the views and assumptions of the researcher (Schwandt, 1994). For example the researcher might place greater importance on aspects of the data that support these assumptions and neglect those that challenge their existing views. The processes of memo writing, adopting the constant comparative method, maintaining a reflexive journal, which allows space to reflect on the research process, may reduce the impact of the researcher's biases and help prevent them from seeping into this process. Striving to constantly ground theory in the data will help make explicit the thought processes behind decisions made and the evidence for them (Tweed, 1998). This will then enable a reader to see for him or herself how theory was generated.

From a more epistemological perspective, it could be argued that the small number of participants often involved in qualitative research and the very specific nature of enquiry prevents generalisibility of the findings. The findings could be argued to be only relevant to that person at that time. However, it is not intended nor claimed that the very detailed, in-depth findings are generalisable. Instead, the aim of such research is to provide an insight into, and greater understanding of, the psychological processes involved in phenomena. Instead of generalisability the researcher is striving for theory, which has explanatory power (Strauss & Corbin, 1998). Some researchers stress that the onus is actually on other researchers to apply

the findings to different contexts rather than on the original researcher to demonstrate generalisability (Erlandson, Harris, Skipper & Allen, 1992).

However, particularly in grounded theory analysis, many of the psychological processes in the theory generated may have a wider applicability than just the area being explored. For example many of the psychological processes generated in a study of chronic illness, such as social isolation or effects of stigma (Charmaz, 1990) may have applicability, be 'transferable' (Lincoln & Guba, 1985) and inform understanding in other areas, for example drug use.

Other criticisms come from those that question whether grounded theory is truly an inductive process. The very act of deciding what to study is in itself a deductive process and no researcher can be free of assumptions as to how analysis might proceed. In addition, as has been previously discussed, Glaser and Strauss' (1967) claims that theory is *discovered* suggests that psychological processes exists objectively and are waiting to be discovered. This is a very empirical stance (Richardson, 1996) akin to that adopted in the biological sciences. The constructionist revision of grounded theory does go some way toward addressing this notion although there is still a tension between the idea that a researcher can, at the same time, be objectively reflecting participants' accounts (adopting a realist stance) and recognising that multiple perspectives on the world exist (adopting a constructionist stance) (Richardson, 1996). This tension has become known as the "dilemma of qualitative method" (Hammersley, 1989) and as yet no method of qualitative research has been able to lay claim to being entirely without the influence of empiricism. This therefore reiterates the need for the researcher engaging in qualitative analysis to be as transparent as possible as to their epistemological position within the research process.

Other researchers put forward the view that just because a researcher is using a qualitative method of enquiry, one should not assume that it is by definition a more reliable means of accessing accounts of experience. (Woolgar, 1996) Effective analysis is determined by engaging in the analysis fully and by adhering to the principles of good quality analysis outlined above. Researchers need to acknowledge that it is not the method of analysis itself but rather its application that leads to

further understanding of phenomena. Constructionists would also argue that the resulting theory is just one account of reality and there can never be right or wrong, as there are multiple realities that are constructed between the researcher and researched.

2.8 The Present Study

Researcher Stance

Given the importance of the role of the researcher in grounded theory analysis and the concept of transparency, it was felt important to have a brief section outlining the epistemological stance of the researcher within the present study, along with some information about previous experience, biases and assumptions about possible findings.

The researcher's epistemological stance was influenced by Madill, Jordan & Shirley (2000) and the researcher identified most strongly with the position of critical realism espoused within that paper. Essentially, critical realism asserts that "the way we perceive facts, particularly in the social realm, depends partly upon our beliefs and expectations" (Bunge, 1993, pp. 231, cited in Madill et al, 2000). Related to hearing voices, this equated to accepting that there was such a phenomenon as voice hearing but that each individual voice hearer perceived this differently. In addition, critical realism also asserts that people make sense of their experiences through complex interactions with other people and social factors. With reference to the present study, the critical realist stance adopted by the researcher essentially accepted that the accounts that would be obtained from each participant would represent their own realities and experiences. However, the researcher also acknowledged the inherent subjectivity in the production of knowledge within a critical realist stance (Madill, et al 2000) and accepted that her presence within the research would influence the accounts given by participants.

The researcher had no previous experience of using grounded theory, or other methods of qualitative analysis but had an interest and some clinical experience in

working with people who hear voices. From this work, the researcher had developed an awareness of the increase in user movements for people who hear voices and had begun speculate as to the factors underlying this. As such the researcher was aware of perhaps having a bias towards perceiving users as dissatisfied with existing services. These biases were monitored throughout the research process in a reflective journal and during regular research supervision.

2.9 Procedure

A protocol detailing the research and addressing ethical considerations was completed and forwarded to the Research Ethics Committee of the host trust. This committee was then able to confer the ethical approval necessary to proceed with the study. A copy of the letter of confirmation is included in the appendix (Appendix 1.) No service users or clinicians were approached prior to this being received.

Research Design

As previously discussed, it was felt that the nature of the research questions necessitated the adoption of a qualitative approach to address these adequately. The data that were analysed were the transcribed interviews with six voice hearers who agreed to participate and a grounded theory analysis was applied to the data. Grounded theory was chosen as it was felt that the contextualist epistemological stance assumed by the method (Henwood, 1996) was consistent with the researcher's own position and that it was the most appropriate method for gaining understanding of participant's experiences of hearing voices. The generation of theory, or conceptual description, which resulted, has both a theoretical and pragmatic relevance to clinical psychology. Analysis was guided by the procedures laid out by Strauss and Corbin (1998) and Charmaz (1995) and was an amalgamation of the two approaches.

Sampling and Recruitment of Participants

All participants were recruited from the Hearing Voices Network and Treatment and Recovery Service within the host trust. It was felt that individuals accessing these services were likely to have been users of mental health services for some time and therefore were likely to have formed judgements about this experience. In addition, as the study sought to explore users' perspectives, it was considered appropriate and indeed desirable to access a user forum such as the Hearing Voices Network. Psychologists involved in the Hearing Voices Network and/or working within the Treatment and Recovery Service were briefed as to the nature of the study and informed of the inclusion criteria for potential participants, (Appendix 2.).

The psychologists were also briefed as to what would be expected of potential participants. With reference to the inclusion criteria they then suggested current clients they thought might be suitable. These clients were then approached by their psychologists and asked if they would be interested in finding out more about the present study. Those who expressed an interest were given a letter of introduction (Appendix 3.) from the researcher. If interest was maintained they were invited to meet with the researcher who then discussed the study in more detail and gave the potential participant an information sheet (Appendix 4.), which explained the study in detail. Potential participants were encouraged to discuss their involvement with anyone they felt relevant and given the opportunity to ask any questions before being given at least two weeks to think about their participation.

The potential involvement was discussed with key health care professionals involved with each potential participant and consent was obtained from the lead clinician to confirm that they were well enough to participate (Appendix 5.) Consent was then obtained from participants themselves (Appendix 6.)

An important consideration when recruiting participants was to find the balance between giving them sufficient information to make an informed choice to participate but not so much that they might feel led to talk about specific themes or areas. Similarly, the researcher sought only to obtain sufficient information about

participants prior to each interview to satisfy herself that the inclusion and exclusion criteria had been met and to ascertain that there were no specific risk factors concerning each individual's participation.

Participants

The large amount of data generated and the depth of analysis possible when working within a qualitative framework means that only a small number of participants need be recruited. It is recognised that within grounded theory, data collection should continue until 'theoretical saturation' is reached. This is the point at which no new information is being discovered. However, it is generally accepted that within the remit and limitations of research for a D.Clin.Psy qualification, between 6-10 participants is satisfactory (Turpin *et al*, 1997).

A total of six individuals agreed to be interviewed, two males and four females aged between 28 years and 56 years who had been consumers of psychiatric services for between 2 years and 24 years, although contact with professionals was not necessarily constant during this time. Each participant reported hearing voices for some time prior to coming into contact with mental health services. All described their ethnic origin as 'White British', except for 'Hattie' who was 'Afro-Caribbean'.

Data Collection

As discussed previously, the data for qualitative analysis can come from a variety of sources. In depth interviews are one frequently used method (Holstein & Gubrium, 1997). Such an interview was considered the most pragmatic method for the present study and much has been written about the use of interviewing for qualitative research (Burman, 1994). Once consent had been obtained, each participant met with the researcher to engage in the interview.

A topic guide was constructed in order to address the research questions, detailing areas to be explored. This was drawn from the researcher's own interests

and experiences and via a process of discussion with colleagues and within supervision.

The main areas covered by the topic guide were as follows: -

- Some demographic information as to pathways to the Treatment and Recovery Service/Hearing Voices Network and length of time involved with the psychiatric system
- The experience of voice hearing
- Exploration of participants' feelings when they first started to hear voices
- Participants' ways of attempting to make sense of what was happening
- Their experience of health professionals in relation to voice hearing
- Exploration of disagreements over treatment for hearing voices and how these were these managed
- Recognition of any changes over time during their 'psychiatric career'

This topic guide (See Appendix 7. for completed version) was designed as a guide to facilitate discussion and elicit information for exploration rather than to limit discussion by searching for definitive answers. The areas for exploration were very open ended and each interview itself had no fixed sequence in terms of how it should proceed. The aim was to use the topic guide to facilitate open and in-depth expression of experiences and the meanings attached to them and to enable the participants to have a major role in determining how interviews would proceed (Burman, 1994).

Given that a fundamental part of grounded theory is the notion that data collection and analysis are simultaneous, as the analysis progressed, additional areas were added to the topic guide to be investigated further. For example, early interviews identified the importance of feeling listened to by professionals and of having knowledge. These issues were specifically addressed in subsequent

interviews. Exploring how voice hearers' explanations for this phenomenon were dependent upon interactions between themselves and professionals also became a more important area to focus on as the research progressed.

It was recognised that the mental health of participants may have fluctuated and changed between consent being obtained and the interview taking place. Prior to the start of each interview, advice was sought from the lead clinican involved in the care of each participant as to whether they were well enough to engage in the interview. Each participant was also asked if they felt well enough to proceed prior to beginning.

Although full details of the interview procedure had been given to participants well in advance of interviews, it was felt important to reiterate the confidentiality of the process and the limits of this in terms of risk. It was emphasised that information collected for research purposes was in no way related to any ongoing treatment. Participants were also reminded that they could stop the interview at any point. This was considered especially important, as the researcher had no way of knowing beforehand what might be covered in each interview. As such arrangements were made for both parties to seek support immediately after each interview if they felt it necessary to do so. Participants were interviewed either directly before a Hearing Voices Group meeting or prior to an appointment with a professional who had been primed to offer support if necessary. The researcher made arrangements for support from her supervisor to be available at these times also.

Considerable time was spent at the start of each interview trying to establish rapport and create a safe environment to obtain the trust needed to facilitate open and honest expression (King, 1996). The researcher was careful to ask open ended questions wherever possible and to reflect back what was being said to check she understood participants' meanings, as well as being mindful of the need to guard against asking leading questions.

Each interview was tape recorded, with the full consent of the participant. Interviews lasted between half an hour and an hour and a half depending on the participants' willingness and ability to explore some of their experiences. Interviews

were made as informal as possible so as to promote rapport and facilitate the disclosure of information. They all took place in one sitting, on occasion with short breaks depending upon the needs of each participant. Generally interviews began by focusing on the ' here and now' experiences of participants to develop rapport before moving on to the experience of voice hearing itself. The researcher's thoughts and feelings immediately after each interview were recorded in the reflexive journal. An example of which is given below: -

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18th March 2002
Interview with 'Hattie'. Went well. Decided to follow her lead in terms of areas for discussion. 'Hattie' very keen to tell her story. Appeared very angry at times. Was aware that towards the end of the interview I was also becoming both angry and frustrated at the way she had been treated by professionals. I wonder whether 'Hattie' was aware of this? Appeared similar to interview with 'Kathy' in terms of frustration with 'the system' but very different to 'Joseph' not sure why yet. At the end of the interview, 'Hattie' spoke about how good it was to have a forum to discuss her experiences. Is this what she hasn't had so far?

Fig. 1. Extract from researcher's reflexive journal

As documented previously, in grounded theory data analysis occurs at the same time as data collection. Therefore, participants should be recruited to test the developing theory and sampling should revolve around theoretical supposition. In the present study, the first two participants were sampled in an opportunistic way, to begin the process of generating theory. They were then coded – see subsequent sections of this chapter – and the subsequent four participants were sampled more theoretically as the theory developed. For example, the first two participants ('Kathy' and 'Joseph') were members of the Hearing Voice Group. It was considered desirable for the third participant ('Hattie') to be a past member to see if this yielded a different account. The fourth participant ('Tony') had never been a member of the hearing voices group and was known by colleagues to be more satisfied with mental health services than the accounts of the previous participants suggested. 'Sarah' was sampled, as she was the only participant living in a group home receiving 24-hour professional support. The researcher sought to ascertain whether this level of support had any effect on identity formation. Lastly 'Jackie' differed from the others in that

she was being considered for discharge from mental health services and therefore in receipt of considerably less professional support than 'Sarah'.

Whilst attempts were made to sample as theoretically as possible, it is important to acknowledge that this process was constrained by pragmatic concerns such as the availability of participants and a finite amount of time available to complete the analysis. McLeod (1996) recognises this as a common difficulty amongst qualitative researchers.

Data Management

The researcher transcribed each interview. The names of participants and others described in the interviews were changed, as were any identifying features, e.g., place names. Apart form this the interviews were transcribed verbatim. Linguistic details such as length of pauses and intonation were not included on the transcripts, as they do not feature in grounded theory analysis. Completed transcripts with an explanation of notation have been submitted separately. The coding processes are described below.

Open Coding

Although described here as separate entities, the coding procedures generally overlapped so that the researcher was engaged in considering different types of coding simultaneously. This was particularly noticeable in terms of overlap between focused and selective coding.

The first stage of the coding process was to engage in 'open coding' with the interview transcripts. This is the most detailed and generative form of coding (Strauss & Corbin, 1990) and refers to the process whereby each line of the transcripts is considered separately and the data are broken into small chunks or 'meaning units' (Rennie et al, 1988). Each meaning unit or concept represents some aspect of the phenomenon under investigation. For each concept, the researcher

considered what was being represented. Engaging in open coding allows the analysis to be built from the ground upwards (Charmaz, 1995). Examples of open coding are included in the appendix (Appendix 8.).

Each concept was given a label, which reflected what was being conveyed. As the research progressed the number of concepts increased. Concepts were written on index cards to keep track of them. Each concept had its own card. Those concepts that seemed to represent aspects of the same phenomenon were grouped together to form categories (Strauss & Corbin, 1998). For example, two concepts relating to *'Being listened to'* and *'Feeling cared for'* were identified. They were then placed together to form part of a category called *'Feeling supported'*. Gradually categories began to contain more and more concept cards.

Categories were given a name at a more abstract level than concepts. The concepts contained within categories were then compared with one another and similarities and differences were explored. Many concepts were moved between categories as part of this constant comparative method. The concepts gradually began to add detail and density to the categories. Some categories appeared to have considerable variation in terms of composite concepts whilst others displayed little variation. It was these latter categories that became the focus of future data collection, as participants were then selected so that they could help add accounts that could fill these 'gaps'.

Once categories appeared to show a degree of variation in terms of their properties, and dimensions, the researcher spent more time focusing on comparing the categories themselves. This formed the basis of focused coding.

Focused Coding

Focused coding, or axial coding as described by Strauss and Corbin (1998), involves the detailed comparison of categories and their components. The data were treated at a more abstract and conceptual level than during open coding. The components of each category were compared to one another, and categories were

compared to other categories. Some categories were collapsed into other categories, whilst others were split to form new categories.

Charmaz (1995) stressed the importance of identifying substantive processes as categories and, as such, the categories identified generally reflected the means by which participants considered their experiences of hearing voices. In an attempt to keep the categories grounded in the responses of participants, in addition to reflecting their main concerns, the names given to categories were taken from the interview texts. The categories were then considered in more detail in terms of structure and process, that is, looking at why things were happening and the mechanisms by which these events took place. In doing so, the explanatory power of the categories was increased.

Although focused coding is concerned more with categories than concepts, the researcher frequently returned to the interview transcripts to compare the categories that had been generated with the raw data itself, to ensure it remained relevant and grounded. After engaging in focused coding, the researcher had identified 28 different categories. Selective coding principles were then adopted in an attempt to 'fit' these categories together to make conceptual sense.

Selective Coding.

Selective coding is essentially the process of choosing a core category that represents the central phenomenon around which all other categories are integrated (Tweed, 1998). The categories were considered in terms of the degree of conceptual sense they made in helping to make sense of participants' experiences of voice hearing. A core category should "...represent the main theme of the research and contain all of the products of the analysis condensed into a few words that explain what the research is all about" (Strauss & Corbin, 1998, pp. 146).

As suggested by Strauss and Corbin (1990), the researcher attempted to use the categories to tell a story that reflected and was all the time grounded in the accounts of participants. When categories did not seem to 'fit' or felt forced into the

storyline, the researcher went back to the transcripts and re-examined the concepts making up each category to ascertain if there were alternative ways of coding them. Likewise, if categories appeared too vague, particularly judgemental or overly reflective of the assumptions of the researcher, attempts were made to consider alternative ways of conceptualising these. The researcher also discussed the categories with peers also conducting qualitative research, who were asked to be critical of them. Having to defend why various decisions were made regarding category generation is regarded as a mark of both transparency on the part of the researcher in terms of showing a willingness to consider how they influence the process.

As will be seen in the next chapter, a core category was identified that appeared to encompass all other categories. A further five categories appeared to represent themes that emerged from the participants' accounts most often and these were elevated to the status of 'main categories'. Each main category comprised a number of lower level categories that served to give variation and detail to the story being generated.

Use of Memos

To aid the process of theory generation, the researcher regularly wrote memos that contained thoughts on the coding process. Such memos not only help the researcher to keep track of research in progress, they also form part of the constant comparative method as they can help to identify and describe the properties of categories (Strauss & Corbin, 1990). As such they are regarded as an important step towards making the link between coding and theory (Charmaz, 1995). They can also be used to form a vital part of the data trail, making the thought processes of the researcher transparent. From a constructionist perspective, memos are vital in that they present an opportunity for the researcher to consider their own role within the research process (Henwood & Pidgeon, 1995). An example of a memo taken form the researcher's reflective journal is given below: -

'Kathy' describes times when she has felt very frustrated with mental health services and professionals. Describes feelings of helplessness and powerlessness. Yet in the interview with me she comes across as the opposite, very assertive and empowered. Clearly this has not always been the case. When and how did things change for her? Was it response to changes within her? Changes in her environment? Or changes in the attitudes of professionals? Did I do something in the interview that gave her 'permission' to be assertive?

Fig. 2. Extract of a memo from researcher's reflective journal

The memos written by the researcher became more complex and abstract as the research progressed. They were constantly referred to throughout coding and were an invaluable resource in terms of putting the categories together to generate a coherent theoretical account of participants' experiences of voice hearing. This account is considered in detail in the next chapter.

CHAPTER 3
ANALYSIS

3.1 Overview of Chapter

This chapter provides an account of the analysis of the six interview transcripts. This account offers one way of attempting to understand the experience of voice hearers within the psychiatric system. Following on from the detailed coding procedures described in the previous chapter, a core category was identified, and is described in the next section of this chapter. This is followed by discussion of five main categories (themselves comprising intermediate level categories and sub-categories) pertaining to this core category. A process model has been developed to depict how these categories are related and explores the movement between them.

To aid the reader, the different levels of categories are represented using different text formats as follows: -

CORE CATEGORY - Represented in bold, italicised, capital lettering.

MAIN CATEGORY - Represented in bold capital lettering.

INTERMEDIATE CATEGORY - Represented in capital lettering.

Sub-Category - Represented in lower case lettering

In the account that follows, all of the categories are grounded in the interview texts of participants. Whilst the core category represents a more abstract conceptualisation, it too remains grounded in participants' accounts. It represents an attempt to highlight the central tenet or story contained within each transcript when read as a whole.

The main categories developed in this account of the analysis were identified in the transcripts of all of the participants. Each category will be described in terms of its characteristics and properties. The category's relevance to developing an understanding of voice hearers' experiences will be made explicit and illustrated through the use of quotes from the interview transcripts. Whenever quotes are used,

they are referenced with the name of the participant, the page number and line number of the text quoted.

3.2 Overview of the Core Category and Process Model

The Core category identified in the analysis was termed 'Reconstructing a sense of identity'. This represented an overview of the analysis and was the focus of the storyline. As a core category it encompassed five main categories, essential in giving detail to the story being generated. These were 'Being Psychotic', 'Disclosing Information', 'Receiving Treatment', 'Attempting to make sense of experiences' and 'Sense of self in relation to the psychiatric system'.

'BEING PSYCHOTIC' as a main category was characterised by participants' subjective experiences of this state: -

> *"Well, thought I was going mad. You know, crazy. Well I suppose I am. I was just confused a lot and things" ('Tony', pp. 2, 57-58).*

'DISCLOSING INFORMATION' reflected the processes underlying and affecting communication between participants and mental health professionals: -

> *"I told my Doctor, I had to come clean with him. I said, "I'm hearing, I think I'm hearing voices" ('Joseph', pp. 17, 547-548).*

'RECEIVING TREATMENT' reflected participants' experiences of receiving treatment within mental health services. The characteristics of this category were essentially professionals' responses to participants' disclosures about their voice hearing.

"The whole system is pretty de-stabilised in the fact that some of the professionals are kind of going, "Take responsibility", and this kind of, even before you're ready for it and sort of pushing you away. And then the others are sort of pulling you towards them sort of saying, "Right we'll sort this out, this is the way". So that just creates even more sort of turmoil, there's no sort of party line" ('Kathy', pp. 36, 1186-1193).

'ATTEMPTING TO MAKE SENSE OF EXPERIENCES' as a category, represented participants' attempts to make sense of their voice hearing experiences and of their experiences of receiving treatment within mental health services: -

"I think it's 'cos of things that happened in my childhood. The doctors told me I was schizophrenic. That was horrible. I didn't know what that was. I haven't really ever thought much about that though. They haven't said much the doctors. I've talked about it a bit with Wendy [psychologist]. *She understands me I think" ('Sarah', pp. 7, 210-215).*

'SENSE OF SELF IN RELATION TO THE PSYCHIATRIC SYSTEM' described how participants perceived themselves within the psychiatric system. This incorporated their experiences contained in each of the categories described above: -

"I'm more happy within myself like. I feel more happier, you know. I don't feel so miserable. It's frustrating at times you know, but (.) it's better than the past. A lot better than the past" ('Tony', pp. 14, 439-442).

The intermediate and sub-categories contained within each main category added density to these main categories and contributed to a deeper understanding of the core category of 'Reconstructing a sense of identity'. The main categories were

all interdependent and the process model in Fig. 3. represents the movement between them.

The Process Model illustrated the interaction between the main categories involved in enabling participants to reconstruct a sense of identity. It can apply equally to both the first episode of hearing voices and subsequent contact with professionals and to more enduring contact with the psychiatric system. Essentially, the experience of being psychotic influenced what was disclosed to professionals. This then influenced how treatment was experienced, which in turn affected how an individual perceived being psychotic. There was continuous movement and overlap between the three stages of contact with the psychiatric system. All the time, participants were attempting to make sense of these experiences in order to develop a sense of their own identity within the psychiatric system.

Each of these five main categories will now be discussed in greater detail. A diagrammatic representation of the lower level categories comprising each main category is provided to aid clarity.

RECONSTRUCTING A SENSE OF IDENTITY   (Core Category)

(Process Model)

BEING PSYCHOTIC

ATTEMPTING TO MAKE SENSE OF
EXPERIENCES

SENSE OF SELF IN
RELATION TO
THE
PSYCHIATRIC
SYSTEM

RECEIVING TREATMENT   DISCLOSING INFORMATION
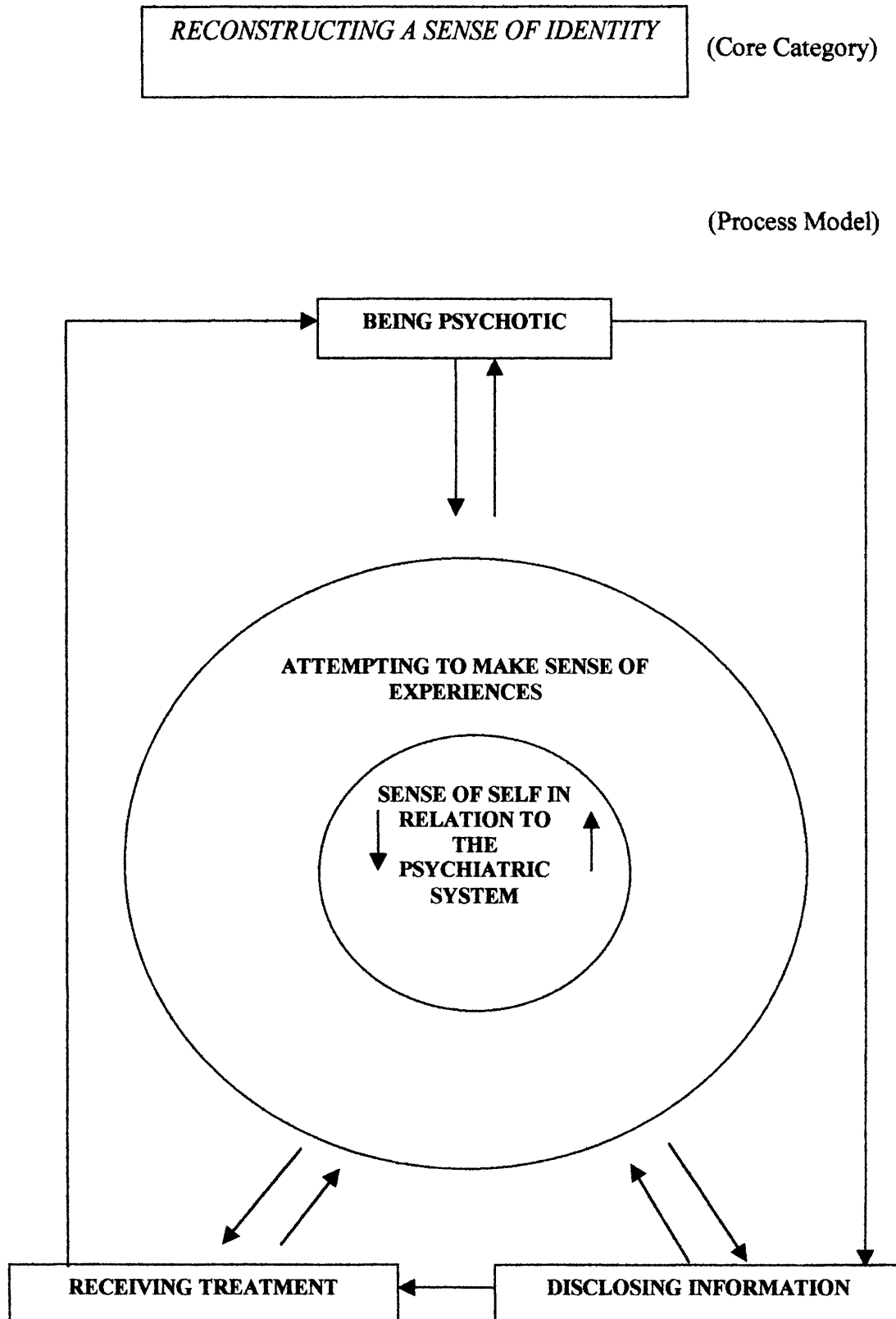
Fig. 3. A Process model relating to the experience of hearing voices

and having contact with the psychiatric system

3.3 Core Category – 'RECONSTRUCTING A SENSE OF IDENTITY'

Participants appeared to equate the onset of hearing voices with a serious threat to their existing sense of self. Essentially the core category presented here represented a breakdown in voice hearers' existing sense of identity following the onset of psychosis and their struggle to make sense of the experience of hearing voices.

Within this core category, changes in participants' sense of identity were related to how they experienced contact with the psychiatric system. Participants indicated that shortly after first contact with the psychiatric system, they saw themselves as 'ill' and believed that professionals had the expert knowledge needed to make them better. Thus participants appeared to adopt an identity based around the core belief that they were ill: -

"When you first enter the Services I think it's very much they're the experts, we're just the people that are ill and have the problems"
('Kathy', pp. 2, 47-50).

If the contact with professionals ultimately led to the successful management of their voices (the voices were often still present but less distressing), then participants were inclined to maintain the belief that they were 'ill' and from that point on adopted an external locus of control when thinking about their voice hearing experiences. Essentially they felt that they had little control over this phenomenon and appeared comfortable with attributing the successful management of the voices to professionals involved: -

"I mean, I couldn't do anything about it if the doctor couldn't"
('Jackie', pp. 13, 407).

They also saw themselves as different from others, and very enmeshed within the psychiatric system. 'Tony' commented on his thoughts about how his future would have looked had he not come into contact with the psychiatric system: -

"Well, I'd be an animal. I'd be a monster, 'cos I'd really get into crime you know; get myself into prison and things. Or perhaps, I'd have been dead by now" ('Tony', pp15. 471-473).

However, if contact with the psychiatric system ultimately resulted in unsuccessful attempts to manage their voices, participants were more inclined to reject an identity based on the notion of being ill. As a consequence of the psychiatric system not being able to 'cure' them, participants adopted a more internal locus of control. This was characterised by an increased sense of responsibility to actively search for explanations and find ways to cope with the experience: -

"...Because you're told it's an illness and can be fixed and you want an answer and you want to know why you're ill and that it can get better. It took me a couple of years to kind of think well no, this isn't quite right, there's something more to it than this and to kind of take more control of it" ('Kathy', pp. 29, 961-968).

For some participants this process was traumatic and characterised by feelings of bewilderment. Indeed, the belief that participants were ill appeared to be very functional and resulted in them expecting professionals to take control and alleviate their distress: -

"Initially I thought the psychiatrists had the answer. Erm, that I didn't know what was going on and they obviously did and they could save me" ('Kathy', pp. 29, 953-955).

'Jackie' elaborated on this point about psychiatrists being able to save people: -

"And when he doesn't it's really disappointing" ('Jackie', pp. 13, 421).

Fig. 4 provides a diagrammatic representation of this process of movement within the core category of 'reconstructing a sense of identity'.
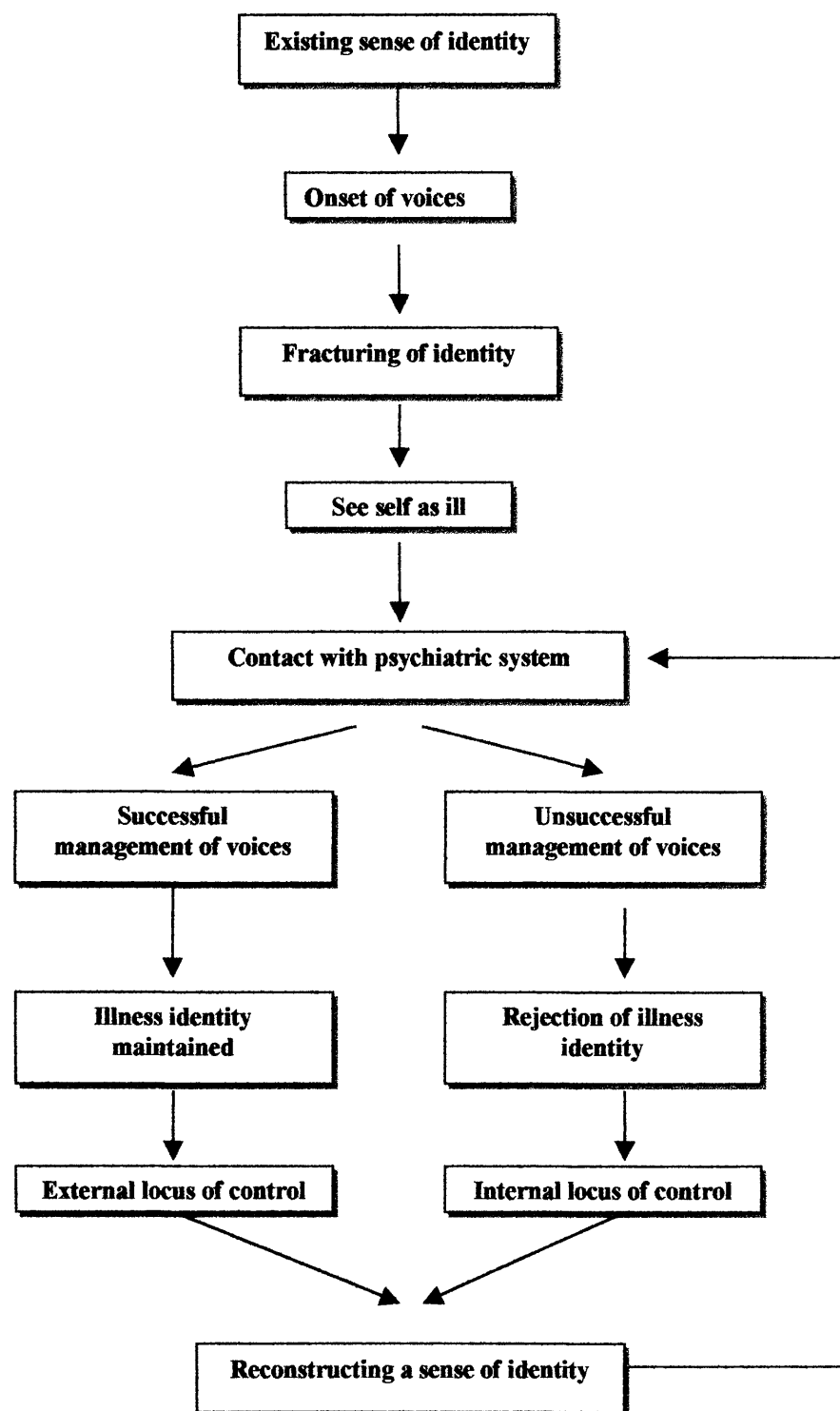
Fig. 4. Diagrammatic representation showing movement within the core category –
Reconstructing a sense of identity

Ultimately, whether as the result of adopting an identity based upon the acceptance or rejection of an illness model, a new sense of identity was constructed in participants. This reconstructed sense of identity represented an amalgamation of the experience of hearing voices into participants' existing sense of self and was heavily influenced by contact with the psychiatric system: -

"But it's taken me a while 'cos losing the illness label is quite difficult because it's something you cling to because you're told that it's an illness and it can be fixed" ('Kathy', pp. 29, 961-964).

Running through the accounts of each participant appeared to be an underlying tension of wanting to be more independent and able to cope without (or with decreased) support but also having a strong need to be cared for and dependent upon support from professionals: -

"That's how I am at the moment. 'Cos I've said I want to go into a residential home but then I want my own home so I'm not sure. Sometimes I want to do it and sometimes I want people to look after me" ('Sarah', pp. 9, 279-282).

These apparently contradictory positions appeared to emerge in all of the participants' accounts to differing degrees and at differing stages in their psychiatric careers. This was closely related to the beliefs participants adopted about their voice hearing and the amount of responsibility they attributed to themselves in terms of managing this experience.

Once they had developed a sense of themselves within the psychiatric system, participants then appeared to be considering how and where they fitted in within society generally with their reconstructed identity that incorporated the experience of hearing voices: -

"...You start to get your own identity back outside of the mental health thing" ('Kathy', pp 34, 134-135).

Accounts suggested that participants varied in the degree to which they felt comfortable talking about voice hearing to people outside of mental health services. Some participants did not feel comfortable discussing their experiences: -

"I don't tell people" ('Jackie', pp. 6, 190).

Whilst others did not seem to regard this as difficult: -

"It's still there. I'm not bothered about it now I couldn't care less. I just tell anybody I used to hear voices and they were very horrible" ('Hattie', pp.27, 901-904).

3.4 Main Category – 'BEING PSYCHOTIC'

From the analysis a main category, 'Being Psychotic', was generated. Fig. 5. shows the lower level categories within this. The intermediate categories were 'Not Knowing', 'Awareness of Stigma' and 'Attempting to Cope'. The sub-category of 'Feeling different' was related to an awareness of the effects of stigma.

All participants identified a state of being psychotic, which was best understood in retrospect. This was not a unitary construct, and was accompanied in all participants by the presence of visual hallucinations and unusual belief systems: -

"It's horrible. They're all in your body. You can feel small things in your body" (Sarah, pp. 2, 49-50).

Five of the participants described this as initially a shocking state, leaving them bewildered, confused and frightened: -

"And I heard this voice and I looked round and I said, "Who's there?" and you know, it was so frightening I actually thought there was somebody in the house. I ran to the front door to look outside if somebody had shouted through the letterbox. And it was only after several times that I realised that it was actually coming from within myself. I didn't know what to do I was scared." ('Hattie', pp. 5, 136-143).
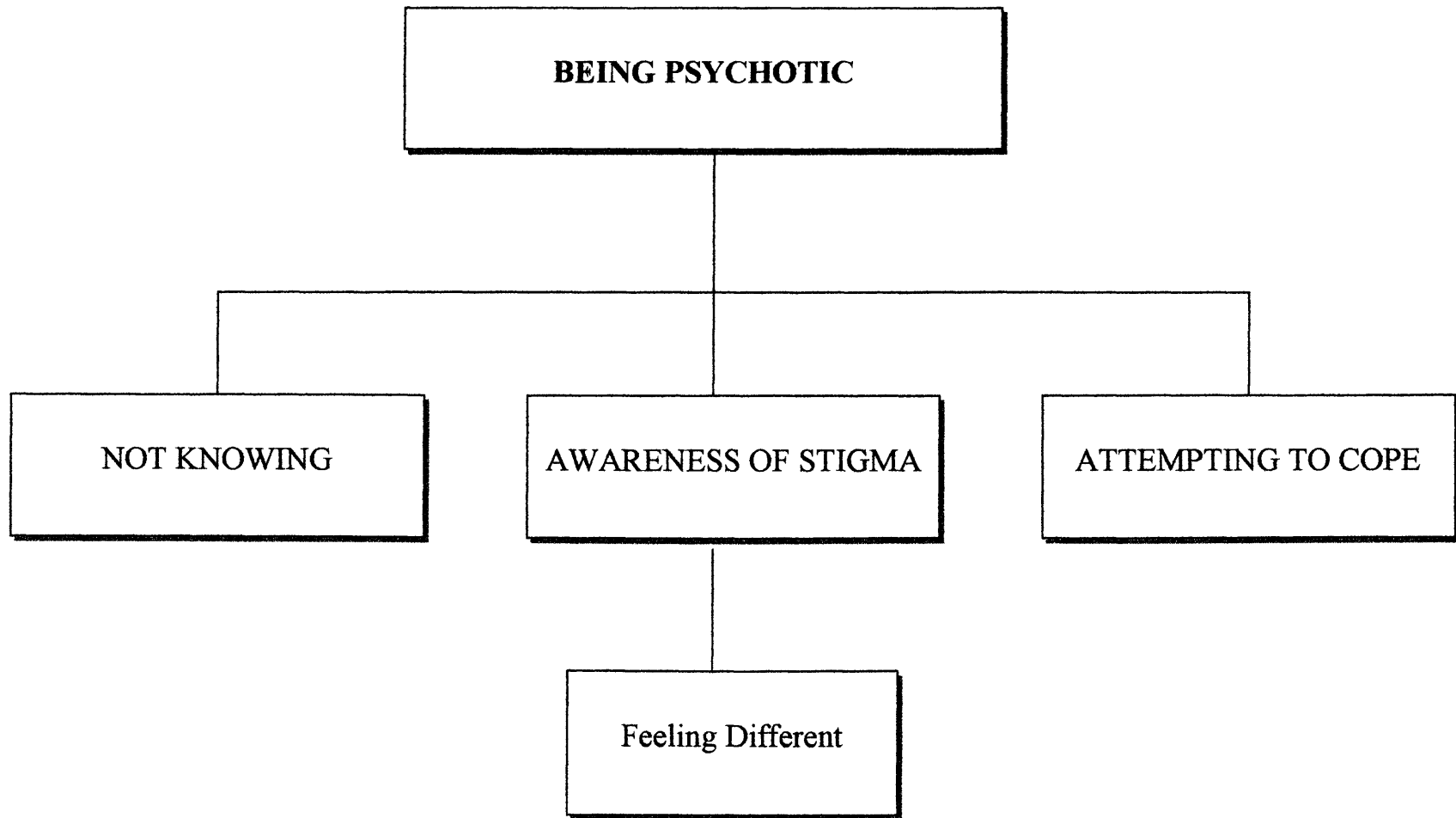
Fig. 5. Being Psychotic

Potential negative case example

In contrast to the accounts of the other five participants, 'Jackie' indicated that she did not feel frightened or particularly distressed when she first started to hear voices: -

"And then suddenly I started to withdraw. And then about a week later I started hearing voices. And I was sitting there, and I weren't particularly perturbed about them you know, I just accepted them. You know, I didn't go potty or scream or anything like that you know" ('Jackie', pp. 2, 68-72).

This initially appeared to be a negative case example. The reasons for her lack of distress were explored and it transpired that initially 'Jackie' heard benevolent voices, which made supportive comments towards her. Therefore, although sensing it was unusual, she saw no reason to be distressed by this experience. However, later on the voices adopted a more malevolent stance and 'Jackie' identified feeling anxious and distressed at these times. Therefore what appeared to be a negative case was integrated into the main category thus giving it greater explanatory power.

Intermediate Category – 'NOT KNOWING'

A theme that emerged as participants described the state of being psychotic in more detail was that it was often characterised by a state of 'Not Knowing'. This took two distinct forms. Firstly, there was an initial period immediately after the onset of voice hearing where participants talked about not knowing what was happening to them. Participants recounted feeling that in retrospect, they didn't know anything about hearing voices or what it meant: -

"I think I'd never really heard of hearing voices...and you know, I had no real sort of idea what things were... There was not much of it about in the news or any positive things about it" ('Kathy', pp. 9, 288-296).

Once this initial stage had passed, participants, including 'Jackie', then described a sense of not knowing how to talk about it: -

"I didn't quite know how to explain them then" ('Jackie' pp. 7, 208).

This was particularly salient as all participants identified considerable distress during this stage. For example, there was a sense of not knowing where to go to get help, what type of help was available, not knowing what would happen if they told someone about their voices: -

"Asking for help can be very difficult 'cos you feel like you're attention seeking or something and you're not really sure what help is available" ('Kathy' pp. 7, 226-228).

In 'Hattie's' interview, she indicated she had some prior knowledge of hearing voices. This was explored as a negative case, to ascertain whether possessing a degree of knowledge about the experience made it less frightening. In her experience, having knowledge had the opposite effect in that she was more acutely aware of the stigma surrounding the phenomenon of hearing voices and even more reticent about wanting to discuss her experiences: -

"I knew a little bit about people that hear voices and the stigma that was attached to it. And the fact that I was bringing up children on my own, I was a bit worried that I might lose my children. So, I took on the decision not to say anything about the voices" ('Hattie', pp. 1, 25-29).

Whilst not knowing was a major characteristic of being psychotic, it was interesting to note that the presence of some knowledge about hearing voices did little to reassure 'Hattie'. Indeed her distress seemed to increase as a result.

Intermediate Category – 'AWARENESS OF STIGMA'

In a similar fashion to 'Hattie's' experience described above, participants discussed their perception of having to grapple with the stigma and lack of understanding that surround voice hearing especially related to society's concerns that they might be violent: -

> *"Cos if you, if you tell anybody else who's not hearing voices, they tend to shy away from you. They think you're a dangerous lunatic and think you shouldn't be out, out on the streets, walking the streets, you know" ('Joseph', pp. 2, 59-62).*

Participants were also concerned about how others would perceive them: -

> *"I think they would have called me mad and you know, my life would have altered really" ('Hattie', pp. 2, 37-38).*

Sub-Category – 'Feeling Different'

Related to awareness of stigma, participants also identified feeling very different to other (non-voice hearing) people. From the analysis it was not possible to say whether one caused the other: whether being aware of stigma caused participants to feel different or vice versa. Indeed, it is perhaps more useful to look at the two categories as affecting each other. Participants indicated they did not feel normal. This was a defining property of this sub-category: -

"Well I just knew it weren't normal. I didn't want people knowing I was hearing voices" (*'Jackie', pp. 6, 178-179*).

'Hattie' talked about considering her position in relation to professionals: -

"They're more sane. The consultant just thinks I'm a loony, you know. Nothing I say is all there. The fact that you're hearing voices, you're completely off the planet" (*'Hattie', pp. 15, 498-500*).

Intermediate Category – 'ATTEMPTS TO COPE'

A major characteristic of 'Being Psychotic' was an attempt, by participants, to cope with these new and frightening experiences. Such attempts to cope were drawn mostly from their own resources. Participants adopted a number of different coping strategies. These were divided into active coping strategies: -

"Well, if sometimes, they're off, (and they're making me damned head ache) I've had a shower installed over the bath so I go under the shower and I sing loads and loads of songs Frank Sinatra, Beatles er anything" (*'Joseph', pp. 31, 1030-1033*).

And more passive coping strategies: -

"Well I just locked myself away like. And said as little as possible" (*'Tony', pp. 5, 135-136*).

There was considerable variation in this category with some coping strategies affording an individual temporary relief from the voices whilst others were not particularly effective. What was striking in the accounts of all participants

was that they all found ways of coping with the experience of voice hearing. Ultimately, these coping strategies may have been ineffective as they sought help from the psychiatric system, but they made active attempts to try and cope.

3.5 Main Category – 'DISCLOSING INFORMATION'

The second main category identified in the accounts of the participants was termed 'Disclosing Information'. This centred on the process of voice hearers disclosing information about themselves, their voices and their distress to professionals. This was a very significant process in terms of influencing relationships between voices hearers and professionals.

Disclosure of information referred here to both the first contact voice hearers had with the psychiatric system and also to ongoing contact. Some of the lower level categories that will be described here have greater applicability to either first or more ongoing contact and it is made explicit where this occurs.

A diagrammatic representation of the lower level categories comprising the main category 'Disclosing Information' is shown in figure 6. As can be seen, there were three intermediate level categories. These were split into two sections. The first section includes the two categories of 'Barriers to Communication' and 'Aids to Communication'. The former was made up of essentially the processes that participants indicated acted as obstacles to disclosing information to professionals. The latter were the conditions needed for disclosure to occur. It appeared that participants experienced both barriers and aids, often at the same time. Their experience of these two conditions led onto the consequences of disclosure. This was the third intermediate level category. As will be shown there were positive and negative outcomes for voice hearers when they disclosed information to professionals.
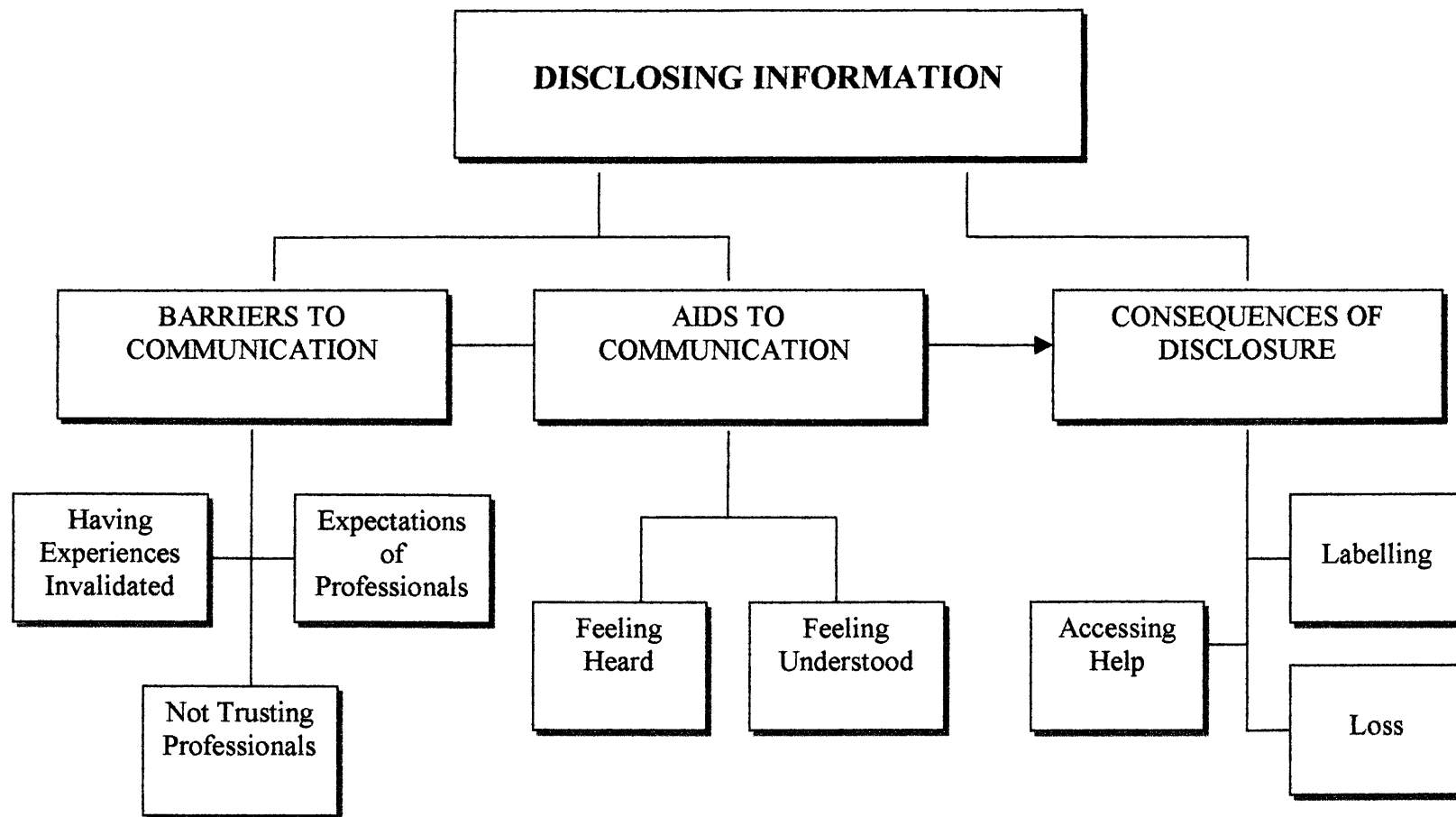
Fig. 6.Disclosing Information

Intermediate Category – 'BARRIERS TO COMMUNICATION'

Participants identified a number of barriers to communicating openly and honestly with professionals about their experience of voice hearing. Some of these barriers represented tangible obstacles born out of limitations within the psychiatric system. Participants stated that they set out to deliberately mislead professionals and not reveal the extent of their distress for fear of negative consequences: -

"I think you're quite aware of hospital, about kind of the sense of what you tell the professionals because it impacts a lot on whether you're allowed out for 15 minutes in the courtyard, the whole sort of obs system Whether you're on 24 hr observations or 15 minutes or whether you can go out with your parents or get leave. So, you spend a lot of time once you've settled in trying to convince everyone that you're really ok" ('Kathy' pp. 12, 379-386).

Others were rooted in the often-erroneous expectations users of services had about professionals: -

"I thought no one would believe me" ('Joseph' pp. 5, 143).

Implicit in the accounts of three of the participants was the notion that in order to overcome these barriers to communication they had to take drastic steps. 'Hattie' explains this process succinctly: -

"I took drastic steps.... I refused my drugs because I realised they wasn't doing anything for me. I asked them to look at my diagnosis again. You know, and I just fight. I did a lot of fighting for myself" ('Hattie', pp. 20, 650-654).

There were three sub-categories relating to 'Barriers to Communication'. These were, 'Having experiences invalidated', 'Not trusting professionals', and 'Expectations of professionals' and are explored in more detail below.

Sub-Category – 'Having Experiences Invalidated'

This subcategory was perhaps more applicable when participants had been involved with professionals for some time rather than at the point of first contact. It represented an active dynamic between voice hearers and professionals in which participants felt that professionals had in some way undermined or been dismissive of their distress. This resulted in participants not disclosing information: -

> *"But some nurses will just go, "Oh, no it's a trick of the light." (as I'd see things) and it would just feel like they were just sort of not believing you or trivialising it whereas it's something very big or they'd say, "It's just 'cos your stressed." And it's something very major to you and having it dismissed like that is really difficult"* ('Kathy', pp. 14, 475-481).

In addition participants felt that professionals had a tendency to interact with them in a somewhat depersonalised way: -

> *"The doctors told me I was schizophrenic. That was horrible. I didn't know what that was. I haven't really ever thought much about that though. They haven't said much the doctors"* ('Sarah', pp. 7, 211-214).

Or they felt patronised by being excluded from discussions of treatment options: -

"I think they think that they're protecting you from certain things, as like in ward rounds or in CPAs [Care Programme Approach] you don't go in straight away, they talk about you and get all the stuff over and done with first, and that really grates me" ('Kathy', pp. 33, 1102-1105).

Sub-Category – 'Expectations of Professionals'

Initially when participants first experienced the process of disclosing information about their voice hearing, they demonstrated that they held a number expectations from professionals. For example, there was a pronounced sense that all professionals were more knowledgeable than them: -

"It's like, if I'm getting down they'll say, 'You're hearing your dad's voice again aren't you?' They know anyway"('Sarah', pp. 5, 147-149).

Or had some expert knowledge that they could apply in order to alleviate participants' distress. By talking about only discussing her experiences with professionals, 'Jackie' implied that she had elevated professionals above the status of 'ordinary' people by virtue of the expert knowledge she perceived them as having: -

"Only to psychiatric people. I don't discuss it with ordinary people" ('Jackie', pp.12, 378-379).

The accounts suggested that by assuming that professionals were experts and very different to themselves, participants felt intimidated and inhibited in terms of truth disclosure.

Another characteristic of this category was that participants often expected professionals to behave in a certain way. There was a degree of anticipating or predicting what professionals might do or say in response to potential disclosure of information. 'Sarah' wondered whether others would believe she was hearing voices:

"Because you don't think they will believe you. So you don't want to tell them in case they say, "Oh no you're not" or something like that" ('Sarah', pp. 5, 158-160).

Sub-Category – 'Not Trusting Professionals'

This subcategory related largely to participants' first contact with the psychiatric system but did have a degree of relevance for more ongoing interactions. Participants identified a number of states within themselves that made it difficult to trust professionals and therefore served as a barrier to communication with them. A major factor was the mental health of participants at the time of disclosure of information. Disclosure became much harder when individuals were experiencing greater distress relating to being psychotic. Yet it is at this very time when it is perhaps most important that voice hearers can turn to professionals for support. For example, the presence of paranoia about the motives of professionals made it very difficult for participants to develop the degree of trust needed to tell them about the voices: -

"But initially when you first have your contact with the services, especially if you're feeling quite paranoid, and that just having someone that you have no knowledge at all about and you feel suspicious of new people anyway and for them to be asking you all sorts of questions that you've maybe not even answered before is really difficult I think a lot of, in my first year of the Services down here I did, erm, not answer everything quite as fully as I should. I mean I still don't answer everything quite as fully as I should

sometimes, but I did kind of mislead people into thinking I was better than I was because I just didn't trust them" ('Kathy', pp. 5, 163-174).

This was compounded by the perceived lack of opportunities to get to know professionals well enough to challenge some of these paranoid beliefs: -

"You just get to know them in their big nursey role. And if they sat around with you or watched TV or just had a chat about just normal things then I think I'd find it a lot easier to confide in them because they wouldn't just be this sort of very remote mental health professional" ('Kathy', pp. 14, 444-449).

A lack of trust in professionals in this sense was related to the recognition that it took a long time to develop the trusting therapeutic relationships needed to facilitate disclosure. 'Sarah' talked about her relationship with her psychologist: -

"Because I've been seeing her such a long time that I trust her. I don't trust other people very well. I know her very well"(Sarah, pp. 6, 169-171).

Participants felt that many professionals had so little time to spend with them that they began to feel in the way. A common complaint on inpatient units was that professionals only engaged in 'functional talk.' Professionals would only communicate with participants in response to a specific purpose: -

"On the ward a lot of the time spent with staff is just medication times or if you're in a crisis or if erm, just before ward rounds or whatever so you don't get to know them" ('Kathy', pp. 13, 441-444).

All participants regarded not knowing about the lives of professionals as a major barrier to the development of trusting therapeutic relationships. Participants talked about finding it very difficult to share very personal and emotive experiences with professionals if they knew nothing about their lives: -

"But it's like, you don't know when you're in a situation with professionals you don't know what their life is at all, you have generally no, you don't even know their first name" ('Kathy', pp. 5, 140-143).

An apparent consequence of not trusting professionals was that participants would either simply not talk to professionals about their experiences or would censor their accounts and offer only the information that they felt was acceptable or what they thought professionals wanted them to say.

Intermediate Category – 'AIDS TO COMMUNICATION'

The intermediate level category of 'Aids to Communication' effectively represented the opposite of the previous 'Barriers to Communication'. Essentially it was defined in terms of the conditions needed in order for participants to feel comfortable discussing their experience of hearing voices with professionals. In contrast to the 'Barriers to communication' that can leave participants with serious reservations about sharing information about their experiences, the aids to communication enabled participants to have a positive experience of sharing experiences. A consequence of this was often increased self-esteem. Participants indicated that it was almost always easier to manage if they were asked about their voice hearing experiences rather than having to volunteer information. However, one participant equated being asked too many questions by professionals as intrusive: -

"They ask me if I'm hearing voices. It feels horrible sometimes. Sometimes you just want to tell them to mind their own business. It feels like they're being nosey" *('Sarah', pp. 5, 140-142).*

Although participants generally regarded being asked about their voices as supportive, this negative case example qualified this by suggesting that this was only the case if voice hearers actually feel able to discuss their experiences.

Two sub-categories relating to 'Aids to communication' emerged from the analysis.

Sub-Category – 'Feeling Heard'

This sub-category represented things that professionals did that promoted a feeling of being listened to in participants. All felt it had been a very powerful experience to have someone listen to them. A feeling of being heard appeared to lead to a sense of feeling understood which was experienced as being very validating: -

"To get a lot of my problems out, you know, just to speak out, it was nice to do that. It felt a little better. You know, once I could get all the confusions out" *('Tony', pp. 3, 96-98).*

Participants appeared to be suggesting that they did not need to like professionals in order to disclose information to them. It was more important for them to see professionals as humans who would listen: -

"I mean you don't even have to like them all that much it's just that you want to know that erm, yeah, you just want to know that they're going to see you as a person and that you're seeing them as a person" *('Kathy' pp. 31, 1050-1053).*

Sub-Category – 'Feeling Understood'

Participants indicated that talking to professionals was beneficial -

"If I've got any problems I talk to my CPN and it's always been helpful" ('Joseph' pp. 35, 1167-1168).

An important part of feeling understood for participants was to have their experiences either normalised or not focused on exclusively, in order for them to feel professionals were interested in more than just their voices. One way in which professionals could do this was to disclose a degree of information about themselves. This was considered very important in terms of developing and maintaining therapeutic relationships: -

"If you're finding it hard to talk, erm, if you can't talk to someone about what was on telly last night then you've got pretty, not much, not at all chance of telling them your most intimate mental health secrets" ('Kathy', pp. 31, 1042-1045).

An interesting observation from 'Sarah' was that: -

"The more highly graded you get the less you understand. 'Cos they're pen pushers then" ('Sarah', pp. 11, 349-350).

She appeared to be suggesting that many of the more highly qualified professionals she was in contact with were not able to spend sufficient time with her to get to know and understand her.

Intermediate Category – 'CONSEQUENCES OF DISCLOSURE'

The final intermediate level category in 'Disclosing Information' was 'Consequences of Disclosure'. As the title suggests, this category encompassed the outcomes of disclosing information about their experiences to professionals. These were influenced both by the barriers to communication and the aids to communication and can be both positive and negative. Three main consequences were identified.

Sub-Category – 'Accessing Help'

This category represented the predominantly positive outcomes from disclosure. There was a sense of relief in having shared almost a guilty secret with someone else and the belief that in doing so participants would not have to cope alone. Participants were able to access help and support appropriate to their needs. Despite initial uncertainties about whether to tell people, participants experienced this as beneficial: -

> *"I didn't know how to put it to him, you know, I didn't know where to start and how to put it and I felt anxious of making a fool of myself and things. But I eventually got it out like and think with the psychologists some other things are unwinding like" ('Tony', pp. 4, 113-117).*

Joseph talked about what it was like to be able to share his experiences with someone who understood him: -

> *"Well, to say it lifts me spirits is an understatement" ('Joseph' pp. 20, 664).*

A further benefit was gaining access to potential explanations for these experiences and an opportunity to discuss these with professionals. These could be medical or non-medical depending on the professionals involved.

In essence, the consequences of disclosing information provided a context for future disclosure. If participants had experienced disclosure as positive they were more likely to be honest with professionals in the future than participants who experienced disclosure negatively.

Sub-Category – 'Labelling'

This represented the consequences of disclosure that were perceived more negatively. Participants identified a feeling of being labelled by professionals following disclosure, and that their experiences were too quickly reduced to a diagnosis: -

> *"First they said it was posttraumatic stress disorder. Then they said it was something else, then they said it was Schizophrenia. And it just kept changing and changing and changing"('Hattie', pp. 11, 359-362).*

Once a label had been given, participants talked about feeling that professionals then only looked for information that supported their assumptions and therefore confirmed the beliefs already held. This was so pronounced that often professionals would not listen to aspects of disclosure that seemed incongruent with the diagnosis given These labels often appeared to act as guides to subsequent treatment. This had both positive and negative connotations in that it could help access appropriate support as described above or it could restrict access to possible alternative sources of support for participants: -

"I think he'd made a picture of what was happening with me in his mind and then he was taking all the bits that I was giving him that backed it up but the bits that didn't back it up were just kind of ignored" ('Kathy' pp. 19, 639-643).

This category was given considerable variation from the account of 'Joseph'. He talked about labelling as being a positive consequence of disclosure. In contrast to the accounts of the other participants, he regarded receiving a diagnosis as having some protective qualities in that it explained his experiences. He made a direct connection between having a diagnosis and receiving help as a result: -

"Well they said that they would prescribe something for the Schizophrenia" ('Joseph', pp.17, 561-562).

Sub-Category – 'Loss'

This category is defined in terms of the actual personal losses for participants as a direct consequence of being psychotic and telling people about their voices. These losses had a profound effect on participants' sense of self and took a variety of forms. For example, loss of relationships: -

"I think that was what wrecked the marriage really because I couldn't tell him" ('Hattie', pp. 8, 246-247).

Loss of liberty in one participant who had been sectioned: -

"And he don't know anything about you and he's just writing clippits in these little, things, to have you sectioned. They take you off and start pumping you with drugs. They don't listen to you" ('Hattie', pp. 16, 530-534).

And loss of confidence, loss of choice in two participants who described being medicated against their wishes: -

> *"I've had injections forced on me when I've not wanted them, tablets forced on me. I mean sometimes, erm, there's been as many as six nurses holding me down and I just said to them, "I don't want the injection". I didn't get violent. But they held me down and injected me" ('Jackie', pp. 18, 580-585).*

3.6 Main Category – 'RECEIVING TREATMENT'

The third main category pertained to participants' experiences of receiving treatment within the psychiatric system. Fig. 7. offers a diagrammatic representation of the lower level categories encompassed by 'Receiving Treatment'. There was considerable variety in how treatment was perceived by participants and indeed within each individual participant over time. Responses to treatment ranged from actively seeking treatment, passively accepting it, resisting it and feeling that it had been a damaging experience.

Intermediate Category – 'TYPES OF TREATMENT'

The types of treatment described by participants were divided into three main groups, which formed the sub-categories of 'Taking Medication', 'Receiving Psychological Input' and 'Receiving Practical Input'. Participants' accounts suggested most received a combination of all three types of treatment and gained different amounts of satisfaction from each. Sometimes participants knew what kind of intervention they wanted: -

"It was only three years ago that I got the Cognitive Therapy, which I needed, not the drugs. I didn't need any drugs. I just needed someone to talk to. Someone to help me unravel my life. 'Cos my life was completely a disaster. From my childhood right up to adulthood" *('Hattie' pp. 13, 415-419).*

Whilst at other times they did not and were often prepared to leave decisions of this nature to doctors: -

"Erm, I can make the decisions yeah. But sometimes I leave them to make the decisions, you know, sometimes I do" ('Tony', pp. 8, 240-241).
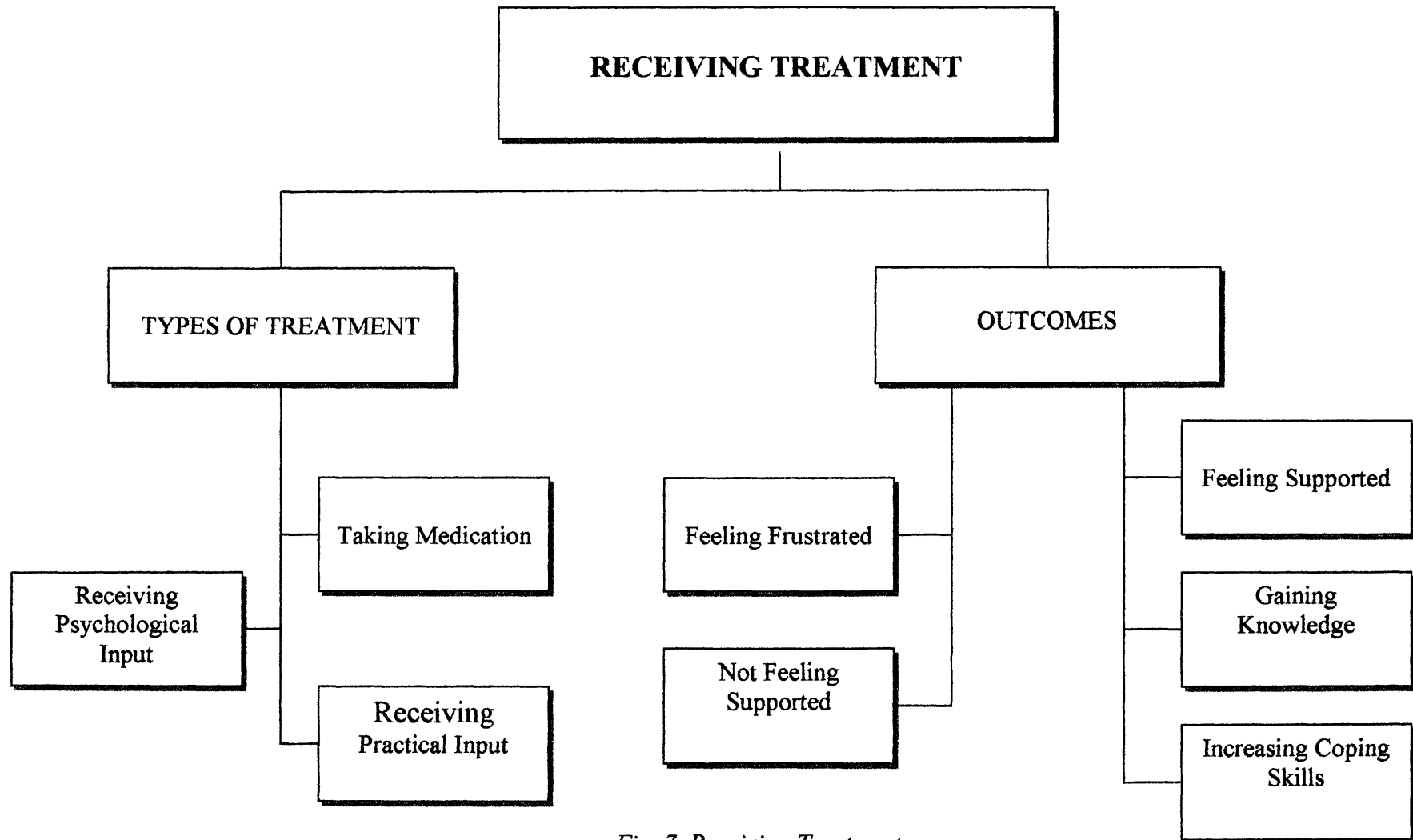
Fig. 7. Receiving Treatment

Sub-Category –' Taking Medication'

This sub-category became a very complicated and saturated category. There was a sense that both participants and professionals placed considerable importance and emphasis on taking and prescribing medication to help manage the voices.

Participants identified definite advantages to taking medication: -

"Without Depixol, I wouldn't be here now. It's been a Godsend to me" ('Joseph', pp. 18, 573).

Whilst others identified disadvantages: -

"The drugs that they gave me caused me not to concentrate, you know, and this is why I was arguing with him, do I need to have these drugs 'cos I can't even cook now. I can't even concentrate. You know, I don't want to get up and have a wash now because this tablet is causing me not to concentrate" ('Hattie', pp. 25, 813-818).

Whilst others adopted a pragmatic view: -

"It tends to dampen them down. Not completely get rid of them but sometimes, er, the airways are cleared" ('Joseph', pp. 12, 397-398).

Medication appeared to be a very emotive area for participants. Faced with constant dilemmas and choices, participants had to make difficult decisions about medication centred on whether the potential benefits of the drugs outweighed the side effects. Also they had to weigh up the extent to which they should go along with advice from professionals about taking medication. Participants appeared to be reliant on medication. Even those who explicitly stated there were considerable limitations to taking medication were able to appreciate the merits of medication. There was a

strong sense that participants had become very enmeshed with the notion of medication, as they were able to converse fluently about antipsychotic drugs. They knew names, doses and uses for medication and often became actively involved in discussions with doctors about any changes to their medication regime: -

"So they took the dose down and I was on 125mg but for the last month or so, last two months I've been on 90mg plus my Respiridol" *('Joseph', pp. 31, 1015-1017).*

The differing pathways that participants took through the psychiatric system in order to reconstruct their identities were made explicit here. For those participants where medication seemed to bring some symptomatic relief there was a reliance on it. Medication was seen as the answer to everything. However, failure to respond to medication induced a number of distressing feelings in participants: -

"It's like the blame can be loaded on to you, for not, it's your fault you're not responding to the medication or the interventions that they do. They probably don't even think that but it's, you know" ('Kathy', pp. 23, 752-755).

Such participants cited an over reliance on medication within the psychiatric system as being problematic and felt that alternatives needed to be considered. Interestingly this appeared to be echoed by those participants for whom medication had been helpful. There was a suggestion that the over-emphasis placed on medication was often perceived as impersonal: -

"The nurses before the Rehab centre took me over, well they used to come in just to give me my injection and then they'd clear off again. That were all I had, just nurses giving me my injection" ('Jackie', pp. 2, 41-44).

Sub-Category – 'Receiving Psychological Input'

This category was surprisingly underdeveloped in the accounts of the participants. Although all made reference to it, it was referred to much less than issues pertaining to medication. For many participants, this category represented the first time they had actually been asked to talk about their voices and had their explanations taken seriously. Being given space and an opportunity to explore their experiences in a non-judgemental atmosphere was viewed as extremely important and positive: -

"So it was a Godsend when my psychologist came along and he talked me through it. It took a whole year but it was good"('Hattie' pp. 13, 431-433).

For many it represented exposure to alternative explanations and the development of new coping strategies. Indeed many participants alluded to the fact they knew they needed to talk about significant events that had happened in their lives as they felt these were important factors in their voice hearing experiences: -

"But I eventually got it out like and think with the psychologists some other things are unwinding like. I'm doing other things you know. See I come from a family of 10....I'm the youngest of 10 and I had all, I had 5 sisters and I had them on to me and that and me brothers you know. And my dad was pretty strict like" ('Tony', pp. 4, 115-124).

Five participants felt that more opportunity to work psychologically would be beneficial.

Negative case analysis

'Jackie' did not feel helped by psychological input: -.

"I saw a psychologist before. He tried his hardest by suggesting I should try this and try that. He tried but it were not help" ('Jackie', pp. 21, 681-683).

The reasons why were not fully explored. 'Jackie' talked about having developed her strategies for managing her voices reasonably effectively. It was possible that she was not able to think psychologically, or that she felt exploring ways of conceptualising voice hearing that differed from her own were regarded as too threatening to consider. Conversely, it may also have been the case that the interventions she described were too directive and not sufficiently exploratory for her.

Sub-Category – 'Receiving Practical Input'

The third type of support that participants indicated they received from professionals was help with practical activities such as cooking, cleaning, organisational skills, planning activities and housing agencies. They identified a range of statutory and voluntary agencies that delivered specialist practical help. 'Kathy' described the support she was offered from one such agency: -

"They're much better at helping with practical things like erm, time management and you know, those kinds of things. I need lists 'cos my brain when everything's inside it gets very hectic so I need to have everything written down. And they sort of helped me do that kind of thing. So that's a big help, the more sort of practical things" ('Kathy, pp. 25, 837-843).

All participants were either currently in receipt of these services or were previous recipients of these. There was a feeling that practical support was often overlooked and given a lower priority than emotional or psychological support, which in turn was given a lower priority than the use of medication.

Intermediate category – 'OUTCOMES'

Responses to treatment were often based in part on the experience that participants had had when they first disclosed information about their voices. These were divided into largely positive and negative outcomes. Each participant indicated that they had had both positive and negative experiences of receiving treatment. This reflected a degree of variation in interactions with professionals and complex individual differences within participants themselves.

Sub-Category – 'Feeling Frustrated'

This represented the reflections of participants on the process of receiving treatment as a whole. A major frustration for one participant was a feeling that professionals were too quick to pathologise her actions: -

> *"It's when say if I was talking to you and erm. I'd maybe not want to talk about a certain area or I could even be, for no apparent reason I could just be thinking about what I'm going to have for tea, so I look distracted or look this way or another then they kind of read in, "Oh, was avoiding this, was ambivalent or whatever about that." Or, "Didn't seem to take much notice." "No affect, response" or whatever. Yeah, it's really frustrating" ('Kathy', pp. 18, 600-607).*

Another major frustration was being misrepresented by professionals. Frustrations often induced a sense of learned helplessness in participants, who then appeared to lose the energy to defend themselves: -

> *"...Especially when erm, you find out later what they've kind of, what's gone on report about what you've been like and it's like you kind of give up trying in a way. You think, "What's the point?" ('Kathy', pp. 18, 607-611).*

Sub-Category - 'Not Feeling Supported'

Participants cited a number of conditions that resulted in them not feeling supported by professionals. There was often a perceived lack of continuity and consistency in treatment. This was characterised by frequent staffing changes and professionals varying in their professional approach. 'Kathy' described how she perceived this as de-stabilising: -

"So that just creates even more sort of turmoil, there's no sort of party line" ('Kathy', pp. 36, 1191-1193).

Participants were divided over the degree to which they felt professionals really understood what it was like to hear voices. However, all agreed they felt less supported by those professionals who appeared to them to have a more limited understanding of the associated distress: -

"I want to do things in my own way. Not be told what to do by other people that don't really understand" ('Sarah', pp. 9, 294-295).

How professionals managed relatively 'normal' day-to-day worries was revealing of the lack of support participants felt at times. Such worries often got overlooked. There was also a sense that participants found it hard to feel supported by professionals whom they regarded as rather remote or too boundaried: -

"There's quite a distinct line between patient and professional, or client and professional, like, erm you don't really know what's going on, it is more about focused on you and not focused on them so you wouldn't really go up to your psychologist or psychiatrist and say, "So are you married then?" "How many children have you got?" Whereas they'd be asking you all sorts of personal questions" ('Kathy', pp. 3, 95-102).

Receiving treatment was also associated with more positive outcomes for participants, as highlighted in the sub-category below.

Sub-Category – 'Feeling Supported'

Participants were able to cite a number of conditions necessary in order for them to feel supported. These involved feeling contained by professionals. Here the type of treatment was less important than the sense of safety and containment engendered by professionals. An example of feeling contained was knowing that support systems were in place and how to access them: -

> *"Well 'Contact', they help us out with little bits and bobs you know. If we're not very well we tell them about it and then they either refer us to Dr Smith or Fiona the CPN. And erm, they sort our letters out you know, things like the Council and you know, all the papers, paperwork and finances, you know stuff like that" ('Tony', pp. 1, 5-10).*

Also important was knowing that professionals would be able to contain participants' distress in times of crisis. 'Kathy' talked about the concept of 'Panicablility': -

> *"When people are dealing with psychosis and stuff, some of the things that go through your head are quite disturbing and all, and some professionals will hear it and then panic. You can see the look of fear, almost ...Which is understandable in a way, I mean you, that you need to know, to know that erm, that yeah, that they don't scare easily, and, erm, and that they will sort of talk to you about it and not run and find a psychiatrist as soon as they can. Again it's the trust" ('Kathy', pp. 32, 161-172).*

In addition, participants talked about just having someone to be with them. Rather than being focused on removing symptoms, just having someone available to sit with them whilst they were distressed was regarded as very beneficial. 'Sarah' sums up the essence of what feeling supported means to her when she describes her key worker: -

> *"She shows her emotions. Yeah. Some members of staff just ask you if you want PRN medication or tell you to go and sit down and do some breathing exercises. They just leave you to it. 'Trudy' wouldn't do that. She'd talk to me and if that wasn't good enough I'd have PRN but she don't leave me on my own until it's calmed down a bit and that's helpful"* ('Sarah', pp. 8, 266-272).

Interestingly, 'Tony' talked about professionals being too supportive which he perceived as overly prescriptive at times. This appeared to have a detrimental effect on therapeutic relationships: -

> *"I thought they was trying to control us like. So we never really got on"* ('Tony', pp. 12, 371-372).

Sub-Category – 'Gaining Knowledge'

Gaining knowledge was seen as a positive outcome. It essentially involved three mechanisms; self-help, learning from other voice hearers or gaining knowledge from professionals.

Knowledge gained via self-help was acquired through reading around topics such as schizophrenia and accessing Internet educational resources: -

> *"Well. I've done a lot of reading on it throughout my life"* ('Joseph, pp. 15, 493).

The process of gaining knowledge required participants to be active agents and appeared related to the length of time they had spent within the psychiatric system. The longer the duration of contact with the system the more knowledge that was acquired. As the knowledge base of participants grew so too did their ability to 'work the system' to get what they needed: -

"Now I know enough about medication and enough about what I think's going on that I can just use them for what I need, which is if I need extra services, or support I can go and ask them. If I need my medication changing then I can go and ask them, that kind of thing. So I'm just taking what I need and kind of leaving the rest" ('Kathy', *pp. 29, 941-946).*

'Hattie' talked about applying her acquired knowledge and considered helping to train professionals: -

"I think they should have real users going in and doing their talking about their experiences before they qualify to consultants. It shouldn't be all textbooks, textbook is not real" ('Hattie, pp. 22, 731-734).*

Sub-Category - 'Increasing Coping Skills'

This category was closely related to gaining knowledge in that as the knowledge base of participants grew, so too did their access to coping strategies. This often resulted in their increased ability to cope with distressing voices. In particular, this helped them to develop an awareness of early intervention and relapse prevention strategies and to actually take more control over their recovery: -

"One question that you did ask me is how I cope with the voices. Well, if sometimes, they're off, (and they're making me damned head ache) I've had a shower installed over the bath so I go under the shower and I sing loads and loads of songs...It helps. It kind of dampens them down." (Joseph, pp.31, 129-135).

3.7 Main Category –'ATTEMPTING TO MAKE SENSE OF EXPERIENCES'

The fourth main category, 'Attempting to make sense of experiences' was more abstract than the previous main categories. It made most conceptual sense when considered as a whole rather than in terms of being comprised of lower level categories. It represented the culmination of all of the above experiences for participants and their efforts to make sense of these.

As might be expected, there proved to be enormous variation in the ways participants attempted to understand the experience of voice hearing and put this into a context from which they could begin to make sense of it. This category was characterised by a number of ongoing tensions and dilemmas for participants as they embarked on this struggle.

Firstly the process of attempting to make sense of experiences was a gradual one. Participants needed time and space to think about, and develop their own explanations. At some times participants were clearly actively attempting to place experiences into some form of context: -

"I think it's 'cos of things that happened in my childhood" ('Sarah',
pp. 7, 210-211).

At other times, participants actively avoided having to reflect on their experiences: -

"I was running from it a lot. Drinking [Laughs] doing lots of
drinking and partying and erm just trying to escape what was going
on" ('Kathy', pp. 9, 304-306).

A tension inherent in this process for participants was having to consider the degree of responsibility to accept for their recovery and how much to attribute to professionals. 'Kathy' illustrates this tension: -

"Doctors make you well', that's what you're taught when you're young you'll go to the doctor and mental health is so different but the whole services haven't caught up to the fact that it is very different, erm, so you still, erm, buy into the doctor making you well thing. And especially if you're feeling very vulnerable and confused, you need, or you want someone to step in and say, "It's going to be all right". Or, "This is what you should do," or, whatever" ('Kathy', pp. 35, 1173-1180).

'Hattie' also described fundamental changes in her attempts to make sense of her experiences over time: -

"I was just worried that they might put me in an asylum and that I would be there forever. But then I realised that, they told me that it's not, like that and maybe what had happened to me wasn't my fault because, that's the word, I didn't get any counselling" ('Hattie', pp. 9, 294-298).

3.8 Main Category –'SENSE OF SELF IN RELATION TO THE PSYCHIATRIC SYSTEM'

As the process of attempting to make sense of experiences continued, participants appeared to develop an increased sense of their position in the psychiatric system. For example, whether they were a patient there to get better, or a victim of an abusive system were perhaps the two most extreme ends of the spectrum. Fig. 8. depicts the lower level categories related to this main category.

There was a degree of variation in the sense of self that emerged in participants from their contact with the psychiatric system. Three different traits were identified and form the intermediate categories described below. These were 'Asserting self', 'Feeling Empowered' and 'Feeling Powerless'. In the early stages of participants' psychiatric careers there was considerable movement between each stage. Over time each participant began to identify with one of these traits to a greater degree.

Sense of self as a main category was given further richness by participants developing an awareness of change both within themselves and in the psychiatric system itself over time.
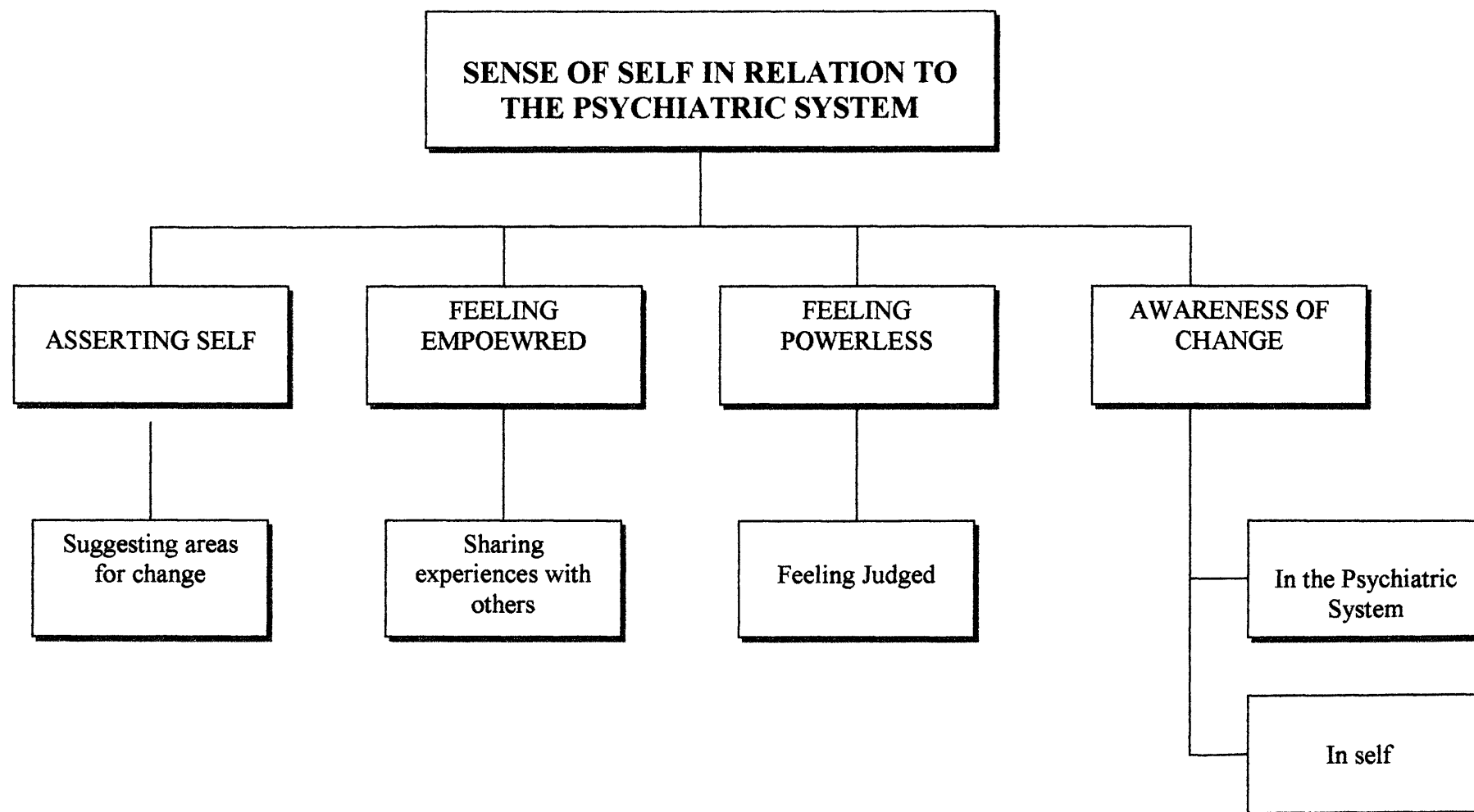
Fig. 8. Sense of Self in Relation to the Psychiatric System,

Intermediate Category – 'ASSERTING SELF'

A defining characteristic of the intermediate category 'Asserting self' was that participants were able to articulate their thoughts and needs openly and frankly with professionals, for example, by questioning professionals' actions: -

> *"My psychiatrist, before the one I've got, diagnosed me initially with Schizophrenia I think. But then changed it to Borderline Personality Disorder for a little while until I sacked him [Laughs].... Until I got a second opinion of another psychiatrist. He'd begun to completely disregard things that I was saying"* ('Kathy', pp. 16, 525-534).

'Hattie' described this process rather like she was engaged in a battle: -

> *"They don't listen to you. The Consultant don't listen. I had a very difficult time with my consultant. I've still got him. He didn't listen to me and that's the first thing I said to him. ...I said, "the first one didn't listen to me, I said can you listen to me please. Can you stop reading those notes and listen to what I've got to say?" ...And it was only when he stopped and listened that he could treat me"* ('Hattie', pp. 14, 443-454).

Participants who asserted themselves with professionals tended to be those who had experienced the barriers to communication and negative outcomes of treatment. Rather than becoming assertive through a process of working with professionals, these participants appeared to have achieved this *despite* professionals.

The ability to be assertive was largely dependent on the mental state of the participants at the time. But even if they were feeling relatively well, the process remained distressing. 'Kathy' recalled how she felt after 'sacking' her psychiatrist: -

"Afterwards I was an absolute mess of jelly. I was shaking and I was crying and everything, it was horrible. But I just had to try and keep it together then 'cos I knew that if I showed my emotions or broke down or whatever I'd just be reinforcing what he thought. So that's really difficult" ('Kathy', pp. 21, 704-709).

Sub-Category – 'Suggesting areas for change'

Participants who asserted themselves were able to gain a different level of access to professionals than those who were less inclined to do so. However, it was interesting to note that in proportion to the intensity of frustration with the psychiatric system described earlier, relatively few suggestions were made as to areas for change. 'Hattie' suggested increased user involvement (see sub-category 'Gaining Knowledge') whilst 'Kathy' speculated as to how she felt mental health services should be in the future: -

"I really hope my ideal is that it moves away from the medical. Not, there's a lot of people with the whole anti-psychiatry thing and I don't think that psychiatry is necessarily a bad thing. I just think it needs to be more balanced so that there isn't, at the moment the Consultants sort of have ultimate power" ('Kathy' pp. 40, 1345-1350).

Intermediate category - 'FEELING EMPOWERED'

In contrast to the previous category, 'Feeling Empowered' was indicative of greater collaboration between voice hearers and professionals. Professionals were seen as active in promoting opportunities to enable voice hearers to become more independent, resourceful and able to make their own informed decisions on aspects

of their treatment. The accounts from participants seemed to suggest that professionals were good at helping them to help themselves: -

"But now we're here, they help us to pay our own bills and if there's any maintenance that's needed we get in touch with the council ourselves and things like that" ('Tony', pp. 10, 322-324).

Participants embraced this concept to varying degrees. Those who had developed a sense of wanting to take responsibility for their recovery appeared keener to respond to professionals' attempts to empower them. In contrast those relatively content to attribute responsibility to the professionals tended to be less receptive to opportunities to become more involved in service development or to become more independent within the community.

Sub-category – 'Sharing experiences with others'

Sharing experiences with other voice hearers emerged as being closely related to 'Feeling empowered'. The opportunity to share experiences offered an excellent source of support. Participants indicated that this was fundamentally different from sharing experiences with professionals, as other users had first hand experience of hearing voices in a way that professionals did not: -

"It felt like I had a great big boulder took off my shoulders because I could talk about it with other people that were hearing voices" ('Hattie', pp. 4, 104-106).

This happened informally in a variety of inpatient and outpatient settings. However, a more structured forum for doing this was in the local Hearing Voices Group. 'Kathy' and 'Joseph' were current users of this group whilst 'Hattie' was an ex member. All stated that it was beneficial: -

"It's quite a small group, but it's really been, really positive. Erm, it's one of the few bits of the Mental Health Service where you feel like you're just about equal with everyone that's in there" ('Kathy', pp. 1 14-17).

Intermediate Category – 'FEELING POWERLESS'

'Feeling Powerless' as an intermediate category referred explicitly to aspects of the psychiatric system that made participants feel as if they had less power than those around them. Accounts suggested that participants felt a hierarchy of power existed from the consultant psychiatrist down. As such, the psychiatrist adopted a very significant role in the accounts of participants as their views influenced the actions of other professionals.

'Kathy' talked about how she felt professionals responded to user involvement in services. Whilst she indicated in her interview that many newly qualified staff were probably in favour of this, she felt others might not be: -

"But then I think there are also a number of sort of, some psychiatrists and some ward staff and some of the erm, professionals that are maybe kind of threatened by it because they're not yeah, it's change and it's new and it does de-stabilise things a bit because they're not as needed or they're needed in a different way. I mean one quote that I've got from a psychiatrist was, 'We don't have patients dictating what wards they go on'" (Kathy', pp. 39, 1321-1328).

'Hattie' was the only participant to talk about being the recipient of a section under the mental health act and described the process as follows: -

"So I was sectioned. Humiliated in the street. I tried to get away from them but I couldn't. Humiliated in the street. Towed off in a great big van and just shoved in a bed at the psychiatric place. They came with the injection and that was it. I've never seen anything like that before" ('Hattie', pp. 17, 568-573).

Participants saw themselves as having very little power. 'Hattie' talked about not feeling listened to unless she had an advocate to support her. She gave her thoughts on why the psychiatrist would listen to the advocate but not her: -

"They're more sane. The consultant just thinks I'm a loony, you know. Nothing I say is all there. The fact that you're hearing voices, you're completely off the planet" ('Hattie', pp. 15, 498-500).

'Jackie' talked about having no power to make decisions regarding her own treatment: -

"I've had injections forced on me when I've not wanted them, tablets forced on me. I mean sometimes, erm, there's been as many as six nurses holding me down and I just said to them, "I don't want the injection". I didn't get violent. But they held me down and injected me" ('Jackie', pp. 18, 580-585).

Sub-Category - Feeling Judged

As with 'Barriers to communication', described earlier, 'Feeling judged' as a category encompassed both participants' anticipation of being judged: -

> *"I know they don't believe me. I don't think anyone believes me really" ('Sarah', pp. 3, 86-87).*

And the actual reality of it: -

> *"And he was like, "No, no. It's quite typical of someone with your diagnosis to resist therapy" and that, and I was like phew, "There's been no therapy to resist". It was just a no win battle" ('Kathy, pp. 19, 629-632).*

Intermediate Category – 'AWARENESS OF CHANGE'

'Awareness of change' as an intermediate category held particular salience for those participants who had had the longest contact with the psychiatric system. It represented changes in their understanding of the psychiatric system as a whole and a more subtle awareness of changes within themselves.

Sub-Category – 'In psychiatric system'

This sub-category represented participants' considered reflections on the experience of being in the psychiatric system. In terms of their awareness of how the psychiatric system had changed over time, participants adopted a philosophical approach. There was recognition of many positive changes: -

"Well there's more like services like the cognitive therapy, and the Hearing Voices Group and they're sort of doing the care plan now. That wasn't done at the beginning. It's every three months I think. To see where you are. And where you need to be. So yeah it's changed" *('Hattie', pp. 30, 985-989).*

Sub-Category – 'In self'

Participants described a variety of thoughts and feelings about how they felt they had been changed by contact with the psychiatric system. Thinking specifically about hearing voices, participants felt they had developed relationships with their voices: -

"Well they [the voices] don't scream as much for starters. They're in the background so I can deal with them now" *('Jackie', pp. 16, 522-523).*

By understanding more about their voices, participants were able to assert more control over their influence. A common feeling was an increased sense of reassurance that their distress was not their fault. As a consequence, participants felt happier and more content with their lives: -

"I'm more happy within myself like. I feel more happier, you know. I don't feel so miserable" *('Tony', pp. 14, 439-442).*

In recognising how they had changed within themselves and being aware of the ever-evolving nature of the psychiatric system, participants were able to carve out a place for themselves within the psychiatric system and begin to reconstruct their sense of identity.

Chapter 4

Discussion

4.1 Overview of Chapter

This chapter provides a summary of the analysis of voice hearers' experiences of mental health services. It seeks to discuss these findings with reference to some of the existing psychological literature in this area. The implications of the present study are discussed in relation to clinical practice and policy development. Consideration is also given to methodological concerns and reflections on the research process are also presented. Suggestions for further research arising from both the implications and the methodological limitations are put forward. Finally, some conclusions pertaining to the study as a whole are put forward.

4.2 Interpretation of the Analysis

The aim of the study was to develop an integrated and coherent theoretical account of the experience of hearing voices and of the interaction between voice hearers and professionals working within mental health services. The transcripts of interviews with six voice hearers were analysed using grounded theory and both a core category and a process model emerged. These will be discussed below. As described in the analysis itself, the core category and process model incorporated both the first contact and further ongoing contact that participants had with professionals.

The Core Category – 'Reconstructing a sense of identity'.

For the participants in the present study, the onset of psychosis appeared to pose a serious threat to their existing sense of identity, so much so that this resulted in a breakdown in their ability to cope. This inability to cope led them into contact with mental health professionals. The notion that individuals who have psychotic experiences often experience a profound disturbance in their sense of self is supported by existing literature (e.g. Lysaker & Lysaker, 2002). In response to these disturbances participants actively tried to assimilate the experience of hearing voices into their pre-existing sense of identity. The result of this process was the emergence of a reconstructed sense of self.

The processes by which participants attempted to reconstruct their identity were both complex and constantly changing. It has been shown that factors implicated in identity formation include individual personality factors, life events and interactions with other people (Crapanzano, 1982 cited in Estroff, 1989). For participants, interactions between themselves and a range of professionals and contact with the psychiatric system as a whole appeared to be important in helping to reconstruct a sense of identity. Interactions with other voice hearers and being able to recognise changes in oneself over time were also considered important.

This attempt by participants to assimilate the experience of voice hearing into one's sense of self has similarities with Romme and Escher's (1989) three-stage model of understanding voices. The phases of 'startling', 'organisation' and 'stabilisation' together perhaps represented voice hearers' attempts to incorporate the experience into their sense of self.

The identities adopted by participants were often very different, ranging from total acceptance of the illness model to a qualified rejection of it. This served to give variation to the core category. Although the experiences of participants were very different, they still reflected the central theme of reconstructing a sense of identity. Participants made sense of their experiences in a way that was functional for them. For some the medical model appeared to have intrinsic value; for others it did not.

The sense of identity adopted by participants was not necessarily static and did change over time as participants progressed through their psychiatric career. Identities based around acceptance or rejection of the medical model were not mutually exclusive, and participants appeared to fluctuate between such ideas, and even entertained both at the same time. 'Kathy' talked about initially believing she was ill and of hoping that the doctors could cure her. Once she realised that a cure was not forthcoming she was forced to reconstruct another identity for herself based around rejecting the idea she was ill. How individuals make sense of their experiences and reconstruct a new identity out of this has important implications for recovery from enduring mental health problems (Davidson & Strauss, 1992).

'Joseph' and 'Tony's' identities appeared to be largely based around a belief they were ill. 'Joseph' spoke a lot about medication and actually described himself as schizophren*ic*. Linguistically, this implied his whole self was defined by being schizophren*ic*. This is in contrast to someone who perhaps might describe themselves as having schizophren*ia*, which implies that whilst schizophrenia may be a part of their life, it was not the defining feature of it. 'Kathy' and 'Hattie' focused more on considering the role life events had played in their understandings as to hearing voices and did not seem to describe themselves as ill. As can be seen from the analysis, participants discussed their experiences of being labelled and labelling themselves.

Labelling theory suggests that individuals who have been diagnosed with schizophrenia and who accept that label would function less well than those who reject their diagnosis (Warner, Taylor, Powers & Hyman, 1989). Sub-optimal functioning may result from the stigma that surrounds such a diagnosis, the negative way others view and respond to such individuals and the way they view themselves. However, many professionals would believe the opposite and assert that acceptance of the fact that one is suffering from a mental illness is a necessary pre-requisite to coping with the illness and therefore achieving a good outcome. The analysis of the participants' accounts suggested that those who maintained function based around the notion of being ill, developed an external locus of control and attributed responsibility for their recovery to professionals working with them. This was consistent with previous research in this area (Warner *et al*, 1989).

Mental health services often appear to be centred around this belief that in order for recovery to occur, an individual needs to develop insight and accept they are ill (Thomas, 1997). Services traditionally emphasise the need for individuals who have psychotic experiences to take medication for the rest of their lives and do not generally promote hope and optimism for the future (Williams & Collins, 2002). Indeed, it could be argued that this conveys a sense that professionals have very low expectations for users in terms of their future, i.e. employment prospects, ability to live independently of the psychiatric system. The very design of the psychiatric system, for example, hospitalisation and medication, reinforces the sick role in users and creates a degree of dependency (Estroff, 1989). There is also the risk of being institutionalised after prolonged contact with the services.

Individuals may reject the notion of being ill but be surrounded by a system that reinforces and actively promotes this. 'Hattie' talked about having numerous differences of opinions with professionals regarding her theories as to the origin of her voices. This resulted in the development of a profound sense of frustration at not being listened to. This may reflect a psychiatric system unable to accommodate views different to its own.

Much of the literature in this area suggests that in order for an individual with mental health difficulties to experience recovery they must reconstruct an enduring sense of self as an active agent in this process (Davidson & Strauss, 1992). In effect, they must develop an internal locus of control and take responsibility for their own recovery. However, 'Joseph' and 'Tony's construction of themselves as ill and their belief that professionals were responsible for their recovery suggests that the concept of recovery is subjective and may mean different things to each individual voice hearer. It also raises important issues regarding how users perceive professionals.

Professionals as having expert knowledge

All participants spoke about regarding professionals as experts. For some participants this was a belief that was quickly modified in the light of their experiences, whilst for others it was more enduring. At times participants appeared to want professionals to take an expert role and make decisions for them whilst at others they were concerned with being regarded as equals. The observation that the participants in the present study did sometimes want professionals to be experts is particularly salient given the wealth of literature described earlier suggesting that professionals should not adopt such a role.

It is possible that the expectations of service users can at times create tensions in professionals who may not want to see themselves as an expert yet may feel pressure from users to do so. This pressure is also often reflected in the dominance of the medical model within mental health services and also in the training of professionals. For example, the recent introduction of doctoral status in clinical psychology training conveys a sense of the holders of such a qualification having some expert knowledge. This is perhaps reinforced in those undertaking such training as the learning of a range of specialist techniques and theory is emphasised (Moorey & Markman, 1998).

There continues to be much debate as to whether professionals can and should be regarded as experts within mental health services. Much of the debate has focused to date on how *professionals* feel they should portray themselves. The findings herein suggest that at times, *users* themselves need to regard professionals as experts. This introduces a different dimension to this debate. It highlights a need for professionals to be able to respond to the needs of individual clients. It is possible that should voice hearers such as 'Joseph' regard professionals as having less of an expert role it might be perceived as being very destabilising and as a threat to their illness identity. Other factors that might influence the reconstruction of identity are highlighted in the discussion of the process model that follows.

Consideration of the process model

Being Psychotic

The process model attempted to account for some of the factors that influenced the reconstruction of identity. The main categories developed from the analysis depict the stages of contact with professionals and how the participants experienced this. Essentially, the model suggests that voice hearers are active agents searching for a meaning for their experiences. As might be expected, each participant's experiences within this model were unique but a number of shared themes emerged.

In relation to 'Being Psychotic', all participants in the present study identified a state of not knowing. This encompassed a sense of not knowing what was happening to them; not knowing where to find help and not knowing what people would do if participants shared their experiences with them. This has resonance with Romme and Escher's (1989) 'startling' phase. Being psychotic was described by all participants as distressing. What was particularly interesting about this was that initially 'Jackie' did not appear to be distressed. This was because the voices were perceived as benevolent and communicated pleasant ideas to her. This is not an uncommon phenomenon (Romme & Escher, 2000) yet professionals have a tendency to assume all voice hearers are always distressed by the experience. Many voice hearers may actually court the voices and draw interpersonal strength from their presence (Leuder, 2001). Although such people are least likely to have contact with mental health professionals, it is still important that professionals appreciate that not all experiences of hearing voices will be distressing. Applying therapeutic interventions designed to reduce the impact of voices without first ascertaining the level of distress associated with them may lead to voice hearers resisting such interventions or obtaining no value from them.

In addition to distress, all participants alluded to being affected either by their preconceived ideas about voice hearers or the stigma that society attaches to it. From the accounts of the participants it seemed that this was a very real concern that

caused considerable distress and potentially acted as a barrier to open communication with professionals.

Disclosing Information

It appeared that the participants were affected by stigma in different ways. 'Kathy' talked about feeling able to discuss her symptoms of anxiety and depression with her GP but unable to disclose that she was hearing voices. Indeed the language used by participants in discussing their voices with professionals was suggestive of them experiencing considerable ambivalence as to whether to disclose the information or not. There appeared to be a tension between wanting to tell people about the voices but being scared of the response. For example, the accounts of 'Kathy', 'Joseph' and 'Jackie' refer to information 'slipping out' having to 'come clean' and of 'giving myself away' respectively. 'Sarah' also indicated she felt she would not be believed by professionals.

Participants also talked about misleading professionals and being economical with the truth regarding the severity of their distress. This appeared to be related to a fear of the consequences of honesty. This is an important consideration, as much of the psychiatric system is centred around understanding and managing risk. If professionals feel that an individual is at risk of hurting themselves or others, they may place restrictions on that individual. One consequence is that service users often perceived this as them being punished for their honesty. Therefore a fundamental barrier to open communication was created. This is particularly salient in light of proposed changes in the Mental Health Act (Department of Health, 1998), which seek to give clinical psychologists more involvement in the sectioning process. It is possible that service users may censor their accounts and therapeutic relationships between users and psychologists, which are so important, may be damaged.

Another barrier to communication cited by participants was not knowing anything about the lives of professionals. Often professionals were perceived as distant and somewhat reluctant to share anything about themselves. This perhaps reflects the belief in much of the psychotherapy literature that in order to help

patients, therapists must remain blank canvasses upon which patients can project their distress (Casement, 1990). However, participants in the present study suggested that they wanted professionals to be genuine and to share some information about themselves so that they could see them as real people with real lives and therefore more like themselves and people who they could talk to.

When professionals did do this, for example, took time to talk about something other than their voices, participants regarded this very positively. In particular the three participants who had had contact with the Hearing Voices Network indicated that this was a forum where this happened all the time rather than being a rare exception to the norm. Measured personal disclosure from professionals during meetings of the hearing voices group was perceived as very beneficial in helping to normalise experiences and reduce stigma.

Receiving Treatment

Participants regarded the Hearing Voices Group as an unusually collaborative aspect of the psychiatric system. With regard to much of the rest of the system, participants identified feeling they had to constantly weigh up the potential advantages and disadvantages of sharing their experiences with others. This often equated to having to take risks in disclosing information. For example, participants identified a state of not knowing the likely consequences of engaging with others. Participants also identified the need to decide what information presented to them by professionals they should accept and what they should reject.

It appears then that not only do voice hearers have to manage the distress associated with the experience itself, they also have to make constant evaluations as to the potential costs or benefits of engaging with treatment. In the analysis, many of the categories related to receiving treatment appeared to contradict each other (e.g. 'Feeling Supported' and 'Not Feeling Supported'). This perhaps reflected the realities of some of these internal dilemmas.

Whilst all accounts contained examples of participants feeling helped and supported by aspects of the psychiatric system, all were also critical of inpatient care. This is consistent with the results of a MIND survey (MIND, 2000 cited in British Psychological Society, 2000) in which 30 per cent of hospital patients surveyed felt unsafe in hospital. A further 37 per cent felt they did not have enough contact with staff whilst 82 per cent had less that 15 minutes of direct contact with staff a day. This latter statistic is supported by 'Kathy's account of staff only engaging in 'functional' talk with her, 'Hattie' in her account implies that as a voice hearer in hospital you have very little power and in order to be listened to she needed to employ the services of an advocate.

Interestingly, given the critical nature of many of the accounts, when asked if there was anything they would change about mental health services, very few suggestions were offered. It could be that participants were not able to articulate this or that they had not considered this question in any detail before. It may also be the case that generating alternatives is very hard in any situation. Or it could be born out of a sense of 'learned helpless' (Seligman, 1975) in which participants no longer try to suggest things, as they know they won't happen. Varying degrees of a state of helplessness emerged in the accounts of 'Hattie' and 'Sarah' in particular.

Finding meaning

Attempts to make sense of these experiences pervaded all categories. At times participants were actively looking for explanatory frameworks to adopt whilst at others they did not wish to think about their experience of hearing voices as having any significant personal meaning for them. This is similar to McGlashan *et al*'s (1975) 'integrative' and 'sealing over' coping styles (Chapter One). Participants' accounts reflected them struggling with the idea of how much responsibility to accept for recovery and how much to attribute to professionals. Similar to this was the theme running through all the accounts of a tension between wanting to be independent but often at the same time, being very dependent on the system. Those that were most dependent on the system generally had an identity based around being

ill. However, the process of reconstructing a sense of identity was more complex than that. Identity changed in relation to participants' awareness of changes within themselves and changes within the psychiatric system as a whole. Identity then is neither fixed nor static and changes in response to individuals, environmental, and social factors.

Much has been written about identity and, in particular, how people respond to threats to their identity. Threats to an individual's sense of identity can take many different guises, for example, being confronted by unemployment or chronic illness. Important contributions in this area come from social psychological models of identity. One such model is purported by Breakwell (1986). She provides an integrative framework within which identity, threat and coping strategies are explored.

Essentially, Breakwell's (1986) identity process model suggests that identity is a dynamic social product, which is constantly monitored and reappraised by an individual in response to "changes in social value systems and modifications in the individual's position in relation to such social values" (Breakwell, 1986, pp. 191). Changes in the structure of an individual's identity are brought about by a process of 'assimilation' or 'accommodation'. This is the degree to which new information about an individual's internal and external world is integrated into their existing sense of identity.

This process of identity formation, i.e., the integration of new information into the existing sense of self, is guided by a set of principles, which are regarded as 'desirable' by each individual. What an individual believes is desirable is in turn socially and culturally determined, and thus identity is created within a specific social context. As such, identity is heavily influenced by, for example, education, perceived social status or the media.

Threats to identity occur when, for some reason, an individual is unable to assimilate or accommodate some aspect of experience into their existing identity structure because it contradicts those elements of identity regarded as desirable. By way of an example, it could be argued that within this theory, accommodating or

assimilating elements of identity based around being 'mentally ill' are threatening as such elements are not recognised by society as desirable. Threats to identity are by their very nature perceived as aversive and an individual will always seek to restore a less threatening identity. Therefore, any activity designed to remove or modify a threat is regarded as a coping strategy. The participants in the present study all faced a threat to their sense of self and developed very different coping strategies in attempts to manage this threat. For example, those participants that managed the perceived threat to their identity by rejecting the notion that they were 'ill', within Breakwell's (1986) model, were reducing the stress associated with possessing aspects of identity that they felt were undesirable and threatening by modifying their beliefs accordingly.

The fact that multiple factors are implicated in identity formation suggests this process is very complex and the account of the analysis here is but one way of attempting to explain it. The account does not suggest cause or effect or claim to be inclusive. More research is needed to explain the process more fully. However, a number of implications for clinical practice can be made on the basis of the findings from the present study.

4.3 Implications

Whilst the present study did not focus exclusively on voice hearers' experiences of contact with clinical psychologists, there are a number of implications of relevance to psychology. These take the form of implications for clinical practice, development of theory and policy making.

The present study adds to the small but growing body of literature that emphasises the need for clinicians to seek to understand the meaning of voice hearing experiences for each individual voice hearer. Perhaps more importantly, the present study has demonstrated that in order for services to remain relevant for voice hearers, professionals working within them need to go beyond mere understanding and actually start acting on feedback from users. An example of this is the need to understand the significance of the experience in order to develop appropriate coping

strategies. If services are not relevant to users, they may not engage in them. Or, if they do, both themselves and professionals may become frustrated at the lack of shared understanding. Research of this nature compels clinicians to listen more to the views of users and to consider how they themselves may influence the experiences of voice hearers.

There are further implications for the training of professionals. Clinical psychologists are rarely exposed to the views of service users throughout their training, nor are they taught how to access these views or to promote an environment where service users are encouraged to be more prominent. As well as training for clinical psychologists, the present study highlights the need for all professionals to think more about the way voice hearing is conceptualised and look at ways of offering alternatives to the medical model. There is scope for psychologists to be involved in the promotion of this perhaps through the delivery of teaching and training to others.

This study also suggests that psychology can have a role to play in reducing stigma within society. Participants' accounts suggested that the effects of society's attitudes towards voice hearing are a cause for distress. There is a need for an educational role and to present the general public with information about voice hearing in the hope that stereotypical attitudes can be challenged. This is already within the remit of organisations such as the British Psychological Society (British Psychological Society, 2000).

Participants also highlighted that there needed to be a significant shift in the attitudes of many mental health professionals. It is often easier for professionals to continue to treat symptoms rather than take into account and work with the factors underlying the onset of voice hearing. Professionals need to embrace consideration of social and environmental factors more fully. This will inevitably involve a change in both therapeutic emphasis and resource allocation. As a profession, psychology already strives to work holistically. Therefore, it needs to take a lead in disseminating many of its existing insights to other disciplines, as it is vital for all mental health professionals to work together in this way. Attempts to do this are already under way. For example, within the Trust hosting this research, there is a regular

psychology presence on many wards and group homes. The aim of this is to introduce staff to psychological conceptualisations of voice hearing.

The present study has helped to illuminate specific areas of concern for voice hearers and begin to explore how differences of opinion are managed. For example, participants highlighted that a major barrier to communication was not knowing how professionals would respond to disclosures about hearing voices. As such, it is important for clinicians to look at ways of ensuring users have more access to information, are more involved in their care and understand the processes which they are likely to be involved in.

Psychological interventions should be accessible to every user of mental health services for psychosis (British Psychological Society, 2000). All participants had worked with psychologists but there was a feeling that this was not accessible enough and there were long waiting lists. Evidence suggests that early intervention in terms of psychological work has been shown to be effective in preventing relapse (Chadwick, Birchwood & Trower, 1996). This highlights the need for more psychological resources to be made available and is documented as a key target area within government legislation (Department of Health, 1999).

Much of the psychotherapy literature suggests that often it is not what treatment is done that is important, but rather the process itself that influences outcome (Casement, 1990). This has very important repercussions in the area of psychosis. Much of the research in this area focuses exclusively on proving the efficacy of psychological interventions like CBT. The findings herein suggest that there needs to be greater emphasis on considering the relationship between professionals and voice hearers. With its intrinsic emphasis on working collaboratively with clients, psychology is in a good position to lead by example in this area. The need to respect the belief systems of voice hearers and work within their frameworks of understanding is vital. It is very easy to underestimate the existing coping resource of voice hearers. Professionals need to be mindful of the need to preserve and build upon these resources rather than impose an entirely new and often irrelevant set of strategies. 'Jackie's' account highlights this. She spoke about retreating to bed when her voices became overwhelming in order to sleep them

off. Professionals working with her were quick to dismiss this as being ineffective and sought to introduce their own ideas. 'Jackie' indicated she resisted these.

As was highlighted in Chapter One, at present much emphasis is being placed on empowering users. Whilst undoubtedly positive, the themes contained in participants' accounts suggested this must be carefully considered. When working with individuals whose identity is based around illness, professionals need to be careful not to place too much pressure on them to take responsibility or reduce support too soon. Too much 'empowerment', too soon could be perceived as unwelcome, stressful and quite disempowering. It may result in deterioration in the mental health of voice hearers. Therefore, clinicians need to approach clinical work with a view to fully understanding each individual client.

In terms of service development there is much evidence to suggest that peer support is very important to voice hearers (Marshall, 2003). For example, participants spoke highly of the Hearing Voices Network. Peer support is very valuable in instilling a belief that voice hearers are not alone. However, the dominant form of therapy remains individual work with a professional. Groups such as the Hearing Voices Group are not found in every Trust and are generally run by sympathetic clinicians. From an organisational level, there is a need to look at harnessing the potential for peer support and placing greater emphasis on this area of service provision.

The present study used a qualitative approach in an attempt to access experiences and meaning. This my help to broaden the evidence base from which future policy is developed (Roth, 1999). Such studies focus on how interventions are experienced rather than solely judging them on the basis of clinical outcome. Research of this nature helps to 'open up' this not very well researched area and can act as a 'springboard' for future research.

4.4 Methodological Considerations

There are a number of methodological issues that need to be considered when evaluating the research. Firstly, in terms of recruitment, all participants were recruited through colleagues of the researcher. It is possible that colleagues could have suggested individuals whose comments would reflect their own agendas. For this reason, colleagues were only presented with general information about the project and it is felt that the range of experiences voiced by participants addresses this concern.

Theoretical sampling techniques were applied, but rather less than was ideal. Access to participants and time constraints necessitated the need to recruit on a more opportunistic basis. Negative cases were analysed which adds to emerging theory but it is recognised that the resulting theory and in particular many of the categories may not contain as much variation and richness than if more rigorous theoretical sampling techniques had been employed (Pidgeon, 1996).

The researcher did not know any of the participants prior to the research and the fact that she was not involved in their care perhaps allowed them to be more open than if someone familiar to them had conducted the research.

Participants were not re-interviewed nor asked to give feedback in light of the emerging theory during the research process. Some of the difficulties with respondent validation were presented in the method chapter and it was felt that attempting to obtain participants feedback would prove difficult due to the inherent power imbalance between the research and the participants. Indeed three of the participants were clear that they did not wish to be involved in feedback.

However, the researcher did approach two of the participants to present summaries of the emergent model after completion of the research. The main findings were discussed, and whilst neither identified totally with the findings both participants indicated that the model had resonance with them. Both particularly identified with the suggestion that spending time within the psychiatric system had resulted in changes within their sense of self.

The findings of the present study have also been disseminated at both local service level and within a regional special interest group. Clinicians working within psychiatric rehabilitation have commented that the model has resonance both for themselves and for clients that they have worked with in the past. Further attempts at dissemination could perhaps take the form of presenting the findings to a meeting at the Hearing Voices Group as well as to obtain feedback form participants themselves. The findings of this research could also be disseminated at a more organisational level and presented to staff teams to help increase their understanding of the experiences of voice hearers.

The researcher began the analytic process using Strauss and Corbin's model of Grounded Theory (1998). Whilst this proved very helpful, the researcher felt at times it was a little prescriptive. As the research progressed coding drew more on the work of Charmaz (1995). Drawing on alternative sources of information whilst the research process is under way is not regarded as problematic as applying grounded theory principles should not be done dogmatically but in a way that allows the researcher to "pick and choose" amongst methods (Strauss & Corbin, 1990, pp.127).

Proponents of grounded theory have suggested that theoretical saturation generally begins to occur after the analysis of 5-10 cases (Rennie *et al*, 1988). Although the analysis in the present study was based on 6 cases, it is recognised that whilst some categories (e.g., 'Feeling Supported') appeared to be nearing saturation point many were not. More interviews would needed in order to claim theoretical saturation.

There was a degree of variation in the interviews in terms of length. Whilst it would perhaps be desirable that the interviews be of a similar length, this was not practical and perhaps reflected the different levels of engagement with the researcher and participants' differing ability to articulate their experiences. The researcher was mindful of not giving the longest interviews preferential treatment. 'Sarah's' account, although relatively short contains considerable information that was explored in the same degree of detail.

The researcher was also aware of having a 'favourite' interview. 'Kathy's' account appeared to make the most conceptual sense and was used to 'unlock' the accounts of other participants. During the coding process care was taken not prioritise her account and alternative ways of coding many aspects of it were considered. However, it is possible that the researcher did at times overly rely on this account.

4.5 Reflections on the research process

As previously documented, this was the first piece of qualitative research undertaken by the researcher. The present study posed a number of challenges, not least the fact that the structure of the research was very different to quantitative research of which the researcher was more familiar.

A fundamental concern for the researcher throughout the research process was to ensure that the data collection and analysis reflected attempts to understand the experiences of voice hearers themselves, not the researcher's thoughts on voice hearing. This was particularly important as, in parallel to the research process, the researcher was also working clinically with individuals who had psychotic experiences as a member of a psychiatric rehabilitation team. The researcher was very aware of being part of the psychiatric system. Being mindful of Thomas's (1997) warning of the dangers of reinterpreting clients experience into professional language, attempts were made to ensure the coding of the transcripts reflected the experiences of the participants not the researcher's interpretation of this. It was often quite difficult to hear participants being critical of parts of the service that the researcher represented. At times it was hard not to reinterpret these comments into codes that portrayed the professionals in a more favourable light or invalidated that particular experience for the participants. It is hoped that through rigorous application of the constant comparative method, the account of the analysis does remain grounded in the experiences of the participants.

The interviews with each of the participants were very important. As in any clinical setting, individuals' accounts are always layered. As such, the researcher felt

it was vital to use her clinical skills to facilitate rapport with participants and promote a safe, non-threatening space for them to think about their experiences. The participants in the present study revealed more as they felt comfortable to do so. This process is revealed in the completed transcripts in that they show the use of summarising and reflecting back on the part of the researcher. These techniques appeared perhaps more frequently than would be expected in a research interview, but the researcher felt it was important to communicate to participants that she understood what they were saying. The transcripts also reveal participants' willingness to discuss very personal and difficult experiences, which suggests that these techniques did have the desired effect in facilitating shared understanding.

Interviewing individuals who have psychotic experiences also presented a number of challenges for the researcher. Although none of the participants appeared to be responding to voices during the interviews, at times it was difficult to follow the thought processes of some of the participants. This was especially the case with 'Joseph'. It was considered important to allow such participants the space to 'go with' their thoughts rather than to constantly bring them back to the prepared topic guide. As can be seen from the completed transcript of 'Joseph's' interview a number of very insightful and important comments derived from what appeared initially to be irrelevant information. Had the researcher been more rigid in her interview style not only would much of this information not have emerged but rapport may have been damaged as a result.

During the interviews and transcription of these, the researcher became aware of her own patterns of responding to participants and to experiencing a tension between being a researcher and a clinician. At times the researcher felt she was operating more in clinician mode. It would be interesting, although possibly impossible to determine whether the contrast in interviewing styles influenced the participants' responses in any way.

Each interview felt very different in terms of the presentation of each participant, the rapport established between researcher and participant and the degree to which participants had thought about their experiences. As such this serves to emphasise the uniqueness of the voice hearing experiences and the importance of

professionals seeing each voice hearer as an individual. It was very interesting to note that both 'Kathy' and 'Hattie' who were perhaps the two most vocal critics of the psychiatric system and whose identities did not appear to be defined by illness representations appeared to regard the researcher as an equal and the interview process as an opportunity to speak out against the system. Whereas, 'Joseph' whose identity was perhaps most centred around the notion of being ill, appeared to regard the researcher as more of an expert and spoke about his belief that without the psychiatric system he would be unable to cope.

Perhaps even more interesting was the researcher's awareness that in response to the different presentations of the participants, her presentation changed. There was little sense of a power imbalance between the researcher and 'Kathy' and 'Hattie' during the interviews, yet during the interview with 'Joseph' the researcher was aware of times when she adopted an 'expert' approach and even offered advice. The researcher asked more direct questions and there was also a definite sense that 'Joseph' was acquiescing in response to many of these. This is particularly pertinent given the earlier discussion about voice hearers looking to professionals to be the experts and interacting with them accordingly. It demonstrates how easy it might be for professionals to be encouraged to adopt such a role.

It was also noticed from reading through the transcripts of interviews that often participants either responded to questions in a different way as anticipated by the researcher or would provide information that had not explicitly been sought. Initially the researcher resisted this, as it was felt important to limit data collection to areas identified on the topic guide. However, as the research progressed, such deviations from the topic guide were focused on to a greater degree as it was felt that pursuing these lines of enquiry rather than the researcher's interests would help minimise the effect of the researcher's biases and assumptions.

With regard to the coding process, the researcher found it initially very difficult to think abstractly about the data. Supervision was used to explore this and the researcher realised that pervading the coding was a fear of 'getting it wrong', for example selecting the 'wrong' codes. It was felt that this concern was inhibiting the ability to think abstractly. A quote from an editorial of The Lancet (1995, pp. 1451)

helped to free the researcher to think more creatively and abstractly: "A leap of faith will always be needed. Information does not, and cannot provide all the answers".

In their discussion of the role of the researcher in qualitative research, Henwood and Pidgeon (1992) state that the researcher should not remain unchanged by the process. The present study has influenced the clinical practice of the researcher, especially in the sense of reiterating the importance of trying to understand the explanatory frameworks of clients and work within their frameworks more.

4.6 Areas for further research

There are a number of ways in which the present study can identify and inform potential areas for future research. Firstly, 'Reconstructing a sense of identity' was the core category that resulted from the analysis. Whilst the interpretation of the analysis documented earlier sought to highlight many of the factors involved in this, it would be interesting for future research to focus more on explicitly seeking to determine more about the relevant psychological processes involved to develop understanding further. It would be particularly interesting to focus more on comparing how the identities of voice hearers' differed pre and post contact with mental health services.

Due to some of the practical constraints described earlier, it was not possible to develop many of the categories to 'saturation' point. Therefore another possibility for future work would be to extend the present study and seek to do more theoretical sampling in an attempt to more fully develop and expand the existing categories.

All of the participants in the present study, at the time the interviews were carried out, were receiving ongoing support from professionals. If at some point in the future they should no longer be in receipt of psychiatric support, it would be potentially revealing to re-interview them in an attempt to uncover any changes in their views of the psychiatric system. In a similar vein, understanding the experiences of voice hearers who no longer receive psychiatric support and whose

accounts are coloured by a degree of distance from the psychiatric service would be just as revealing.

The present study only sought the experiences of voice hearers themselves. As has been demonstrated, the interaction between voice hearers and professionals is of fundamental importance in terms of the reconstruction of voice hearers' identity. Therefore, it would be very interesting to interview professionals working in this area to increase our understanding of their experience of being part of the psychiatric system. In particular it would be revealing to gain insights as to whether professionals adopted a professional identity based around being a provider of expert knowledge or a more collaborative worker able to recognise voice hearers as experts in their own experience.

It might also be interesting to conduct a similar exploratory analysis in an attempt to understand the experiences of individuals with other difficulties who have contact with health care professionals, for example, to perhaps explore how individuals with chronic physical health problems experience encounters with professionals. A comparison of the present study with research of this nature may reveal the presence, if any, of similar psychological processes implicated in successful recovery.

As has been described earlier, Romme and Escher (1989) attempted to compare individuals who hear voices and whose ability to cope successfully negated the need for psychiatric care with those who were less able to cope and thus required professional support. However, they did this quantitatively and the reliability of their study has been questioned. It would be very important to return to this issue and explore it using qualitative methodology to develop a deeper understanding of the subjective meaning of the experience.

It might also be interesting to compare peer support with clinical interventions and explore whether mutual support between voice hearers is more beneficial than more traditional interventions from professionals. This could be evaluated not only in terms of outcome but the processes underlying peer support and clinical interventions could also be explored in greater detail.

In order to fully address many of the above areas for potential future research, it is believed that a qualitative methodology needs to be applied. In light of government legislation advocating the greater involvement of users in the development and delivery of services, it seems likely that research in this area will, by necessity, have to look more towards uncovering the experiences of voice hearers. In particular, it will need to focus on exploring, understanding and acting upon the holistic experiences of voice hearers, rather than relying on investigating the efficacy of specific therapeutic interventions as is a common focus of much current research.

Garfield (1963, cited in Lysaker & Lysaker, 2002) suggests that qualitative research should focus on 'breaches' in social action, i.e., where people don't do what is expected of them. Their behaviour deviates from what is regarded as socially appropriate. It is regarded as important to research the significance of such breaches as they may illuminate processes not normally accessible or obvious or well researched. So it would be interesting to explore qualitatively the views and experiences in more detail of those who speak out against current psychiatric practice

4.7 Conclusions

The present study has demonstrated the need for clinical psychologists and mental health professionals in general to move away from focusing on regarding hearing voices as a symptom of psychosis and look to understanding its meaning. Understanding the significance the voices have for those who hear them is very important. Clinicians need to recognise that working within the explanatory systems of voice hearers has to become the norm rather than an exception to the norm. Some commentators have suggested that it may be hard for clinicians to change their way of conceptualising voice hearing yet only by doing so can clinicians begin to treat clients as equal and reduce their power over them (Rowe, 2003).

Understanding the explanations and experiences of voice hearers does not offer a solution per se but does foster a collaborative approach to working which helps the therapeutic relationship develop so that clinicians and voice hearers can begin to get to the social and emotional concerns at the root of the problem.

Whilst policies such as the NICE guidelines will promote a more uniform approach to the management of schizophrenia, such guidelines still reflect the medical model and remain rooted in pathologising the experience and emphasise the need for medication. They contain nothing about the role of peer support (Barker & Buchanan-Barker, 2003) nor consider the wider social context of mental health. This demonstrates that the mental health services remain very illness based.

Voice hearers are more than a diagnosis, and to place too much emphasis on diagnosis often shuts down opportunities to look beyond this both for professionals and voice hearers themselves. To have a chance of remaining relevant in the future, services need to move away from being symptom driven and become more meaning focused in order to consider views of those who use them as integral and not as an optional extra.

Some service users have commented that services need to move away from the notion that users of mental health services must accept their limitations (Bassman, 2000). Rather than emphasising the limitations of service users, there is a need to promote a greater sense of optimism and hope for the future. Some models of psychiatric rehabilitation are beginning to do this and it has been demonstrated that this can improve outcome (Williams & Collins, 1999).

Professionals also need to recognise their own role in how voice hearers and indeed other users of mental health services make sense of their experiences. They need to acknowledge their own experiences and be aware of how these colour their relationship with users. They cannot be detached observers of other people's experiences; their very presence influences other people's experiences (Thomas, 1997).

There are a number of challenges for clinical practice, research and policy development highlighted in this thesis. It remains to be seen to what extent mental health professionals will take up these challenges in the future.

Appendices

Appendix 1.   Letter of confirmation of ethical approval

Appendix 2.   Inclusion / Exclusion Criteria

Appendix 3.   Letter of Introduction for client

Appendix 4.   Information Sheet

Appendix 5.   Clinician Consent Form

Appendix 6.   Client Consent Form

Appendix 7.   Topic Guide for Interviews

Appendix 8.   Examples of Open (line by line) Coding

Completed transcripts for each interview are submitted separately

Leicestershire, Northamptonshire **NHS**
and Rutland
Strategic Health Authority

Ethics Administration
Direct Dial 0116 258 8565

Our Ref: pgr/sl/328
29 November 2002

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Ms H Reader
Centre for Applied Psychology
Clinical Section
Ken Edwards Building
University of Leicester

Dear Ms Reader

Service Users' explanation of voice hearing: the interface between the service user and the healthcare provider – our ref: 6773

I am in receipt of your letter of 10th November 2002 responding to our letter of 19th August 2002.

You have addressed all the committee's concerns and final approval for this study is hereby given.

For information only, the font size on the revised patient information sheet is smaller and we usually recommend size 12 aerial.

Yours sincerely

[signature]

P G Rabey
Chairman
Leicestershire Research Ethics Committee

(NB All communications relating to Leicestershire Research Ethics Committee must be sent to the Committee Secretariat at Leicestershire, Northamptonshire and Rutland Health Authority. If, however, your original application was submitted through a Trust Research & Development Office, then any response or further correspondence must be submitted in the same way.)

Appendix 2.

Inclusion and Exclusion criteria for the present study

Individuals were to be considered appropriate to participate in the study if they met the following criteria: -

- The individual's main presenting issue was/had been hearing voices
- The individual had a psychiatric history of greater than 6 months
- The individual was a current or past consumer of Treatment and Recovery Services or member of the Hearing Voices Network
- The individual was considered well enough by the Responsible Medical Officer/Consultant Clinical Psychologist to participate

It was felt inappropriate to consider potential participants if they met any of the following exclusion criteria: -

- The individual had a diagnosis of drug induced or transitory psychosis
- The individual had an organic disorder
- The individual had a co-morbid alcohol / drug dependency
- The individual was unable to converse fluently in English. It was felt that due to the nature of qualitative research, participants must be able to talk fluently about their experiences. Working via an interpreter would have resulted in the loss of the participant's original meaning
- The individual was considered unable to give consent

Appendix 3.

Letter of introduction for participants

Date:

To: (Name and contact address of potential participant)

Dear (name of participant)

Re: Participation in a research study:

Service users' experience of voice hearing:
The interface between the service user and the health care provider

I am currently planning a research study, at Leicester University, as part of my professional training to be a clinical psychologist. This study is to be carried out within psychiatric rehabilitation services and the Hearing Voices Network in   .
I am undertaking this research as part of my professional training to be a Clinical Psychologist.

The study has been designed to explore the beliefs that people who hear voices have about their voices. It will also explore what voice hearers feel about the way that health professionals work with them in managing these voices.

As you are currently or have recently been involved with rehabilitation services and/or the Hearing Voices Network, I would be very interested in talking with you about your experiences of hearing voices and the treatment you have received.

The results of this study will help mental health professionals working with people who hear voices to understand how people make sense of this experience and what is important to them in terms of treatment.

If you are interested in taking part or would like to find out more about this study, please complete the reply slip attached and return it in the pre-paid envelope provided. Alternatively, you can talk to your psychiatrist/psychologist. I will then contact you to arrange a convenient time to meet you to discuss the research in more detail.

I would like to thank you for taking the time to read this letter and hope to hear from you soon. If you have any queries, please feel free to contact me on   , and I will call you back. Or you could talk to your psychiatrist/psychologist.

Yours sincerely,

Helen Reader
Trainee clinical Psychologist
Centre for Applied Psychology, University of Leicester

Please return the slip below in the enclosed pre-paid envelope

Thank you

- I am interested in taking part in the above study and agree to Helen Reader contacting me

- I understand that I am under no obligation to take part in the study

Name: ....

Address: ....

....

....

Telephone No: ....

Date: ....

Appendix 4.

Information Sheet

Title of Study: *Service users' experience of voice hearing: The interface between the service user and the health care provider*

Principal Investigator: *Helen Reader*

Supervising Clinicians   *ChrisStowers –ConsultantClinical Psychologist*
                                  Dr Jon Crossley – Clinical Psychologist

1. Who is conducting the study?

Helen Reader, a trainee clinical psychologist at Leicester University. This study will be submitted as part of her Doctorate in Clinical Psychology.

2. What is the purpose of the study?

The study will look at the way people understand their experience of hearing voices. It will also investigate what voice hearers feel about the way health professionals manage their care. These findings will help people who set up services for people who hear voices know whether there are things they could be doing to help make these services better for people who use them.

3. Why have I been asked to take part?

As you are currently or have been involved with rehabilitation services and/or the Hearing Voices Network, you are in an excellent position to comment on your experiences.

4. What will happen if I agree to take part?

i) You will be interviewed by Helen Reader; this will be an informal interview, very much like a conversation. She will ask you to talk about some of your experiences of hearing voices and how you understand this. This will last for no more than 90 minutes and will be tape-recorded. You can stop for breaks during the interview at any time and if you don't feel able to finish the interview in one day another session can be arranged. You can have your own tape-recorded copy of the interview to keep if you wish.

ii) This interview will then be written up and Helen will look at what you have said in detail along with the other interviews to help identify the things that are most important to voice hearers.

iii) Helen may want to meet with you once more after all the interviews have been looked at in detail to feedback some of her ideas and check whether she has understood you properly.

5. Will the information from the study be treated as confidential?

Yes. During the interviews only first names will be used and these will be changed when interviews are written up to make sure that no one can identify you. The tapes will be identified using a number rather than your name and no one other than Helen will know who was given what number.

When the interviews are written up they will be stored on computer hard drive and will be protected by a password. Any computer disks will be locked away all the time when not being used

None of the information collected for the study will be written up in any case notes nor used as a basis for changing your treatment in any way. The people normally involved in your care will not be told what you have said. The only possible exception to this is if Helen feels that anything you discuss places your safety or that of others in jeopardy then she will have to tell your psychiatrist/psychologist about this but will discuss this with you first. When the research has been completed all information collected from you will be destroyed.

6. What will happen if I decide not to take part in the study?

Helen will not contact you again and any current treatment will not be affected

7. Am I allowed to change my mind about taking part?

Yes. You can change your mind at any time and you do not have to give a reason for doing so. Any information that Helen has already collected from you will be destroyed immediately. Again, any treatment will be unaffected by your decision.

8. What if I am harmed by the study?

This research is covered for mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

9. Will I be paid for taking part in the study?

No. However, you will be paid travel expenses (at public transport rate) should you have to make any journey especially to take part in this research.

10. How can I find out what has happened to this research?

When it is completed a summary of the findings will be made available to you should you wish to read it.

11. What if I have more questions?

You can contact Helen to discuss any questions you may still have on
, and she will call you back. Or you can talk to your psychiatrist/psychologist. Please feel free to discuss participation in this study with anyone you feel is relevant.

Thank you,

Helen Reader

Appendix 5.

CLINICIAN CONSENT FORM

Title of Study: *Service users' experience of voice hearing: The interface between the service user and the health care provider*

Principal Investigator: *Helen Reader*

I understand that...(my patient/client) has given their consent to take part in the above study.

I have read the Information Sheet and the nature of the research has been explained to me by Helen Reader. I agree that............................... is well enough to take part in the above study.

Signature of Lead Clinician .... Date..........................

Name in BLOCK LETTERS..

Signature of principal researcher................................ Date..................

Appendix 6.

CLIENT CONSENT FORM

Title of Study: *Service users' experience of voice hearing: The interface between the service user and the health care provider*

Principal Investigator: *Helen Reader*

- I have read the Client Information Sheet and the nature of the research has been explained to me by Helen Reader. I have had the opportunity to discuss taking part in this research with Helen, my psychiatrist/psychologist and anyone else I considered important and I agree to take part in the above study

- I understand that the interview with Helen will be tape recorded and written out and that all information about me or my views will remain confidential

- I understand that I may withdraw from the study at any time without saying why and without this affecting my normal care

- I understand what will happen to my responses after the interview and that the research will be written up and may be published in the future but that no one will be able to identify me

- I understand that if Helen feels that anything I discuss places my safety or that of others in jeopardy then she will have to tell my psychiatrist/psychologist about this but will discuss this with me first

- I understand medical research is covered for mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs

Signature of participant ....……………………….......... Date......................

Name in BLOCK LETTERS ....

I confirm I have explained the nature of the study as detailed in the Client Information Sheet, in terms, which in my judgement are suited to the understanding of the client.

Signature of Investigator ....…........……........ Date..........................

__Appendix 7.__

__Interview Guide__

Introduction

- Background to the research
- Reminder of confidentiality
- Explanation of the format of interview
- Clarification that participant is ok to talk about their experiences
- Questions answered

Background / Pathways

- Pathway to rehabilitation services/Hearing Voices Network
- Length of time involved with the psychiatric system

Experience of voice hearing

- Feelings when first started to hear voices
- Ways of attempting to make sense of what was happening
- How individual came to these conclusions – i.e. were views of others a factor?
- How voices dealt with on a day to day basis

Experience of health professionals

- Views of health professionals when voice hearing first disclosed
- Did this fit with what participant thought was happening?
- Have health professionals ever asked participant what they think about voices?
- If yes – do they feel that they listened to and acted on these explanations?
- If no – thoughts on why they have never been asked
- Does participant think psychologist/psychiatrist understands what it is like to hear voices?
- Any disagreements over treatment for hearing voices. If so, how were these managed?
- Any help sought outside of psychology/psychiatry?

Outcomes

- Have participant's views about voices changed over time? (if so is this in response to influences of other people?)
- How have things changed since seeing a psychologist/psychiatrist?
- Have the attitudes of health professionals to voice hearing changed over time
- How has seeing health professional affected participant? (positive or negative experiences)

Ending

- Any additional information
- Seek feedback on the experience of being interviewed
- Review consent

Appendix 8.

Examples of Open (line by line) Coding

Helen   And that kind of the first time you'd spoken

to the psychiatrist about the voices and about

the belief that there was an alien inside you.

How did it feel to actually tell somebody

else?

Inability to recall events

Kathy   Erm, I can't remember really I think/weird

certainly weird./Part was relief I guess, and it

was a big mix of things./There was suspicion

about telling them,/there was the wanting

someone to make it better and take it away//

but there was also, I felt very uncomfortable

because it's something I'd kept to myself for

so long,/I didn't sort of, it wasn't like a big

outpouring of things/I think it took me quite

a while to open up some of it/And some of

the things like my ideas/that the hospital was,

once I was admitted that the hospital was

part of it and they were trying to, to erm kill

me and so it's things like that I didn't

actually tell them at all because erm yeah/I

was still very confused as to who was ok to

trust and who wasn't/so a lot of it I kept to

myself.

Feeling weird

Range of affect

Experiencing concern about disclosure

Feeling helpless

Keeping distress to self

Expectations about disclosing in p

Measured disclosure (why?)

Acknowledging role of self in disclosure (own barriers)

Feeling suspicious of professionals

Not knowing who to trust

Choosing not to share experiences

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