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**'I'm confused about what my problems actually are'  
Managing King-Kopetzky syndrome**

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**'I'm confused about what my problems actually are':  
Managing King-Kopetzky Syndrome**

**Helen Pryce**

**Thesis submitted towards the award of  
Professional Doctorate in Health**

**University of Bath  
School for Health  
February 2009**

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## **Declaration of own work**

I certify that the work contained in this thesis is my own. It has not been submitted previously for a degree at this or any other university. The views expressed are my own and not necessarily those of the University of Bath.

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## **Summary**

Why do some people complain of hearing difficulties when their hearing thresholds are normal? How should Audiology professionals respond to their presentation?

This problem will be considered in the light of the literature from audiology, psychology, and medical sociology disciplines. The different evidence for and implications of bio-medical and bio psychosocial explanations for such experiences are discussed. In particular the role of help seeking is considered as a coping mechanism and as a key part of the diagnostic case definition applied to this population of audiology patients.

Two original studies will be presented which consider this phenomenon from different viewpoints. The first explored the lived experience of the patient who is coping with hearing difficulties and investigated how seeking help forms part of the process of coping. The second study attempted to quantify the role of illness beliefs and audiological factors in the determination of whether or not someone will seek help with hearing difficulties that they experience. The two different ontological viewpoints have contributed complimentary findings that are presented in themed sections.

The contribution of this work to the understanding of the biological, psychological and social factors in medically unexplained hearing difficulties is discussed. The implications for both future research and current clinical practice are considered.

## Introduction

Mrs Smith comes to the Hearing Therapy clinic. Her notes suggest that she has normal hearing thresholds and no obvious pathology to the ear, yet she is describing hearing difficulties. These difficulties are causing numerous practical and social problems for her. The Hearing Therapist is simply asked to help her.

This scenario is a daily occurrence in rehabilitative Audiology. For the Hearing Therapist concerned there are a multitude of questions and uncertainties about how best to proceed. Should they assume that Mrs Smith has a hearing loss associated with her central auditory pathways, one as yet undetected by the hearing test to date? If so should further diagnostic testing be the first priority? Should the Hearing Therapist assume that Mrs Smith is focussing on her hearing to express deeper underlying psychological issues that needs addressing? Should the Hearing Therapist assume that Mrs Smith's is presenting with a way of avoiding her social obligations and tasks? Is such a case a medical matter or a manifestation of some psychological or social needs?

Given the rationing of Audiology services under the National Health Service (NHS), the Hearing Therapist has an obligation to justify carefully the time and cost of their clinical time with such a patient. There is also the moral imperative to treat such a patient positively and to do no harm to them. As a member of a medical team, the initial approach is likely to be similar to that taken to manage other hearing disorders. In this case, the problems could be assumed to be bio-medical. Perhaps a lesion somewhere in the auditory pathway means that Mrs Smith cannot process auditory signals, this means that she cannot detect phonemes in speech clearly and therefore she is experiencing a hearing disability. If this is the case the Hearing Therapist must focus on detecting the location of the lesion, clarifying expectations of communicative ability with Mrs Smith and enabling her to maximise her communication skills through augmentative approaches such as lip-reading (Alpiner and McCarthy, 1999). Mrs Smith will eventually learn sufficient skills

to manage communication better or at least, after a series of sessions, she will report that she feels better and be discharged.

Such practice is familiar in Audiology. Patients appear to expect to have their hearing investigated. They comply with therapeutic regimes based on improving their individual performance and function and after a time they generally report feeling better about things and ready to manage alone.

However this routine experience masks a great many assumptions about the nature of hearing difficulties and what people who experience them need and want. In an era of evidence-based practice such assumptions can be exposed. Do we really have any evidence that people who present with such hearing difficulties benefit from audiological assessment? How do we decide upon treatments and why? What evidence do we have that they work?

To address these questions there are several bodies of literature to consider: - psychological, sociological, bio-medical and audiological. The World Health Organisation (WHO) proposes an internationally agreed framework with which clinicians interpret health conditions. Their International Classification of Function (ICF) framework proposes that biological, psychological and social factors are deeply interwoven in our experience of health and wellness (WHO, 2001). However, there are tensions between the sociological, psychological and bio-medical perspectives.

The bio-medical perspective is probably the dominant view held by both clinicians and patients alike (Wade, 2006). If someone is complaining of hearing difficulties, the most likely starting point for a health practitioner is to consider the possible biological causes of such difficulties and conduct a check of auditory functions that could have become impaired. But sociologists or psychologists may view this scenario differently.

A sociologist may view Mrs Smith as engaged in a pursuit of a socially sanctioned sick role to justify deviant communication behaviours. In this the healthcare practitioner is a willing accomplice and enjoys status as a gatekeeper to such a socially sanctioned role (Ferrari, Kwan and Friel, 2006, p.70). Alternatively, a psychologist might claim that Mrs Smith is responding to a series of cognitions about her hearing performance. She is evaluating it according to individually held beliefs about normal and impaired hearing

performance and the consequences of these. She may be experiencing the difficulties as a manifestation of psychological distress (Horne, 2006, p.121). Certainly it is the patient's own experience of living with hearing difficulties that the therapist is concerned with, the patient will be the ultimate judge of whether the therapist has enabled him or her to manage his or her hearing better.

This thesis represents attempts to unpick some of these issues. The starting point is the recommendation from the ICF framework that there are biological and psychological and social factors that construct our experience of health including our communicative function (WHO, 2001). Each of these factors will be discussed in relation to hearing difficulties in the presence of normal hearing thresholds.

As each in turn is discussed, possible ways of viewing the patient who seeks help with such difficulties will be proposed and compared. In particular, attention will be paid to the clinical help seeking that the patient undertakes. It will be considered a social act of validation, a psychological coping mechanism and a response to a disordered function.

Chapter one will examine the research literature concerned with the nature of these hearing difficulties. It will consider two alternative sets of literature from audiology and from medically unexplained health conditions.

Chapter two explores the help seeking as both a psychological response and a social act. The literature on illness behaviour, medically unexplained conditions and doctor–patient relationships is examined. It is important to consider help seeking in a wider context as a coping behaviour to a perceived threat to health or illness (Roesch and Weiner, 2001). Therefore, the literature around stress and coping is reviewed and the process of detecting and interpreting internal signs as illness representations is explored (Leventhal et al., 1984). A social dimension is also considered to influence symptom detection (Hagger and Orbell, 2003). Therefore the review considers health and illness as culturally defined concepts. In particular the role of medicalised views of health that predominate in the west will be discussed.

The act of help seeking with medically unexplained hearing difficulties is further explored in two original studies investigating coping behaviour. These studies have the following aims:-

1. To learn more about how MUHD patients cope.
2. To learn how patients experience the clinical encounter with audiology professionals.
3. To learn more about the role of patient beliefs about illness in informing their decision to seek help with hearing difficulties.

Chapter three outlines the aims of the research and the ontological and epistemological positions adopted. Chapter four presents the methods and chapter five presents the findings in themed sections to consider what we have learned about the biological, psychological and social factors involved.

The first of these studies presents a new theoretical framework for understanding how patients perceive their hearing and their requirements from audiology services. The second study provides new evidence for the role of illness perceptions in explaining why some people who experience hearing difficulties seek help and others do not. Chapter six considers how this evidence informs audiology about the role of social and psychological factors in the decision to seek help with hearing difficulties.

So what do clinicians currently understand to be the nature of these hearing difficulties? Firstly the literature from Audiology, speech and hearing sciences and otology is discussed to locate this thesis in a body of research into what has been termed 'King-Kopetzky Syndrome (KKS)' and 'Auditory Processing Disorder (APD)'

### **Terminology**

To summarise the ambiguity over the mechanistic basis and to contextualise the clinical symptoms within a wider literature of medically unexplained or ambiguous conditions, the term 'medically unexplained hearing difficulties' (MUHD) will be used to denote symptoms throughout. In addition the label

'King-Kopetzky Syndrome' will be used to denote the clinical category of patients. To highlight how this population are referred to amongst the professional body for Audiologists the term 'Auditory Processing Disorder' will be used.

This work will challenge the assumption that 'APD' and 'KKS' are synonymous and it will highlight the fact that the case definition is dependent on the individual deciding to seek help with hearing difficulties. To reflect the social and psychological dimensions to this phenomenon 'King-Kopetzky Syndrome' is used in preference to APD as it avoids implicit mechanistic assumptions.

**Chapter one: Auditory processing Disorder or King-Kopetzky Syndrome : What do we know about medically unexplained hearing difficulties? An introduction to the research agenda**

*'Syndrome: A fixed pattern of symptoms not necessarily with the same cause in all cases'. (Penguin Medical Encyclopedia p.459)*

**Introduction**

It is not unusual for people who present for help with hearing difficulties to be found to have normal hearing thresholds. They fall outside standard clinical diagnosis and can be considered 'medically unexplained'.

It has been estimated that such patients account for approximately 5-10% of all referrals to Otorhinolaryngology (Saunders and Haggard, 1989). There are currently no agreed protocols for the clinical activities to assess and treat the difficulties that such patients present with. Instead, there is a range of service provision options, use of which varies from department to department. In some cases patients are simply reassured that there is nothing wrong with them and they are discharged. In other cases the same patients are referred for further testing of their ability to hear speech in noise or they may be referred to Hearing Therapy services where they are offered counselling and advice about communication tactics. There are real problems for service managers in understanding the nature of this problem and deciding how much assessment and rehabilitation to provide, particularly as there is no evidence regarding the effectiveness of treatments.

If people describe hearing difficulties but are found to have normal audiometric thresholds, does that mean that the audiometric thresholds are inadequate in detecting hearing impairment or that there is something other than hearing impairment at work? This confusion and difficulty reflects an underlying tension between bio-medical and psychosocial models of health and hearing function.

This chapter will explore this question by examining the evidence-base currently available to clinicians. In part one it will outline the case definition for such difficulties, the terminology applied to them and the assumptions

that inform the evidence to date. In part two an examination of the contextual literature will highlight the other psychological and social factors that could contribute to the case definition.

### **The case definition and clinical label – Auditory Processing Disorder**

When an individual presents for help with hearing difficulties, their hearing difficulties may be conceptualised in a number of different ways. The Institute of Hearing Research coined the term 'Obscure Auditory Dysfunction' (OAD) (Saunders and Haggard, 1989) and subsequently the professional body, the British Society of Audiology (BSA) adopted the term Auditory Processing Disorder (APD). The Special Interest Group from the BSA defined the problem as follows: -

' APD results from impaired neural function and is characterised by poor recognition, discrimination, separation, grouping, localisation or ordering of non-speech sounds. It does not solely result from a deficit in general attention, language or other cognitive processes.' (2007)

The BSA suggests that 'APD' should be regarded as the term to describe all cases of this type (BSA SIG, 2007). Such a definition characterises the experience that a patient describes as a 'disorder' with a biological basis in 'brain function'. It differentiates this population from those with problems with 'cognitive processes' or language deficits e.g. to distinguish from dysphasia or specific auditory agnosia.

Considerable research activity is currently focussed on neuro-science and, in particular, the role of the central auditory system.

Auditory Processing Disorder (APD) is a term that originated in the USA to describe children who presented with specific deficits in auditory processing which result in linguistic, communication and learning difficulties.

These children demonstrate a range of communication behaviours, which are rather non-specific including: - 'not listening', being 'unable to follow directions' or being 'unable to learn from the information they hear' (Dawes

and Bishop, 2007). The suspected APD is based on these behaviours being present in the absence of apparent hearing or linguistic impairment.

These deficits are currently thought to occur throughout the auditory pathway. For example, Bamiou, Campbell and Sirimanna suggest that to guide appropriate intervention an assessment should be made of: -

- Binaural separation
- Binaural integration
- Temporal resolution
- Frequency discrimination
- Duration discrimination
- Intensity discrimination
- Temporal ordering
- Auditory closure
- Auditory discrimination
- Binaural interaction

(Bamiou et al, 2006)

To date, no one single site of deficit that is thought to explain the hearing difficulties. To explain this apparent diversity the BSA notes: -

‘It is likely that APD will include a variety of different pathologies and abnormalities of auditory function.’ (BSA SIG, 2007)

A search through the literature for adults and auditory processing disorders produces a wealth of reports on factors affecting auditory processing but little that references this specific group of help seekers who have normal audiometric thresholds. (For full details of the search strategy please refer to the methods section.) In general, reports refer to the effect of solvent abuse on auditory processing or speculation that adults with dyslexia may have impaired auditory processing. Otherwise, the assumption seems to be that the adults are simply older presentations of the same cases.

In addition definitions of normal performance in auditory functioning may vary between the USA and the UK. There is also controversy over whether there can be a specific site of deficit at an auditory perceptual level without a linguistic component (Dawes and Bishop, 2007).

## The case definition and clinical label - King-Kopetzky Syndrome

Alternatively, authors have regarded adults presenting for help with hearing difficulties in the absence of measurable hearing loss as a distinct group. Hinchcliffe (1992) coined the term 'King-Kopetzky Syndrome' (KKS) and highlighted the multiple possible underlying causes for this symptom set, in particular the combination of psychological, social, and biological factors that can lead to the experience of 'hearing difficulties'. Researchers adopting the King-Kopetzky Syndrome label have tended to incorporate bio-psychosocial views of the condition. For example, Zhao and Stephens (2000) defined it as a heterogeneous experience consisting of seven subcategories: -

- (1) middle ear dysfunction
- (2) mild cochlear pathology
- (3) central/medial olivocochlear efferent system (MOCS) auditory dysfunction
- (4) purely psychological problems
- (5) multiple auditory pathologies
- (6) combined auditory dysfunction and psychological problems and
- (7) unknown.

This proposed a model of a heterogeneous population who may have difficulties in peripheral or central auditory pathways. A significant difference is that there is an acknowledgement that no underlying biological impairment may exist and that the problems may either be attributed to unknown or purely psychological causes. Such categorisation supports the use of the term syndrome to describe such patients e.g. a collection of possible causes for similar symptom sets as opposed to a singular 'disorder'. However, it is interesting to note that there is still an assumption of deficit or 'problem' as the underlying basis for the experience. When psychological factors are involved the suggestion is that these are alternative sites of impairment rather than normal psychological processes.

This recognition of psychological and social factors has divided the research community in recent years. Some favour a psychosocial approach, recognising psychological or social factors and adopting the 'King-Kopetzky Syndrome' (KKS) term, while other researchers assume a purely bio-medical approach attempting to discover biological disorders responsible for the symptoms described and prefer 'Auditory Processing Disorder' (APD). So the ways in which patients with normal hearing seeking help for hearing difficulties are understood depend on the theoretical model and clinical label that is applied.

Research to date has predominantly been driven by a need to identify the characteristics of this group of patients and to explain the mechanistic basis for their hearing difficulties (Zhao and Stephens, 2007). There has been very little research into the effects of the hearing difficulties on the patient's life quality (Pryce, 2003; King and Stephens, 1992). The studies that have been conducted suggest that patients present with similar levels of disability as those with measurable hearing loss and that the experience of these hearing difficulties can dramatically reduce the individual's participation in their social environment (Zhao and Stephens, 1996; King and Stephens, 1992; Pryce 2003). As yet there is no evidence to support particular approaches to treating adults with these difficulties. Whilst the mechanistic basis is an understandable starting point, this approach reveals much about the ways that a medical model of health informs research in hearing.

Unfortunately this leaves clinicians without a clear plan of management beyond conducting diagnostic tests. As with most other hearing difficulties a realistic aim is to improve an individual's ability to manage their hearing restrictions but an eradication of the problems in the form of a cure is unlikely.

It could be argued that patients presenting with hearing difficulties can also be conceptualised as seeking help and that this, in turn, can be viewed as a form of coping. The contextual literature that exists in the fields of coping, help-seeking and illness perceptions can add another way of viewing these patients. In order to understand the nature of the symptoms this review will

consider social and psychological context in which an individual is seeking help with their hearing.

## **Where do these definitions come from? An overview of the bio-medical model of health and its impact on audiology**

The bio-medical model of health is informed by western approaches to medicine stemming from the scientific revolution during the enlightenment. During this period, man's ability to rationalise the physical world gained philosophical credence. The bio-medical model is based on the concept of an objective reality, precise measurement and the elucidation of cause and effect laws, arrived at through hypothesis testing and experimentation (St Claire, 2003, p.2). It proposes that the disease process leads to physical impairment, which in turn leads to disability and handicap. Thus, the bio-medical explanation of hearing loss focuses upon a mechanistic change such as the degeneration of cochlear hair cells leading to hearing impairment which in turn leads to hearing disability (e.g. difficulty hearing speech without supplementary lip-reading) and hence to handicap (e.g. difficulty using the telephone to communicate). The bio-medical model constructs the audiologist's role as the assessment of impairment, assisting the diagnosis of the disease process and intervening to limit disability and handicap through use of amplification. The American Speech-Language Hearing Association in 1981 classified hearing loss as follows:

'Hearing impairment is used to mean a deviation or change for the worse in either auditory structure or auditory function, usually outside the range of normal.

Hearing handicap means the disadvantage imposed by a hearing impairment on a person's communicative performance in the activities of daily living.'  
(reproduced in Katz, 1994, p.777)

The World Health Organisation revised the use of the terms 'disability' and 'handicap' in the International Classification of Function (ICF, 2000). These revisions reflected fundamental conceptual changes about the relationship between disease process, restriction in activity and level of participation in society. Two changes are of particular importance. Firstly the change in

emphasis from individually held states to domains affected by individual performance and social environment. So the notion that 'disability' exists as a measurable state within the individual has been replaced by the notion of 'activity' as a domain that is influenced by individual function and by social opportunity. Likewise the use of 'participation' in place of 'handicap' reflects the move from an internalised state to a neutral domain that may be influenced by the individual level of activity and the social environment within which the individual is required to function. Secondly the revisions from the International Classification of Impairment Disability and Handicap (ICIDH) to the International Classification of Function (ICF) include the notion that the social influence is significant in determining participation regardless of degree of impairment. A health condition that is socially stigmatising can be experienced as more restrictive even if symptoms of the health condition are mild or non-existent such as the case with mental illness in remission and Human Immunodeficiency Virus (HIV) etc.

However, these revisions do not reverse the prevailing metaphor that Wainwright describes as that of a 'faulty machine'. Wainwright notes that the diagnostic process relies on reported symptoms or diagnostic tests to detect 'faults' in the physical system.

' A fault is identified or diagnosed by observing symptoms or conducting diagnostic tests, a theory of what caused the fault is developed' (Wainwright, 2008)

A recent example from the Audiology literature reflects this viewpoint: -

'There is nothing more fundamental to the role of the audiologist than evaluating hearing, determining the nature of a hearing loss, and communicating that determination to the patient and other professionals.'  
(Margolis and Saly, 2007)

The BSA definition of APD as resulting from impaired neural function reflects this 'faulty machine' metaphor. It emphasises 'impairment' and assumes that restrictions are experienced solely as a result of the change in biological

state and that social and psychological factors do not play a significant role. It also assumes that cause and effect are two discreet processes. The 'impaired neural function' is the cause and the APD symptoms are the effect. A mind-body dualism is denoted in which the symptoms are an inevitable consequence of the impairment. The neural impairment is regarded as a prior, external cause just as degeneration of cochlear hair cells is regarded as a prior cause of hearing loss symptoms.

The bio-medical model of hearing loss dominates the practice of the audiology profession (American Academy of Audiology Task force for Guidelines, 2006) The language of audiology services reinforces the passive sick patient role. Patients become objectified through the process of assessment and fitting. Clinicians are seen as having the expert role with counselling frequently being taken to mean advice giving. (Bamiou, Campbell and Sirimanna, 2006; Benyon, Thornton and Poole, 1997; Kricos and Holmes, 1996).

King-Kopetzky Syndrome challenges the bio-medical model because medical signs do not always support the patient's reports of hearing disability.

The APD literature refers to a medicalised set of 'pathologies' and 'impairments'. In other words there is definitely something physically wrong for this group of patients. This is slightly different in the Zhao and Stephens model which proposes that the 'impairment' may not be auditory. It may be purely psychological or psychologically 'amplified' (2000). These definitions share an assumption that there is an impairment of some sort.

This approach remains grounded in the bio-medical model, and the assumption that there *must* be an objective, observable pathology, which accounts for the patient's claimed disability. The success of the bio-medical model as the basis of curative medicine may make it an attractive starting point to investigate such symptoms.

## What is the evidence for a bio-medical explanation?

In relation to APD and King-Kopetzky syndrome the bio-medical model has underpinned much of the research agenda. There has been a quest to identify mechanistic explanations arising from the function of the cochlea (Lutman and Saunders, 1992; Ferman, Vershuure and Van Zanten, 1993; Higson and Morgan 1996; Pick and Evans, 1983; Zhao, Meredith, Stephens and Ozcaglar, 1996)

Given that these patients present with some form of hearing difficulty, researchers have naturally hypothesised that there may be some early cochlear damage. Yet, as a sole predictor of whether someone will present with APD/KKS, this has failed to identify subjects from controls. (Ferman, Vershuure and Van Zanten, 1993; Higson and Morgan, 1996; Pick and Evans, 1983; Zhao Meredith, Stephens and Ozcaglar, 1996). However, there have been some significant findings as technical developments in testing cochlea function have been refined. Using Audioscan (a form of testing auditory threshold in frequency sweeps) Zhao and Stephens (2006) have identified notches in the frequency range 500-3000Hz as significantly more common in subjects than in controls. Likewise transient evoked otoacoustic emissions (TEOAE) are reduced in KKS subjects (Lutman and Saunders, 1992). Distortion Product Otoacoustic Emissions (DPOAEs) are considered to have frequency specific characteristics and could potentially identify performance in different regions of the cochlea. DPOAEs are significantly lower in KKS patients than controls (Zhao and Stephens, 2006). Evidence from other studies has identified that otoacoustic emissions can be suppressed by contralateral stimulation through the efferent system (Collet, Kemp, Veuillat, Duclaux, Maline et al., 1990; Veuillat, Collet, Duclaux, 1991). The efferent system is thought to influence the sensitivity of the cochlea to quiet sounds and this in turn may have a role in filtering unwanted background sound. It seems likely that poor efferent function is present in at least some KKS/APD patients (Zhao et al, 1996; Zhao and Stephens, 2007).

### **Impact of the bio-medical model on clinical practice**

The faulty machine metaphor of hearing impairment underpins the diagnostic function of the audiologist. The bio-medical approach has affected clinical practice by prescribing test batteries to identify areas of potential deficit in psychoacoustical abilities or cognitive and psychological domains i.e. as an impairment to explain the difficulties experienced (Higson, Haggard and Field, 1994; Saunders and Haggard, 1992; Saunders Haggard and Field, 1991).

Saunders, Field and Haggard devised the Institute of Hearing Research (IHR) Obscure Auditory Dysfunction (OAD) test package in 1992 and conducted further validation in 1994. Using a case control methodology they identified that in a sample of 50 patients and 50 controls, 83% of the deviance in the cases could be explained by four variables with three underlying factors: - psychoacoustical (frequency resolution within the cochlea and auditory pathway), cognitive (including linguistic and attentional factors) and psychological (particularly the accurate estimation of auditory performance). The IHR test battery seeks to identify which factor may be the most important for an individual. It also enables the clinician to examine a patient's speech in noise performance and to ascertain whether their perception is within normal limits or not, in other words to provide a measure of hearing disability. It is interesting that the authors behind this work initially refer to 'obscure auditory dysfunction syndrome' thus acknowledging the multi-factorial nature background to the symptom set (Saunders and Haggard, 1989).

The IHR test battery was, until recently, the only 'off the shelf' package produced for these adult patients in the UK for audiology departments. It is still the package sold over the last sixteen years and therefore the most commonly employed package. In 2008 a revised package became available via the IHR. Departments can access further test batteries over the Internet, which can be used in a range of settings. The most popular of these is the SCAN package (Keith, 2000; Dawes and Bishop, 2007). This package contains four areas of testing which appear similar to the OAD test battery including a filtered word test, auditory figure ground sub-test, competing

words sub-test and competing sentences test. These tests assess a child or adult's ability to detect speech in noise, attend to information from each ear individually and the central auditory pathways. However, the reliance on linguistically based material means that the tests cannot necessarily discriminate between linguistic and pre-cognitive auditory features (Cowan, Rosen and Moore, 2007). In addition such test batteries may be subject to learning effects (Domnitz and Schow, 2000).

Likewise a test battery is proposed by Neijenhuis et al. (2001) including digit span tests, pattern tests, words-in-noise tests, dichotic digit tests, filtered speech tests and binaural fusion tests. The authors state the aim is to identify the aspect of auditory processing that is impaired and train to improve it.

### **Currently proposed interventions**

The nature of this training is not well defined or evidence-based. It appears to be based on repetitive discrimination of phonemic contrasts.

Interestingly Bamiou et al. go on to suggest that social interventions are required to 'manage' APD (Bamiou et al, 2006). For example, to manipulate the environment to improve the sound quality received from a speaker and to use compensatory strategies. The clinician should objectively measure function in different aspects of the auditory pathway and identify any potential areas of disorder despite the lack of a potential bio-medical solution. Instead the patient is asked to make behavioural changes to their communicative behaviour or to change the environment in which they communicate.

Auditory training has been proposed as a way of employing the neuro-plasticity of the auditory system to improve functional performance (Moncrieff and Wertz, 2008). The research supporting auditory training assumes that performance in lab tests of auditory performance equal a valid change in day-to-day function. For example the training conducted by Moncrieff and Wertz (2008) involved samples of 8 and then 11 children who were rewarded for their participation with snacks and toys. No control group was used and so it is not clear if the effectiveness of the treatment was in part to do with the presence of these rewards. There have been no such published assessments of training adults (with less plasticity) but instead there is an emphasis on environmental changes to improve the signal to noise ratio (e.g.

Bamiou et al., 2006). So there is an assumption that psycho-social factors are important in managing the effects of KKS/APD but not in the assessment process (which involves the objectification of the patient's functional abilities). It is not clear how genuinely beneficial undergoing these tests is for the patient, if there is no specific treatment in mind. The advice suggested is broadly similar to managing hearing loss (Bamiou et al., 2006). Indeed what are the risks of iatrogeny from such testing procedures in the absence of an effective treatment? Can their use be entirely ethical?

The value of these tests in clinical practice is debatable. It is not clear what the discovery of a deficit in one of these areas means for the patient. The inevitable difficulty with this type of epidemiological research is that it is not possible to identify causality and to connect the possible poor efferent function with experience of hearing difficulties. It is also difficult to know how to interpret such findings i.e. do people with poor efferent function merely represent one tail of a normal distribution curve or is this a real pathology as the BSA suggest?

Even with a possible bio-medical cause, can the bio-medical process account entirely for a patient's presenting behaviour? The assumption underpinning a bio-medical explanation is that the disease process (e.g. site of impairment) is the direct cause of the illness experienced e.g. hearing difficulties. However, this position still entails it's own controversies. It is not yet established that all patients experience a degree of biological impairment and that this alone is sufficient to determine help-seeking behaviour. As research continues it may well be the case that specific deficits will be identified. Whether those deficits translate directly to the experience of hearing difficulties in all cases is another matter.

To summarise, there is some evidence for biological changes in this group, particularly in early cochlea changes (Zhao and Stephens, 2006). It seems likely that some patients do indeed experience changes in the peripheral or central auditory pathway. This has led groups to focus on possible test batteries to identify an area of deficit with patients and to attribute the hearing difficulties to this area of deficit. However, this raises a key question. If according to the bio-medical model people present for help as a result of biological changes, then why should this group of patients with mild or not

easily detected biological changes present when so many with significant hearing loss (i.e. significant biological changes) do not?

### **Help-seeking in hearing loss**

It has been estimated that people with a biological impairment in hearing will take between 8 and 20 years to seek help with it (Brink, Van Den et al., 1996; Carson, 2000; Getty and Hetu 1994; Kyle, Jones and Wood, 1985; Watson and Crowther, 1989).

It is likely that the stigma associated with loss of hearing contributes to delay help seeking for most people. Even when there are measurable deficits in activity or impairments in hair cell function (Saunders and Haggard, 1993; Zhao and Stephens, 2006; Neijenhuis et al., 2001) or central auditory processing (Neijenhuis et al., 2001) for some of this group, it still does not explain why these people present when so many others with hearing impairments do not. This act of help seeking has not yet been explored.

It seems that there are limitations of the bio-medical approaches in explaining how people overcome such stigma to seek help. To assume that help-seeking occurs solely as a result of underlying biological impairment may be to underestimate the complexity of the patient experience.

In contrast, the contemporary consensus on health is that it is an ecological state consisting of internal and external factors. It attempts to include a psychosocial evaluation of signs and symptoms alongside a biological basis (WHO 2001).

## **The case definition - KKS or APD as a break in homeostasis**

The World Health Organisation revisions to the International Classification of Function (WHO, 2001) now include recognition of the way social factors inter- relate with biological and psychological factors to contribute to individual activity and participation. Borg and Stephens evaluate KKS in the light of this conceptual framework and highlight the fact that KKS can be seen as an individual appraisal of their communicative function as inadequate (Borg and Stephens, 2003). KKS can be viewed as a break in the individual's ecological state by either internal or external factors including a subjective evaluation that their performance in hearing is inadequate. They note 'an inadequate preferendum may well be the whole explanation for the symptoms in many cases' (Borg and Stephens, 2003). This suggests that the detection of symptoms can be seen as a break in homeostasis.

### **Emotional factors**

This bio-psychosocial model of health suggests an interaction between psychological, social and biological factors. There are frequent examples in the literature where health conditions have a possible biological underpinning, which is 'amplified' by emotional response. There are many examples in medicine of patients who suffer from the symptoms of an organic disorder without evidence of that disorder being present (Sarafino, 1994, p.283). A common factor in these patients is that anxiety seems to have a role in starting and maintaining the condition. This has been identified in abdominal pain, headaches, backache and benign palpitations (Mayou, 1992). This has also been identified in Otolaryngology. High levels of anxiety have been associated with vertigo (Hallam and Stephens, 1985), globus pharyngis (Dreary, Wilson, Mitchell, Marshall, 1989) and tinnitus (McKenna et al., 1991).

A pilot study of KKS patients examined the role for emotional responses in the start and maintenance of hearing difficulties (Pryce, 2003). The findings concluded that there was a role for emotional distress in both the experience

of hearing difficulties themselves and also in events that preceded the start of hearing difficulties. For some people the difficulties experienced followed a clear experience of trauma e.g. a car accident, collapse of a business or death of a loved one. Regardless of underlying pathologies, patients note and recall such traumas as relevant to a specific start of difficulties. In interviews participants revealed that such connections were part of their own personal history of the symptoms. They had not necessarily shared this view with clinicians so that their perspective on the causes for their hearing difficulties were not necessarily incorporated into the information they received from clinicians.

What was particularly interesting was the identification of a vicious circle effect. In other words the experience of hearing difficulties became worse as the patient became more distressed about them.

This implies a role for psychological and social factors (based on expectations of performance in listening) in the interpretation and by extension, definition of hearing difficulties.

It was clear from the qualitative investigation that psychological and social factors were linked inextricably with the symptoms described. For example, the relationship with the communicative partner and their perceived sympathy with hearing difficulties would affect the level of distress a participant described experiencing when communication broke down. This level of distress would in turn raise anxiety levels when attempting to communicate in a particular environment and the raised anxiety levels would contribute to greater difficulty hearing (Pryce, 2003).

### **The miss-match between perceived disability and measure of impairment**

The bio-medical model of health suggests that patient experience of disability will relate to the amount of impairment that the person experiences. In other words, the more severe the hearing impairment the greater the chance of experiencing disability. This logic has been challenged by many in the Health Psychology field as inadequate in explaining the cognitive process that leads to clinical help seeking (St. Claire, 2003; Leventhal, Nerenz and Steele,

1984; Moss-Morris, Petrie and Weinman, 1996). The experience of hearing difficulties has been assessed using the Institute of Hearing Research Hearing Questionnaire and the Social Hearing Handicap Index (Saunders and Haggard, 1993). These studies reveal that patients with KKS/APD experience similar levels of hearing disability to patients with measurable hearing losses and more hearing disability than matched controls. It highlights the point that disability may not be correlated with degree of measurable deficit. This is in keeping with the process of interpretation of symptoms (Sarafino, 1994). This evidence seems to support the notion that patients experience disability as a result of an imbalance between their evaluations of how their hearing performance should be and how it is (Borg and Stephens, 2003).

The psychosocial model of health proposes those individual decisions about whether and when to seek help with a health condition are based on a series of complex thought processes. The Health Belief Model suggests that people assess whether the perceived benefits of seeking help outweigh the perceived barriers (Sarafino, 1994). One of the barriers to help seeking for hearing difficulties is the social identity of hearing impairment. People who present for help with medically unexplained hearing difficulties (MUHD) are, in effect, deciding that the benefit of help might outweigh the possible social stigma of having a hearing loss.

### **The clinical relevance of the bio-psychosocial model of health**

The bio-psychosocial model of health proposes that patients have an active role in the interpretation of their symptoms and that their perspective is important. It is important both as a description of their internal appraisal of their illness and also as a means of perpetuating the symptoms themselves. It has been proposed that a vicious circle can occur where individual appraisals of their communicative performance are negative. This can contribute to a stress response that can in itself, perpetuate the hearing difficulties (Pryce, 2003). There is an opportunity to interrupt this vicious circle through the clinical encounter.

It is notable how the lived experience of medically unexplained hearing difficulties has not been the subject of research to date. Indeed searching for 'Audiology' and 'lived experience' reveals no hits at all on PubMed. Thus, the bio-medical literature overwhelmingly dominates the pool of information for clinicians and compromises the evidence base. This results in a limited evidence base. For example, clinicians do not have patient generated outcomes against which to measure their performance. It is unlikely that there will be a biological, medical or surgical 'fix' for the hearing difficulties. Given the chronic nature of the problem, it is particularly important that attention should be paid to how audiologists can help people live with and adapt to the restrictions they experience.

It seems that the biological mechanisms that explain the difficulties experienced by people with MUHD are not well understood. There is a wide range of possible auditory factors involved and there is no clear evidence that a lesion in one site is responsible for symptoms that are detected and that these in turn are prompts to seeking help. At best the literature suggests there may be a heterogeneous group of possible biological factors that are associated with this population. There remains no evidence of any specific 'cause' of the hearing difficulties, but rather a series of exploratory observations about characteristics of the population. The emphasis in research to date has been towards discovery of possible factors, rather than treatment approaches. These observations are assumed to have a link with the detection of the symptoms described, but there is no evidence that this is necessarily the case.

If we consider that these patients are of interest clinically, then we must consider all the factors that contribute to a clinical identity as a 'patient' in this context. Therefore we need to examine the literature on illness behaviour and symptom detection to learn more about the process of identifying a symptom of hearing difficulty and the process of seeking help with such difficulties.

## An alternative view: KKS/APD patients as help-seekers

Medical sociologists propose that disease and illness are different states (Wainwright, 2008). Illness is the state encompassing symptoms and thus it is the state that patients present for help with and audiologists therefore encounter. It is not the same concept as that of a biologically recognised disease. The research to date is reminiscent of what Locker terms the 'epidemiological triangle' (Locker, 1997) in which disease is considered to result from the relationship between an agent, the environment and modifying factors. He notes that such a framework is a useful point to investigate infectious disorders but less helpful with chronic conditions. When considering chronic health conditions a range of social and psychological factors influence the case definition.

In MUHD people perceive themselves to have hearing difficulties and seek clinical help to diagnose and manage such difficulties. In doing so they are defining themselves as deviant by normal standards of hearing performance. This deviance has been characterised as the 'sick role' (Parsons, 1964). They are consumers of health services and as such are influenced by socially and culturally determined values of 'health' and 'illness'.

The bio-psychosocial model of health proposes that the combination of biological, psychological and social factors can inter-relate (e.g. increased psychological focus on a bodily stimulus can make that stimulus appear more pronounced). Therefore the psychological and social factors that influence how individuals perceive their general health are of relevance in considering help-seeking behaviour.

Hagger and Orbell (2003) propose that people create mental representations of their illness based on concrete and abstract sources of information. So the social world influences individual perceptions of health or illness. These representations are informed by three main sources of information.

- The pool of lay information.
- Information from the external social environment.
- Somatic or symptomatic information based on current perceptions and previous experiences with the illness.

## The pool of lay information

St. Claire (2003) suggests that people commonly assume that bodily signs are reflected in symptom perception. This view was first articulated by Descartes' suggestion that pain results from injury and that more severe injury results in more severe pain (Descartes 1664 in St. Claire, 2003 p.23). Patient experience is determined entirely by physical processes. Academic researchers and doctors have rejected this approach as 'basically reductionist' (Salmon, 1999) and yet it still informs much public perception of health (St. Claire, 2003).

Calnan and Williams (2004) note that public understanding of health is becoming increasingly medicalised. For example there is widespread assumption that it is possible to suffer from pre-menstrual syndrome, sick building syndrome or chronic fatigue syndrome all of which may not be explicable in straightforward bio-medical terms. These syndromes are widely considered to have psychosocial components (Salmon, 2000; Wainwright, Calnan, O'Neil, Winterbottom and Watkins, 2006) although the public depiction may still be that there is an as yet undefined biological basis for them. As Hadler puts it:-

'To be well is not the same as to feel well' (Hadler, 1996).

Elaine Showalter has proposed that such medically unexplained conditions constitute modern 'hysterias' and that they have reached epidemic proportions. These epidemics result in people embarking on what she describes as 'patient careers' (Showalter, 1997).

Does the medicalisation of hearing difficulties as a 'disorder' or a 'syndrome' risk constructing and maintaining a 'career' as an audiology patient?

Showalter suggests that such a 'career' requires three components, physician enthusiasts, unhappy patients and a supportive cultural environment (Showalter, 1997). The zeal of some researchers to identify a neurological basis for an individual's 'not listening' (Dawes and Bishop, 2007) could be seen as pathologising by clinical 'enthusiasts'. Clinical caseloads tell us that there is a pool of presenting 'unhappy patients'. The cultural

environment may support the detection of some symptoms over others. It can be argued that physical symptoms are considered more valid and are detected and reported more easily than psychological ones (Showalter, 1997). This reflects the moral dimension to cultural notions of health and illness. In particular there is a shared social understanding that physical illness is legitimate, undesirable and deserving of medical help (Wainwright et al, 2006). However, psychological illness appears more complicated. As Ford (1983) notes, emotional disorders or difficulties in coping with life problems are not by themselves considered adequate grounds for entry into the sick role. It has been suggested that social stigma prevails with psychological illness, which implies a degree of fault with the individual (Ford, 1983; Salmon, 1999; Ferrari and Kwan, 2001; Showalter, 1997). There is a perceived association between psychological illness or distress and lack of moral fortitude or weakness (Ferrari and Kwan, 2001). The patient shifts from being the object, a passive recipient of their health condition, to being the subject of it. Therefore there is a sense that their 'suffering' is partly of their own making and, as such, no longer inevitable and valid.

It is widely considered that hearing loss and deafness, whilst perhaps not well understood, constitute an experience over which the individual has little control. People may be described as 'suffering' from deafness and the common terms 'hearing impaired', 'hard of hearing' etc denote the passive and objectified role of the patient. Therefore while the behaviours associated with not hearing may lead to stigma and embarrassment, i.e. missing conversation, the socially constructed role of the deaf or hearing impaired person is still socially sanctioned. Their position is worthy of sympathy and that, above all, their hearing and communication behaviour is not their fault. So to receive the diagnostic label as a hearing impaired person does, to some extent, provide a socially sanctioned justification for deviant communication behaviours (such as not following conversation). Thus a medical diagnosis has some appeal as bestowing justification for not responding to speech or environmental sounds.

Goldacre, 2008, notes that cultural values of health and illness are reflected and arguably reinforced by media coverage of health matters. For example, coverage frequently associates external factors with straightforwardly causing or curing health conditions. Health stories featuring results from observational studies may be described as though they are from rigorous experimental work. All manner of claims may be made with the prefix 'research has shown...'. It can be argued that this type of coverage positively damages public understanding of health in general what constitutes normal and abnormal states of health. For example, the reporting of pills as solutions to multi-factorial issues (e.g. fish oil tablets to improve children's academic performance) reduces the discussion and reporting of the complexity of social problems (Goldacre, 2008 p.136).

There is evidence that this type of media coverage can have a significant effect on health choices such as the recent decline in Measles Mumps Rubella (MMR) immunisation uptake following the reporting of the research by Andrew Wakefield linking prevalence of autism to MMR uptake. Goldacre (2008, p.273 ) refers to the 'media MMR hoax' to describe the copious coverage of the Wakefield study in the media, very often in a context where the evidence is viewed uncritically in preference for headline grabbing stories.

The proliferation of alternative health practitioners and their contribution to the lay literature on health issues is considerable. A glance at the average colour supplement or health pages of magazines highlights the volume of articles about nutrition for example. Such articles are likely to refer to pseudo-scientific concepts such as 'toxins' or 'de-tox' and suggest that a range of symptoms may be attributable to 'food intolerances'. Lay literature promotes the idea that normal health states are those unaffected by such problems and that the presence of a perceived symptom may be indicative of an underlying bio-medical 'intolerance'. The appeal of such a medicalised view is that it contributes to what Ferrari (2001) calls the 'no-fault' entry into the sick role. In other words, that an external force is responsible for the symptom and that the individual has limited potential to control their experience of the symptom.

Cultural messages about health and well being frequently reinforce the idea that binary positions exist with an objective truth where one either 'has' a condition or does not and where, above all, health conditions exist outside of patient perception. On the other hand there is a move in public health to increase individual responsibility of health and well being through health positive behaviours. In other words to encourage individuals as active subjects rather than passive objects of inevitable health fates. Patient-centred care is now more prevalent and patients are expected to be informed consumers of health services. Patients are assuming this active role in a culture that values objectivity in symptoms and where the dominant cultural belief is that psychological distress is more attractively packaged as a set of physical symptoms (Showalter, 1997).

Therefore, regardless of the clinical view that the patient may be presenting with somatising symptoms, the patient's primary concern may be that there is a physical cause or label for their experience which will validate suffering.

## **Information from the external social environment – the question of validity in help seeking**

The 'sick role' concept was first discussed by Talcot Parsons in the 1950s (in Parsons, 1964) and refers to the socially constructed and sanctioned role that an individual adopts in the presence of illness. Parsons identifies that health and illness are states that are evaluated and regulated by the social environment and culture that the individual inhabits. Illness is defined in this way as a state characterised by an inability to perform usually expected tasks or roles.

One important aspect of the social construction of the sick role is that it is implied to be a role that is beyond the individual's control by decision-making alone. It is a legitimised state for which one is not directly responsible and one that is socially agreed to be undesirable. It is also a state from which the individual is considered to be under obligation to try to 'get well' (Parsons, 1964). As a state for which the individual is not directly responsible, the sick role is a socially sanctioned state. The affected individual may be relieved of family and work responsibilities albeit with the aim of returning to full functioning as quickly as possible (Morgan, 1997 p.50).

Medically unexplained illnesses compromise legitimate entry to the sick role. Partly it compromises it through a sense that if the symptoms are not attributed to a clearly defined physical cause, they do not constitute an objectively verifiable condition and, partly, there lurks the suggestion that if no physical cause can be identified, the symptoms may reflect psychological distress. This psychological distress could be viewed as tantamount to saying that the symptoms are 'all in the mind' or that they are derived from a weakness of character. Such is the perceived value of objectivity and rationalism that not having a visible mechanistic basis is equivalent to not being real at all. The dualism between mind and body permeates our understanding of psychological health. A curious cultural norm is that it is acceptable for depression to be experienced following a disease or illness but not for depression to be the cause of perceived illness (Ferrari and Kwan,

2001). To suffer physically as a result of psychological distress is to lack moral fortitude (Salmon, 1997, in Halligan and Aylward, p.145).

This issue of legitimising the entry to the sick role has been highlighted in the literature around other medically unexplained and chronic syndromes such as Chronic Fatigue Syndrome (CFS). Dickson, Knussen and Flowers (2007) conducted a qualitative investigation into the experience of help-seeking and adjusting to chronic fatigue and found that 'de-legitimising' occurred through other people's interpretations of their described symptoms and through the health professionals assessment of the causes. In the first instance other people would 'de-legitimise' the symptoms by considering tiredness as just a normal response to the stresses of modern life. In the second instance the symptoms could be regarded as manifestations of psychosocial factors. The sense of chronic fatigue being de-legitimised could be extremely distressing for the individuals involved who describe needing a concept of the illness as a distinct condition, partly to communicate to partners, families and friends. Chronic fatigue is interesting because it is a condition, which can lead the affected individual to behave in a way that appears inconsistent. Individuals report that they pace themselves to be more engaged in certain activities than others to conserve energy. These descriptions have some obvious parallels with hearing difficulties in general and MUHD in particular as participants may behave in a way that appears inconsistent. For example they may participate more or less in communication depending on their circumstances and often describe tiredness as affecting their performance (Pryce, 2003). Similarly they frequently report that this inconsistency can be difficult for close friends and partners to understand and that worrying about their interpretation can cause additional anxiety (Pryce, 2003). The accounts from CFS patients highlight the dualism that exists in healthcare and the implicit value placed on physical versus mental disorders. In this case, many patients report that their GPs diagnosed their problems as signs of depression. This diagnosis was not accepted by the patients who did not comply with anti-depressant regimes but instead shopped around for other viewpoints, including from the complementary health sector (Dickson et al, 2007). When a more physical based diagnosis of CFS was offered, participants reported feeling very relieved at the legitimising of their

experiences (Dickson et al, 2007). The authors note that the concept of responsibility seems intertwined with the mental health diagnosis and that this in turn could be mis-interpreted by participants as accepting responsibility for the symptoms and thus blame for them. In addition accepting treatment in the form of prescriptions for anti-depressants was interpreted as synonymous with accepting responsibility for the cause of the condition (Dickson et al, 2007).

The current evidence base in MUHD in a sense preserves the medicalised 'legitimacy' of the symptoms and thus entry to the sick role for the individuals affected. However, this may also cause unwitting harm to patients affected by promoting iatrogenic testing procedures with no actual treatment options at the end of them. Such a case has been described in work into fibromyalgia. Fibromyalgia is an illness characterised by peculiar widespread pain and tenderness. As Hadler (1996) put it:-

'These peculiarities suggest to advocates of the construct that there must be some underlying specific pathophysiology that, although elusive today, will reveal itself someday if pumelled by the scientific method.'

Hadler notes that despite no suggestion of one clear cause for this experience, muscle, endocrine and nervous systems of these patients may be investigated in the hope of identifying an answer. This is a high price to pay for the patient who must undergo such investigations, which may ultimately not reveal any pathology.

'Fibromyalgia denotes a lengthy interaction between a physician wedded to the reductionist diagnostic algorithm and a patient overwhelmed by a sense of vulnerability that leads inexorably to a diagnostic contest.' (Hadler, 1996)

Hadler (1996) is referring here to the vulnerability of the doctor-patient relationship in the context of medically unexplained symptoms, which will be explored further in the next chapter. Balint (1957) documented a clear set of risks in the doctor-patient relationship where there is no clear medically

recognised cause or treatment for difficulties. He notes that to tell a patient following a physical examination that nothing can be found to be wrong implies that the patient's status as someone who is ill is challenged. By emphasising physical causes only for health symptoms there is a risk that the outcome will be unsatisfactory for all concerned.

It is widely accepted that people seek help with symptoms (including hearing difficulties) on the basis of many internal and external signs (Hagger and Orbell, 2003; Leventhal 1990; Weinman and Petrie, 1997). Yet this acceptance has not extended to the lay literature, or to more common sense assumptions about health (St. Claire, 2003). Perhaps in this context it is not surprising that Audiology clinicians have maintained a bio-medical reasoning behind the symptom detection that leads people with hearing difficulties to present for help.

Therefore the social environment may engender particular health concerns and bias attention to particular bodily stimuli and choice of attribution (Barsky, 2002; Barsky et al., 2001). Certainly it seems that symptoms are often required by the patient to have a physical cause. Patient accounts of symptoms frequently reflect a series of tentative possible causes as they seek a coherent explanation (Salmon, 1997).

To consider KKS as an experience that is underpinned by anything other than biological causes is to challenge not only the clinicians and researchers who seek a 'disorder' but also the patients who present for help. They risk being 'invalidated' if their experience is regarded as psychosocial in origin.

Indeed, the role of bio-medical causes for health problems is interesting because their role in symptom detection is often ambiguous. For example, research into pain perception has highlighted the discrepancy between accounts of pain stimuli even where sensation perception is shown to be reliable (Skevington, 1994). Work in tinnitus has highlighted the prevalence of psychiatric symptoms as associated with tinnitus (McKenna 1991) and these psychiatric symptoms may correlate with help seeking rather than with a louder or more distressing tinnitus (Attias et al, 1995). Similarly KKS has

been associated with neuroticism (Saunders and Haggard, 1993; King and Stephens, 1992).

The well-documented placebo effect also provides evidence of the extraordinary power of psychological and social factors in perceiving health and illness. Parkinson's Disease, rheumatoid arthritis, asthma and contact dermatitis have all been demonstrated to be improved by use of placebo interventions, frequently in objective and bio-mechanical ways (e.g. bronchodilation or motor performance) (Goldacre, 2008). Such responses are informed by the individual psychological interpretation, based on social and cultural meanings (Barrett, Muller et al., 2006). This effect is apparent where placebo administered by injection may have a more powerful response than one administered orally and where sham surgery is the most effective way of administering placebo overall (Kirsch, 2006). There is no bio-medical reason why this should be but surgery is a much more powerful intervention in the mind of the patient due to its cultural meaning. The shared cultural meanings of the placebo are thought to feed into the individual psychological response. This effect is considered so significant that researchers have re-labelled the 'placebo effect' as a 'meaning response' (Moerman and Jonas, 2002) to highlight the mind-body interaction that constitutes an effective treatment of any kind. So rather than considering the placebo an inert alternative to an active treatment the meaning responses created by placebo highlight the complexity of healing and the intrinsic mind-body connection that is part of all treatments. The evidence-base for complementary therapies highlights the whole process of clinician-patient interaction and belief as key to treatment effectiveness (Singh and Ernst, 2008).

It seems that there is a growing acknowledgement that cultural meanings of illness have a significant impact on informing individual meanings of health and illness. This is also apparent in literature on symptom detection.

## **The role of psychological factors in detection and maintenance of symptoms**

Amongst the earliest recorded descriptions of medically unexplained hearing difficulties are descriptions of psychological factors.

‘He was a worried tense man extremely anxious lest his defect should be the cause of a disaster, particularly when told that his hearing was normal.’ (Hinchcliffe, 1992).

King reflected that these cases were not malingerers but were further examples of what Kopetzky had termed ‘loss of the capacity for discriminative listening’ (Kopetzky, 1948; Saunders and Haggard, 1989).

These descriptions acknowledge the presence of anxiety and stress symptoms occurring alongside the hearing difficulties and focus on the perceptions of performance rather than an objectively measurable deficit.

Anxiety has been considered to be a characteristic that may influence perceptions of hearing performance in this group (Saunders and Haggard, 1993).

The Crown Crisp Experiential Index (Crown and Crisp, 1956) has been used to profile the psychoneurotic traits of this population. Saunders and Haggard (1993) identified that ‘Obscure Auditory Dysfunction (OAD)’ subjects experienced more phobic and free-floating anxiety than controls.

Subsequently a case control study was conducted comparing OAD patients with a group who experience chronic pelvic pain without obvious organic pathology. They found that both groups had a similar psychoneurotic profile but that OAD subjects performed less well on tests of hearing function, which would imply that the anxiety served to amplify symptoms but not be the sole cause of the difficulties (Saunders and Haggard, 1993). However the direction of causality is difficult to establish here. It might be reasonable to assume that people who do not fit established diagnostic criteria may receive less help from audiology services about their hearing difficulties and might therefore feel more anxious about their situation.

A striking feature of the recent APD literature is that it omits any mention of the psychological literature in symptom detection. Over the last fifty years

there have been changes within the field of psychology to emphasise the role of cognition in understanding human behaviour (Conner and Norman, 2005). In particular social cognition models are now the prevailing way to understand health related behaviour (Weinman and Petrie, 1997). At the centre of these models is the idea that people construct internal representations or schema that reflect pooled understanding of previous experiences and are used to interpret new ones. This process of holding learned beliefs and assumptions about health and illness (referred to as schema) are key in interpreting a bodily sign as a symptom. In particular the concept of illness perceptions has been used to define the detection and interpretation of physical symptoms.

### **Interpretation of symptoms**

A psychological model of illness perception rejects the view that a disease process or pathology necessarily underpins the symptoms experienced. Internal signs are interpreted according to a personal schema of illness (Young, 2004). Illness schemas are derived from shared social and cultural understandings. Therefore the process of a disease becoming an 'illness' involves the interpretation of symptoms by socially determined schema. Health Psychology has focussed work on trying to identify how people assess internal states and the gaps between observed assessments and people's individual assessments (Pennebaker, 1982). It has been noted that people do not always recognise symptoms that are present and may instead perceive symptoms that cannot be observed (Sarafino, 1994). In work comparing help-seekers and non help-seekers with tinnitus, Attias et al. identified that tinnitus help-seekers reported more psychological distress but lower levels of tinnitus itself (Attias, et al., 1995). Determinants of help-seeking status may not be biological in origin. Indeed, the power of interpretation of symptoms has been demonstrated to have such a profound effect that placebo or sham treatment can reduce symptoms of illness (Melzack and Wall, 1982; Shapiro and Shapiro, 1994). These interpretations may be constructed through social interaction. For example, the views of significant others may pathologise an experience. It is commonly the partner

or family of the patient who initiates help seeking for hearing difficulties (Carson, 2000). The perception of hearing difficulties is linked to a concept of social hearing performance.

In the case of MUHD where there is a potential discrepancy between the patient symptoms perception and the observable hearing deficit, it seems particularly important to examine the social and psychological factors that affect the hearing difficulties described. The psychosocial model therefore proposes that psychological effects in the detection of symptoms do not necessarily represent psychological 'impairments' but can be a natural and normal human response.

### **Illness Perceptions**

Leventhal (1990) suggests that the process of detecting symptoms is based on comparing experiences of symptoms or somatic information with bodily signs. Bodily signs may be compared with stored memories and developed understanding about diagnoses or symptoms. Leventhal goes on to suggest that this process is intuitive and automatic. In particular, Leventhal's self-regulatory model of illness perceptions stresses the link between the illness perceptions formed and the outcome of coping. Leventhal suggests that illness perceptions can be grouped into logical themes:

#### **Cause**

These are the beliefs that relate to the factors that are responsible for causing the illness or disease i.e. emotional, physical or environmental.

#### **Consequences**

These beliefs regard the impact of the illness on overall quality of life.

#### **Identity**

These beliefs centre on the illness label and knowledge about it's symptoms.

#### **Timeline**

These beliefs refer to ideas about the course and development of the illness.

## **Cure or controllability**

These beliefs refer to a sense of empowerment regarding performance of coping behaviours.

Leventhal suggests that there are logical connections between these representations and health outcomes. A high sense of control is linked to active coping behaviours, timeline is linked to cognitive reappraisal and consequences, identity and timeline have a negative relationship with psychological well-being, role functioning, social function and identity. Therefore such beliefs inform our decisions to seek help and such beliefs inform the type of help sought. These beliefs are also thought to influence decisions to adhere to treatment options (Horne, 2006).

## **Control over beliefs**

The degree of control that an individual has over such beliefs is a matter for debate. The debate hinges on the role of conscious versus unconscious thought patterns. The concept of the unconscious is based on Freudian psychiatry and suggests that there is a part of our psyche which contains thoughts which influence our beliefs and ideas but of which we have no direct awareness or control. In addition, Freud proposed that we have a pre-conscious state that links conscious and unconscious thoughts. This state enables us to process information about our immediate environment and context and relates this to deeply held but repressed thoughts in the unconscious. The resulting thought enters our conscious mind (Ferrari, Kwan and Friel, 2005). These models of information processing are important in the context of detecting health symptoms, a process of integrating internal signs with externally held ideas about the meaning of such signs.

This interaction between signs and external meanings can contribute some suggestions as to how chronic health conditions occur. It is possible, for instance, that organic symptoms might be amplified by psychosocial needs unconsciously (the process referred to as somatisation). In particular Ferrari and Kwan (2001) note that it is possible that an individual will attribute

subsequent symptoms to one original source, regardless of whether they are, in fact, linked. For example, pain and fatigue may have many precipitating factors but incidents of pain and fatigue may be interpreted as relapses from an original problem and create additional stress and anxiety. This stress and anxiety may then have a role in a vicious circle of inducing more pain or fatigue and generating a chronic health condition (Ferrari and Kwan, 2001). There may be unconscious but clear secondary gains to interpreting signs as symptoms that represent a chronic illness including: -

1. Gratification of dependent strivings.
2. Gratification of revengeful strivings (feeling under appreciated at work but now being paid for not working).
3. A means of obtaining one's entitlement after years of struggling and dutiful responsibility.
4. A means of converting a socially unacceptable psychological disorder into a socially sanctioned form of illness.
5. A means of displacing blame for one's failures to a condition beyond one's control.
6. Attempts to elicit care giving, sympathy and concern from family and friends.
7. As a means to avoid work
8. As a means to withdraw from an unpleasant life role or activity.
9. As a means to maintain status in the family.
10. As a means of avoiding sex.
11. As a means to communicate and relate to others in a socially sanctioned manner.
12. As a means to obtain drugs.
13. As a means to obtain financial rewards such as disability benefits or compensation (Ferrari and Kwan, 2001).

These gains depend on entry to the 'sick role' being legitimised. The legitimacy requires consultation with a health professional that ascribes a diagnostic label to the experience. The diagnostic label exonerates the individual from fault or blame for the health experience. Certainly such gains may unconsciously maintain individual's attention towards their symptoms. It

is possible that someone will more readily identify and remember an incidence of communication breakdown or miss hearing if they feel that they have a hearing difficulty. Yet such experiences of communication breakdown are commonplace amongst both those who do and do not have hearing difficulties.

## **Conclusions**

The existing literature in KKS emphasises possible mechanistic explanations for the hearing difficulties or focuses on possible psychological factors that contribute to the symptoms. Psychological factors are regarded as deviant alternative ‘impairments’ to complement the potential auditory or neural ‘impairments’. As such the literature base reflects a consistent bio-medical model of KKS/APD that is based around individual impairments, which cause the ‘disability’ symptoms.

There appears to be a gap in the literature in reflecting a contemporary bio-psychosocial model. Such a model might draw upon the literature in how social and cultural meanings inform individual perceptions and beliefs about health and illness. One potential issue with the acceptability of medically unexplained health conditions is that cultural meanings that are prevalent about health and illness still maintain an implicit value of physical disease over mental. Therefore it is more attractive for ambiguous symptoms such as hearing difficulties to be attributed to blame-free biological cause than to an ambiguous medically unexplained cause. This may influence how people perceive their hearing and create representations or perceptions of their hearing performance.

The examination of the social meanings that influence help seeking has highlighted the powerful role of the doctor or audiologist in acting as a gatekeeper to the legitimised sick role.

There appear to be gaps in the research base in exploring the perceptions formed by KKS patients about their hearing. There has also been a lack of evidence on the search for validity that is undertaken by patients with KKS and the social meanings of their help-seeking act.

The act of help seeking is examined in the next chapter as a form of coping. The way clinicians respond to such help seeking in the absence of clear medical signs is considered.

### **Summary chapter one:**

1. Medically unexplained hearing difficulties are referred to in the contemporary literature as Auditory Processing Disorders or King-Kopetzky Syndrome. The British Society of Audiology encourages the use of the term Auditory Processing Disorder (APD).
2. APD definitions suggest a biological basis for the hearing difficulties experienced, although the exact nature of this biological basis is not clear.
3. In order to form an individual diagnosis of the disorder clinicians are encouraged to adopt test batteries of peripheral and central auditory function.
4. There is no evidence that such test batteries and diagnoses lead to meaningful changes in either the diagnostic label applied or the therapeutic intervention proposed.
5. The collective evidence suggests that this is a heterogeneous group for whom psychological and social factors may play a part.
6. Contemporary thinking on illness construction and symptom detection has not been included in the KKS or APD literature, although it has informed thinking about other medically unexplained health conditions.
7. There is a moral dimension to social constructions of symptoms with biologically based symptoms considered to be beyond the control of the individual and, thus, implicitly worthier than medically unexplained or psychological symptoms.
8. There is a tension for clinicians between validating entry to the sick role and colluding in the interpretation of signs as symptoms and addressing psychosocial needs.

## **Chapter two: Coping – a review of literature**

Many people describe occasional episodes of not hearing or miss hearing. It is the decision to seek help for this as a distinct problem that leads to a patient 'journey' to ENT and Audiology. This behaviour and the interaction that occurs between a clinician and the patient is key to the maintenance of the 'sick role' as discussed in the previous chapter. The act of help seeking is frequently thought to be a means of coping with the stress of hearing disability. This chapter will therefore examine this assumption and consider what is known about how people cope with perceived difficulties in general and hearing difficulties in particular.

It is assumed that the role of the audiologist is to assess hearing difficulties and provide treatment in the form of amplification and communication advice. It is also assumed that such an approach facilitates coping in those who live with chronic hearing difficulties (Alpiner and McCarthy, 1999). Yet there is little reference in the audiology literature to the wider literature on coping with chronic health conditions or indeed, stress.

### **Coping in the audiology literature**

Not hearing could certainly be considered a stressful experience. Loss of hearing affects many aspects of function and communication and presents several stressors to an individual experiencing it. Donald Ramsdell (1962) outlined three levels of hearing, which provide an overview of the potential experience of loss. He proposed that hearing serves a function on a social, signal and background level. The social level of hearing enables verbal communication between people and also participation in entertainment. To lose hearing to the point where one can no longer enjoy social occasions or participate in visits to the theatre, cinema etc can create a significant stress for an individual. In addition a loss of hearing at the signal level means that an individual with hearing difficulties can no longer be sure of hearing significant warning sounds. Such sounds include traffic noise, sirens and

sounds at home such as telephone, doorbell, alarm clocks, smoke detectors etc. The loss of these sounds could lead to a sense of insecurity in the environment and an additional stress in managing everyday tasks such as travelling by public transport etc.

The background level of hearing is that which Ramsdell suggests orientates us to the world around us and contributes to our sense of being alive. Such sounds include the distant roar of traffic, the sound of the wind, the sound of people moving around us etc. Again the loss of this level of hearing is considered to alienate the individual from their environment, reducing their sense of their place in the world. Ramsdell suggests that this loss can lead the individual to 'feel as if the world were dead'. Such a feeling creates a significant stressor to the individual's sense of themselves and the world and implies that coping processes are crucial in reducing the impact of such stressors. The primary requirement of the deafened individual is to acknowledge the situation 'to admit it frankly and realistically' (Ramsdell, 1962). This suggestion, however, is not based on evidence of how people with hearing difficulties encounter this process or cope.

Andersson and Willebrand (2003) conducted a critical review of the examination of 'coping' in the audiology and otology literature. They identified three important points:-

- That many people use the term coping to indicate a successful intervention. This is different from what most researchers mean by the term.
- They also identify that checklists have measured the experience of coping with questionable validity.
- That what can be regarded as coping in one situation e.g. disclosing a hearing loss, can lead to future problems e.g. Stigma.

In the audiology literature, coping has predominantly been assessed through the use of questionnaires. These assessments of coping are often indirect with researchers concentrating on communication problems and the patient's use of strategies to overcome these (Hallberg and Carlsson, 1991; Andersson, Melin, Lindberg and Scott, 1995). Coping has not been thoroughly investigated in the Audiology literature as the process of coping has been interpreted as a narrow range of behaviours. Coping has been

regarded as equivalent to either use of tactics to manage or degree of distress resulting from communication breakdown. This reflects a trait driven model of coping in which the coping ability rests within the individual rather than as a process response to the environment. For example, Kent and La Grow (2007) use a series of questionnaires to establish the relationship between individual and disability characteristics, hope and adjustment to hearing loss. They conclude that hope is an important trait in moderating adjustment to hearing loss. Likewise, Cox, Alexander and Gray (2005) identify that hearing impaired people who display more 'openness', lower 'neuroticism' and higher internal 'locus of control' are more likely to adopt hearing aids. It is noteworthy that in this report, the adoption of a hearing aid is interpreted as a positive piece of coping with hearing loss.

Indeed the authors, in discussing the small penetration of hearing aids amongst the elderly hearing-impaired population state their assumptions:- 'These disappointing findings, which have been consistent over many years, clearly indicate that there is a need to increase uptake and acceptance of hearing aids among individuals whose lives could be enriched by amplification.' (Cox, Alexander and Gray, 2005).

It is possible that whilst researchers connect coping with use of hearing aids that other coping behaviours amongst those who do not use amplification are being overlooked.

This limits the evidence-base informing clinicians about the coping mechanisms employed by people with hearing impairment as it focuses on approach and avoidance strategies representing the trait coping rather than state coping (Andersson and Willebrand, 2003). Hallberg and Carlsson (1991) explored the use of coping strategies in estimation of perceived handicap. They note that both adaptive and maladaptive coping strategies focus attention on disability and thus to perceived handicap. The same authors explore this idea further in a grounded theory study of twelve middle aged hearing impaired participants. The strategies they identify are linked by a need to try to preserve the semblance of a 'normal identity' (Hallberg and Carlsson, 1991). This means that participants describe using a variety of communicative and environmental strategies to try and preserve their role as communicative partners. In order to achieve this the individual uses

strategies such as not asking for repetition when they have not heard, bluffing their way through a conversation or accepting restrictive access to conversation so that their social role as a communicative partner can be preserved. So it is seen that by not drawing attention to the deviant communication needs the individual seeks to preserve their status as a 'normal' person. This highlights the fact that for people managing hearing loss appears to be a balance between using strategies to access communication (e.g. asking someone to repeat what they have said) and avoidance strategies to preserve the social role as an equal communicative partner (e.g. bluffing that they have heard and 'letting go' of the detail of the conversation). Likewise Jaworski and Stephens (1998) identified that silence was a strategy employed to save face in communication breakdown. Indeed they proposed that avoidance strategies should not be regarded as maladaptive as they served a vital role in preserving the social role of the individual (Jaworski and Stephens, 1998). Furthermore, from the participants' perspective, silence and removal from communication can be regarded as positive (Kerr and Stephens, 1997).

In order to consider the current use of coping approaches it is important to attend to those that might be considered maladaptive as well as adaptive. Some of the most insightful accounts of coping, which include what might be considered 'maladaptive' strategies, have been generated by qualitative research using an inductive approach. For example, Hallberg and Barrenas (1993) have explored the experiences of men living with noise induced hearing loss and the experiences of their partners. Partners identified strategies that the researchers categorise as co-acting, minimising, mediating or distancing. 'Co-acting' is identified as the role a spouse may play in maintaining or supporting the husband's belief that there is nothing wrong with his hearing function. This serves to maintain the social image of a fully normal couple. 'Minimising' occurs when the spouse minimises the problems relating to the husbands hearing loss. The motivation for this is to avoid conflict with the spouse and again to preserve social identity. 'Mediating' strategies are described where the spouse will guide communication, advise their husband in communication or control the situation by listening out for both of them. 'Distancing' strategies occur where

the couple have minimal or no significant communication at all. They co-exist without communication (Hallberg and Barrenas, 1991).

The importance of the social role highlights the presence of stigma in shared cultural understandings of hearing loss and communication. People with a hearing loss may adopt 'maladaptive' strategies to preserve their role as worthwhile communicators and to avoid what Goffman (1963) describes as 'spoiled identity'. Goffman's theory of stigma suggests that stigma has two aspects, visible and invisible. People with a hearing loss may have to deal with a visible stigma in the form of a hearing aid, and also with the invisible stigma that comes from not being able to interact as quickly and easily as others. In this case an individual is unable to access communication and environmental sound in a way that is beyond their control, they are let down by their hearing. To accommodate this, many people rely on bluffing strategies or avoidance behaviours (Kaplan, 1985) to conceal the spoiled identity. As Andersson and Willebrand (2003) note, coping in the audiology literature has often been assumed to mean 'managing or succeeding' when the use of approach strategies may in themselves have negative consequences of identifying a 'spoiled identity' and are therefore, quite reasonably, avoided.

It seems that the qualitative investigations of coping with hearing difficulties have contributed an important understanding of the decisions that people make in adopting particular strategies or coping methods. Certainly, simply listing personality features or commonly used hearing tactics reveal little meaningful or consistent information about the process of coping. To explore this topic further an inductive approach, based on an assumption of multiple realities and where the patient's perspective is explored in detail, could be particularly useful in developing new insights.

The concept of coping has been widely explored in the research literature. A general definition of coping is that it constitutes a response to a perceived stressor (Hill, Chatterton and Aldag, 2003; Folkman, Lazarus, Dunkel-Schetter, DeLongis, Gruen, 1986). It forms mediation between a stressor and a subsequent experience of disorder (Sarafino, 1994). Thus it is of particular relevance to the field of health behaviour and has a complex influence over detection and management of health symptoms, including hearing (Horner,

2003). What role might the presence of a 'stressor' have in the detection and interpretation of hearing symptoms?

### **Biomechanical changes: What happens in 'stress'?**

A 'stressor' is considered to be either an external or internal threat to homeostasis (Hill, Chatterton and Aldag, 2003). Psychology researchers note that stress responses may, in part be learned from childhood onwards and may be a dynamic interaction between an animal or human and their environment (Sarafino, 1994). Such responses therefore also have the potential to change and develop throughout life (Sarafino, 1994).

The stress literature highlights the interaction between psychological processes and physiological ones. In particular the psychological response to perceived threat has been demonstrated to compromise the immune system (Hill, Chatterton and Aldag, 2003).

The role of stress in KKS has not been directly examined to date. It has however been noted that KKS patients display symptoms of anxiety and stress responses (Hinchcliffe, 1992; Saunders, Field and Haggard, 1993; Zhao and Stephens, 1996). However, there are obvious difficulties in establishing a causal relationship between stress and KKS as living with hearing difficulties without obvious cause could in itself be stressful. Yet there are also descriptions of patients experiencing stressful events prior to the start of hearing difficulties (Pryce, 2003). Could it be that stress triggers physiological changes which in turn compromise hearing performance? Bio-chemical responses to stress are well documented. Work in this field focuses on the role of the neuroendocrine system, autonomic nervous system, the sympatho-adreno-medullary system, the hypothalamic-pituitary-adrenal-cortical system and the immune system in forming a response to stress (Hill, Chatterton and Aldag, 2003). Since the 1920s and 30s neurological impacts of stress have been identified. For example, Cannon (1926) identified the role of the sympathoadrenal medullary axis in releasing hormonal responses to stress and in the 1950s the hypothalamic control of the pituitary was demonstrated (Harris, 1955). Selye (1936) described

different stages in the stress system alarm-resistance-exhaustion that became known as the general adaptation syndrome (GAS). In the alarm stage the function is to mobilise the body's resources in a fight or flight response. If a strong stressor continues the resistance stage occurs where the body tries to adapt to the stressor by replenishing the supply of hormones released by the adrenal glands. The prolonged physiological arousal produced by severe long-term or repeated stress results in a weakened immune system. Disease and physiological damage become more likely (Sarafino, 1994; Horner, 2003).

Horner's review of the literature on stress responses and the ear identifies that the role of stress in reducing the capacity of the immune system has been considered to be a contributing factor in several hearing conditions including Meniere's disease and sudden onset deafness (Horner, 2003; McCabe, 1979). So it is possible that stress create physiological changes in the ear. However, human beings respond to stressors through the use of coping strategies. It is possible that these could change the impact of the biomechanical effects.

Animal studies have contributed to an understanding of the physical response to stress and an objective demonstration of a change in physical state as a result of stress (Horner, 2003), but these studies do not particularly help elucidate how the coping process moderates the response to stress.

### **Coping as a mediation – personality factors**

Responses to stress are thought to depend on a number of factors including personality of the individual, their social support network, their perceived level of control and their resilience.

Psychologists conceptualise coping either as a 'trait' e.g. stable characteristics of a person or a 'state' dealing with challenges posed by perceived stress (Lazarus and Folkman, 1984). This has fuelled a debate within the psychology literature as to the extent to which research should focus on the process of coping i.e. the processes people employ to manage the stress or the extent to which coping is regarded as a property of an

individual character with little importance attached to variation of the stressor (Folkman, Lazarus, Dunkel-Schetter et al, 1986).

This approach was most famously described in the work on Type 'A' and 'B' personalities and coronary heart disease (Sarafino, 1994). This work highlighted how personality can mediate coping by both altering the exposure to stressful circumstances and by mediating how stress is managed within the individual.

### **Coping as a dynamic process**

Other researchers emphasise the role of coping processes as dynamic with more emphasis on the context within which the individual stressor and coping occurs. It is seen as a process involving three stages of appraisal; Primary appraisal is the process of perceiving a threat to oneself ('is this a problem to be addressed?'). Secondary appraisal is the process of bringing to mind a response to that threat ('what can I do about it?') and thirdly coping is the process of executing that response (Carver, Scheier, Weintraub, 1989; Andersson and Willebrand, 2003). Lazarus and Folkman suggest that coping performs one of two functions: emotion-focussed coping and problem-focussed coping (Lazarus and Folkman 1984). Problem focussed coping refers to practical attempts to overcome difficulties. Emotion focussed coping refers to attempts to manage the emotional response to a situation. In practice both emotion focussed and problem focussed approaches are used by most people in an attempt to manage stress i.e. Folkman and Lazarus report use of both approaches in between 96-98% of their samples (Folkman and Lazarus, 1980,1985). However, where the stressful situation is evaluated to be less controllable (for example responding to a loss of a loved one) then emotion-focussed approaches are primarily employed.

The use of adaptive or maladaptive approaches to coping is thought to be influenced by the amount of social support that an individual has. So KKS or APD could be conceptualised as a label ascribed to people displaying particular coping behaviours e.g. help seeking.

Pennebaker (1990) highlights the value of being able to talk or write about problems to someone as a way of assisting the process of organising

emotion focussed coping and exploring problem focussed approaches. Certainly counselling approaches such as those advocated by Rogers (1965) are designed to enable individuals to explore their problems verbally and to assist a process of literally 'coming to terms' with a stressor.

This implies that the process of becoming a patient is influenced by individual appraisals of the challenges of listening in particular environments. The appraisal of the challenges of hearing and listening as greater than their existing ability to manage lead to people seeking help to acquire practical diagnosis and treatment (problem-focussed) and to acquire a greater understanding of their difficulties and come to terms with them (emotion focussed).

There is considerable variation in how people form such appraisals, after all we have established that this group of Audiology patients present without the level of expected disease one might expect for their symptoms and simultaneously, many people with significant hearing loss do not decide to seek help with it (Kyle, Jones and Wood, 1985). So what characteristics does the patient group possess that influence their behaviours?

Sociological approaches to examining how populations vary in their coping behaviours have focussed on the concept of 'resilience'.

Resilience is considered to refer to the trait of an individual towards hardiness or ability to overcome adversity. It has been defined as 'the positive role of individual differences in people's response to stress and adversity' (Rutter, 1987). As such it is a socially determined and defined concept of a human trait that pre-disposes people towards adaptive coping, confidence and achievement. A significant component of resilience as a characteristic is the role of self-efficacy. Self-efficacy has been defined as confidence in one's ability to carry out behaviour (Bandura, 1977). It depends therefore on cognitive perceptions of control based on internal control factors. It has long been assumed that individuals who have a greater sense of control over their health will more readily adopt positive health behaviours and coping strategies (Norman and Bennett, 2001). In the field of health promotion this has led to interventions such as 'internality training' (Wallston et al, 1978) and the role of general practitioners giving patient advice on

healthy diet, alcohol and smoking in relation to their health (Norman and Bennett, 2001). The assumption being that greater information will lead to an increase in autonomous control and, thus, to adoption of more healthful behaviours. Health locus of control has become one of the most widely researched constructs within health behaviour (Norman and Bennett, 2001). Control beliefs are significant in coping style as they are considered to influence the individual's expectancy of an outcome arising from one's actions. However, the relationship between locus of control and behaviour has been demonstrated to be far from straightforward. Theoretically, individuals who perceive themselves to have control over health outcomes (an internalised locus of control) could be assumed to engage in more positive health and coping behaviours although evidence for this is mixed (Wallston et al., 1978; Segal, 1994). Generally, the role of locus of control beliefs in predicting behaviours is not strongly supported by evidence (Wallston et al., 1978). Individual beliefs are considered to have a definite role in the coping process in chronic health conditions. For example in multiple sclerosis and spinal cord injuries, the chronic pain patients experience is exacerbated in those with catastrophising beliefs (Hanley, Raichle, Jensen and Cardenas, 2008).

The research evidence into coping cognitions and behaviours is hindered by methodological difficulties. Where coping behaviour is assessed by participant reports, such accounts are inevitably affected by self-report bias. A bigger problem in the assessment of coping behaviours through self-report is the process of creating autobiographical memories. People appear to recall aspects of their personal history based around memory fragments that are constructed according to theory about what is most likely to have occurred (Ross 1989). There are implicit errors in memory and the risk of recall bias as a self-enhancement technique. Unsurprisingly, evidence is compromised by the extent to which retrospective reports of coping are inherently biased (Smith, Leffingwell, Ptacek, 1999; Todd, Tennen, Carney, Affleck and Armeli, 2004).

Researchers commonly categorise coping behaviours as approach strategies that seek to actively manage the stressor or avoidance strategies

that are considered to be attempts to avoid the stressor (Roth and Cohen, 1986). Such behaviours are then categorised as either constructive or maladaptive. Yardley (1994) notes that this categorisation does not tell us about the individual's motivation for behaviour. So information seeking may be part of active problem solving or it may simply reflect an anxious preoccupation with threat cues. Likewise avoidance may include active attempts to minimise the problem or be a reflection of unhealthy pessimism (Yardley, 1994). So studies that attempt to quantify such behaviours are inevitably vulnerable to researchers' interpretation of the meanings communicated in a behavioural act. The act of seeking help is key to the case definition of this group of patients. Yet this help seeking is fraught with potential difficulties as the clinicians' view of valid help seeking and coping may differ from the patients'.

### **The 'heart-sink patient'**

There is evidence from the literature on relationships between Doctors and patients with medically unexplained symptoms that such patients may be characterised by physicians as 'heart-sink' patients (Mathers, Jones and Hannay, 1995).

These patients are perceived to present with multiple complex symptoms and this creates feelings of frustration, inadequacy and powerlessness on the part of physicians (Woivalin et al., 2004). Similarly, the relationship with KKS/APD patients appears not entirely straightforward. Clinicians report that they are uncertain how to treat KKS/APD and how to counsel patients. How do clinicians respond to medically unexplained or ambiguous symptoms in general?

Examples of clinical encounters where patient symptoms can be considered medically unexplained are not uncommon. Medically unexplained illnesses in which patients report symptoms for which no evidence of organic pathology can be found are common in other settings (Pennebaker, 1982, Salmon 2000), for example, accounting for much of the general practitioner's workload; a retrospective review of case notes in a US ambulatory care clinic found that the 14 most commonly reported symptoms could only be

medically explained in a minority of cases. For example, chest pain, headache, back pain and abdominal pain could only be medically explained in 10% of cases, (Kroenke& Mangelsdorff 1989). A review of neurological patients found that 26% were medically unexplained, (Perkin 1989).

Medically unexplained cases are often considered to be difficult to work with. Sharpe, Mayou et al., (1994) defined the following characteristics of patients who were considered difficult to treat:-

- Absence of a disease diagnosis
- More adversely affected by their illness and more likely to misunderstand or disagree with the explanation and treatment they were offered
- Where there are considered to be more psychological factors contributing to complaints
- Patients who are likely to make more frequent clinic visits (Sharpe, Mayou et al., 1994)

King-Kopetzky Syndrome patients present similar challenges to Audiology clinicians, as their symptoms are frequently complex and may involve psychosocial features (Zhao and Stephens, 2000). One of the risks in managing such patients is that physicians may attempt to manage their own responses of frustration and powerlessness by requesting unnecessary investigations and treatments with the underlying psychosocial problems remaining untreated (Woivalin et al., 2004). In a focus group investigation Woivalin et al. (2004) noted that a consistent fear expressed by doctors was that they might miss a condition, which could be medically treated. They reported that certain patients characterised by doctors as having unrealistic expectations about their care, could manipulate this fear. Wainwright et al. (2006) note that in the case of medically unexplained upper limb pain, doctors can collude with patients descriptions of physical symptoms rather than risk a breakdown in their relationship with the patient by confronting the possibility of psycho-social causes. Here the authors note: -

‘The great irony is that adoption of strong patient-centred approach to diagnosis and management of non specific arm pain has not led to holistic methods of treatment but all too often to a parody of the bio-medical approach in which all the rites and rituals relating to the treatment of organic

disease are observed, even though no evidence of pathology can be found.’  
(Wainwright et al., 2006)

If audiologists emphasise diagnostic testing as their management approach there are two risks that emerge: -

1. That they will find nothing and therefore de-legitimise the patient experience.
2. That they will identify a potential area of disorder and overly attribute the difficulties, thus promoting unsatisfactory treatment options or worse still, leaving the patient with no idea how to manage this ‘disorder’.

The potential use of diagnostic findings is presumably to support patient counselling and facilitate a patient-centred approach. However, in focussing on the quest for a bio-medical disorder, the incongruence of symptoms and signs becomes apparent and there is a risk that communication will, in fact, be compromised.

### **Communication breakdown**

Epstein, Shields et al. (2006) studied doctors responses to patients with medically unexplained symptoms by using covert unannounced ‘standardised patients’ with and without medically unexplained symptoms to reduce the risk of the Hawthorne effect obscuring results. They identified that physicians altered their communication style in response to the nature and expression of the patient’s symptoms. In general, communication was considered to be less patient-centred when communicating with patients with medically unexplained symptoms. Their suggestion is that the ‘scripts’ that inform the communication of doctors are influenced by recognisable and coherent patterns of illness. Where such patterns are obscured by medically unexplained symptoms it affects the communication between doctors and patients. In particular ‘Doctors..tend to truncate further exploration of the patient’s concerns.’

The communication behaviours of clinicians have frequently been considered to explain such difficult interactions. Mathers, Jones et al. (1995) note that of

their examination of doctors reports, the doctors who had received no training in communication or counselling skills reported twice as many 'heart-sink patients' as those who received formal training in at least one of those areas. Ong et al. (1995) notes the value of clear communication and a client-centred approach to maintaining a positive relationship with patients. The investigation of psychological and social aspects of the suffering reported by patients is widely believed to be important in maintaining a relationship between doctor and patient with medically unexplained symptoms (Sharpe et al, 1994).

As Salmon notes, there is a widespread assumption that people with physical symptoms consult doctors because they want their symptoms to be treated and removed. However, there is little evidence to support this assumption. Alternatively, there is considerable evidence that patients seek help in order to gain emotional support and explanation for the symptoms and for legitimisation of the sick role (Salmon, 2000; Wainwright et al., 2006). As there may be no clear underlying medical signs to explain the difficulties, patients may find that their complaints may not be regarded a legitimate medical matter and they may be dismissed. This experience is documented in the literature with other medically unexplained symptoms (Woivalin, Krantz, Mantyranta and Ringsberg, 2004).

|                     |
|---------------------|
| <b>Somatisation</b> |
|---------------------|

The bio-medical model has traditionally focused on the detection and treatment of organic disease and only secondarily with disabilities which may have a psychosocial component, (Wainwright et al., 2006).

Research in medically unexplained health conditions has tended to explain patient's presenting behaviour and perceived symptoms as representing 'somatisation' or the physical manifestation of psychological or emotional disorder. In other words that a disorder must be present, if not physical it must be psychological. Hahn et al. (1993) report that from responses to the General Health Questionnaire, 70% 'difficult' patients meet criteria for at least a mild psychopathology compared to 28% of 'non-difficult' patients.

However, the direction of causality is difficult to establish here. It is not surprising that patients who also report feeling dismissed might describe an increase in depressive or anxiety symptoms.

This is particularly difficult when researching hearing as the nature of not hearing can, in itself, create anxiety responses (Ramsdell, 1966). In research into hearing difficulties it has also been noted that depressive and anxiety reactions are common response to the loss of what Ramsdell (1966) identified as the loss of 'auditory background' levels of hearing. In other words the loss of the day to day, non verbal information about one's environment is needed to feel secure and content. Certainly psychological and distress symptoms have been associated with degree of hearing disability and handicap (Eriksson-Mangold and Carlsson, 1991). It has also been established that co-morbid psychological problems are common in noise sensitivity, tinnitus (Attias et al., 1995) and hyperacusis (Baguley and Andersson, 2007).

Unfortunately there is little evidence that screening for psychological symptoms improve patient outcomes (Salmon, 2000).

Indeed, as Salmon has pointed out the evidence for somatisation is far from straightforward (Salmon, 2000). In one sample of 228 primary care patients with symptoms persisting for a minimum of 12 months a significant minority (14%) were neither depressed nor anxious. In addition, levels of emotional disorder frequently do not explain variability in impairment or healthcare use (Salmon, 2000). Therefore as a line of enquiry, examining patients with medically unexplained symptoms, psychological characteristics may not really illuminate why they seek help in the first place. Salmon proposes that the most important area to research is what patients require from their doctors as 'active consumers' (Salmon et al., 1994).

The relationship between help seeking for medically unexplained difficulties and somatisation also perpetuates a dualist assumption that physical and mental health are separate entities, dealt with by separate clinicians. Wade (2006) notes that the term 'physical' is often employed as an adjective to imply a recognised, observed pathology as opposed to a functional non-organic causation. Yet people may have a disease without that disease being the cause of the presenting impairments and limitation to activities.

There may be no categorical distinction between people who present for help for problems that are due to pathology and those who present due to emotional distress. It is important also to retain the social context here. Bodily symptoms are a socially acceptable reason for being sick and are arguably awarded a higher moral status than emotional or psychological symptoms. To experience somatisation does not preclude the presence of a biological disease process also.

## **Conclusions**

The concept of coping in Audiology literature predominantly reflects a deficit led bio-medical view of hearing loss. In this hearing loss is seen as bringing inevitable adjustment and requiring particular efforts to cope (Ramsdell, 1962). Coping is seen as either adaptive or maladaptive and classification of strategies seems to reflect the audiologist or researcher view of appropriate management of hearing loss (e.g. compliant hearing aid use is seen as an adaptive strategy and avoidance of communication as maladaptive e.g. Cox, Alexander and Gray, 2005). However, researchers who have investigated that patient's viewpoint have identified that strategies used may have many functions including the management of social stigma (Jaworski and Stephens, 1998; Hallberg and Barrenas, 1993). This work illustrates that coping is influenced by the desire to manage social role as well as directly to improve communication. Indeed the wider coping literature suggests that coping behaviours are a complex set of activities influenced by multiple social and psychological factors. One coping behaviour that is of particular relevance to the case definition of KKS/APD is clinical help seeking. Indeed it is the inclusion of this coping behaviour that could be seen as an intrinsic part of the clinical case definition as it is not the hearing difficulties per se that define this group but rather the fact that such difficulties are defined as symptoms. The role of help seeking seems in part to be motivated by the need to attribute a clear 'sick role' to the experience. The literature into medically unexplained health conditions suggests that there are risks in the clinical encounter as symptoms without measurable signs may confound the familiar scripts from which clinicians operate. They may also create concerns

in the mind of the clinician that they may be missing pathology either biological or psychological. There is little evidence to suggest that a deficit-repair is what people seek when they seek clinical help (Salmon, 2000). Help seeking is both a social act and a coping behaviour. The literature highlights the complexity of factors that influence how an individual appraises their circumstances and identifies coping acts (Folkman, Lazarus, Dunkel-Schetter et al., 1986). These approaches to coping may differ from the lay definition of coping, which appears throughout the Audiology literature that coping is a socially condoned positive management of hearing problems. It certainly differs from the audiological view that coping equates to socially acceptable attempts to mimic a hearing person through the use of amplification (Cox, Alexander and Gray, 2005).

It is intriguing that despite the help-seeking decision being the one factor that universally links this diverse population, it is an area notably absent from the literature and evidence-base.

### **What conclusions can we draw?**

1. There is a risk that KKS/APD patients may be considered 'heart-sink' patients by audiologists.
2. For audiologists only to assume the role of diagnosticians with this group of patients is to risk overlooking the psychological and social factors that may be influences in their help seeking.
3. Audiologists have a powerful role as 'gatekeepers' to a socially sanctioned sick role.

## **Summary of Literature**

This section has summarised a range of literature that could shed light on the phenomenon of KKS. It has illustrated how KKS is conceptualised as a bio-medical disorder; especially within the Audiology field and that it is defined as such by the British Society of Audiology. Yet we have identified that the site of this disorder is not yet established nor are the auditory mechanisms that influence the hearing function. The literature on medically unexplained symptoms suggests that the presence of symptoms without clear bio-medical explanation is not unusual and that such symptoms may lead people to present for clinical help. The prevailing clinical view that patients present for help on the basis of bio-medical disorders fits within a schema that dominates Audiology practice. This schema suggests that patients constitute passive objects that are subject to changes in hearing function. The fact that KKS patients seek help with their hearing is key to their clinical labelling and as such is worthy of further investigation. The literature on help seeking and coping has suggested that people seek help as a result of a psychological process of forming cognitions about their health and function. The cognitions they form may themselves derive from social and cultural notions of health and illness. Therefore the starting point for further investigation of the help-seeking process in KKS is that this process is informed by biological *and* psychological *and* social factors.

Indeed, there may be many reasons why people present with KKS, which are unrelated to the amount of measurable biological impairment that may affect them. These reasons may be psychological e.g. a somatisation of psychological distress which manifests as a physical symptom. Social forces including cultural messages about health and illness may contribute to this somatisation.

Throughout this review of the literature a fundamental question remains unanswered: Why do people with MUHD seek help when many others with greater auditory impairments do not? To analyse this question, three further research aims are highlighted: -

1. To learn more about how KKS patients cope.
2. To learn how patients experience the clinical encounter with audiology professionals.
3. To learn more about the role of patient beliefs about illness in informing their decision to seek help with hearing difficulties.

Two original studies into help seeking and KKS are presented to address these aims further.

### **Chapter Three: The paradox of help seeking: two new approaches to examining the help-seeking act in King-Kopetzky Syndrome**

We have established that the bio-psychosocial model of health states that a health experience is based on a combination of biological and psychological and social factors. To date the literature review suggests that the Audiology field has focussed primarily on the biological aspect of KKS without much description of the psychological or social aspects. Therefore a key question remains unanswered. Why do people with KKS seek help when so many people with measurable hearing losses do not?

Two new studies, one qualitative one quantitative were designed to address this issue. This chapter will introduce these two projects, discuss their ontological and epistemological roots and clarify the researcher assumptions in undertaking them. The contingencies involved in conducting research will be discussed and made explicit.

#### **Background aim to the research**

The ultimate aim of the research activity was to provide a better understanding of coping, including help seeking in KKS. This would enable development in clinical practice. As a Hearing Therapist, the author starts the investigation from a background of years of clinical work, listening to patient stories. It quickly became clear that little of these stories was represented in the literature from which audiologists drew their 'evidence-base'. There has not, up to now been much description of the lived experience of KKS to inform the development of theory and inform the research agenda.

Given that the help-seeking behaviour and entry to a recognised 'sick role' is what determines these cases, it is important to compare whether illness perceptions might differ between those who choose to seek clinical help and those who do not. An observational design was chosen to explore possible hypotheses that illness perceptions might differ between groups who do and

do not seek help. To denote the clinical population the term King-Kopetzky Syndrome (KKS) is used.

Earlier work into emotional responses to KKS had identified that there could be a moderating process occurring (Pryce, 2003). In effect, the way in which an individual interpreted their experience contributed to their emotional response to it. This emotional response and its significance could then predispose them to have a greater difficulty next time they were in a similarly challenging listening environment (Pryce, 2003). The process of interpreting symptoms appeared to be a specific area to explore further. The theory developed from this inductive study suggested that individual beliefs and cognitions may affect coping processes in King-Kopetzky syndrome, including help-seeking behaviours. In addition it has been established that people with King-Kopetzky syndrome experience similar levels of disability to those with measurable hearing loss despite significant differences between the groups at the biological level (Zhao and Stephens, 1996). Seminal attempts to understand the gap between signs, symptoms and behaviours have focused on the perceiver as an active processor of symptom information who creates illness representations in order to regulate coping with health threats. It seemed important to examine the perspective of the perceiver in more detail, both as a way of generating new theoretical understanding but also as a way of establishing whether, as in other areas of health, coping mediates adaptation and health status (e.g. Leventhal and Nerenz, 1985; Leventhal, Nerenz and Steele, 1984). In order to identify an illness, a perceiver is thought to compare experienced symptoms with prototypical symptom sets (Bishop and Converse, 1986). Because few medical conditions are thought to generate prototypical symptoms sets (e.g. Bishop and Converse, 1986; Pennebaker, 1982), individual differences in assigning illness identity can account for variation in the relationship between signs, symptoms and behaviours.

Although fewer studies have focused on the relationship between components (Steed, Newman and Hardman, 1999), illness representations also guide cognitive appraisals of symptom perceptions. For example, more serious consequences are inferred if an illness is thought to have an internal cause or to be rare (Croyle and Jemmott, 1991; Ingham and Miller, 1986). In

particular, they provide an alternative to the idea that information from medical signs ultimately forms the building blocks of symptom perceptions and appraisals.

### **The relationship between the two studies**

The two studies presented here are designed to be complimentary attempts to address a common issue; that of the relationship between illness perceptions, help-seeking and coping in KKS. Since both have distinct ontological underpinnings, it is important that they are considered in their own context as two distinct but complimentary pieces of work. The first study presents a qualitative description of the way help seeking is viewed by the participants as a coping strategy and how it informs the illness perceptions that the participant holds. The second study looks at the role of illness perceptions in the decision to seek help with hearing difficulties.

### **Literature review methods**

In order to conduct a review of the literature in this area, systematic searches of Medline, CinAHL and Psycinfo databases were conducted. A range of terms were used to access articles relating to medically unexplained hearing difficulties including 'Obscure Auditory Dysfunction', 'Auditory dysacusis', 'King-Kopetzky syndrome', 'Auditory processing Disorder' and 'Auditory Disability with Normal hearing'. Follow up contact was made with key authors in the field (Professor Mark Haggard, Dr Josie Higson, Dr Fei Zhao and Professor Dafydd Stephens) to gather further references and to check that all research evidence available had been identified. There is on-going contact with Professor Stephens and Dr Zhao so that these checks continue. Given the prevalence of this hearing condition, there is in fact very little published evidence into this area. A total of around 27 papers have examined aspects of the condition. In addition there is copious writing on the subject of Auditory Processing Disorder although very little of it refers to this adult clinical group.

## **Ethical approval**

Ethical approval was sought and obtained from Bath, Bristol and Cardiff Local Research Ethics Committees. The key issues in study one were the possibility of increasing distress by encouraging participants to discuss difficult and occasionally upsetting issues. In study two the key issues were the possibility of identifying previously undiscovered hearing loss amongst the non help-seeking group. This was managed by advising participants about the findings and possible help-seeking options. Where necessary and at the patient's request, a brief report letter and copy of findings was sent to the participant's GP. Only qualified Hearing Therapists were involved in conducting the testing.

## **Chapter four: A qualitative exploration of help seeking as a form of coping in KKS**

To explore the act of help seeking as a coping mechanism in KKS it was important to consider the contribution of patient reports. Clinical experience suggests that patient reports regularly include rich descriptions of psychological and social processes that are involved in their clinical presentation. These reports offer a way of examining the meanings that the hearing difficulties have for the individual and the meanings they attribute to the help-seeking process. It was also considered to be a way of providing patients with a voice in the research agenda. Inductive research would enable advocacy for theoretical perspectives already held by the patients themselves. In effect, highlighting the multiple realities that might exist beyond the 'scientific' understanding held to date and to representing the multiple views and perspectives of some patients.

The data were considered the starting point for developing theory. In keeping with the traditions of inductive work, this is an iterative research process with potential to move back and forth between data gathering and theory development.

**Theoretical assumptions:** That patient accounts would illustrate a process of coping from the patient's viewpoint and that these accounts could be compared to identify common themes



**Data collection:** Open ended interviews with patients who had a variety of help-seeking experiences from two separate clinics



**Findings:** Patient accounts of help seeking and coping with hearing difficulties. Accounts would be analysed to identify common themes and a core category would be sought which, in each account, had an explanatory role in determining the difference in experience from individual to individual



**Theory developed:** from paradigm identifying core category and process

### **Methodological issues**

A study informed by grounded theory crosses between social constructivist and positivist paradigms. The starting point assumes that, whilst there are multiple realities to the experience of hearing difficulties, there is such a thing as a 'process' in coping and that this can be explored by gathering accounts from people who experience it. There is a long history of debate within grounded theory research about the extent to which a researcher should use prior knowledge to generate hypotheses about data and these arguments are explored more fully in the next chapter. In the present case, the clinical standpoint of the researcher led to informal gathering of patient stories and thus the starting position was informed by a number of assumptions. These assumptions were:-

1. There are processes to coping that people enter into for a variety of psychological, social and audiological reasons.
2. The people best able to inform clinicians about how coping occurs are the people who are experienced in coping with these hearing difficulties day in and day out.
3. Coping processes had not been explored from a patient's perspective before and that this was a timely and necessary additional approach to open up new possible areas of enquiry.
4. It would be possible to access the variation of coping styles and approaches through patient reported account.
5. There would be a variation in coping styles and strategies adopted.

The assumed advantages of this approach were: -

1. Using a qualitative interview-based approach would enable the collection of detailed and rich data.

2. This approach would be able to highlight new areas for further investigation beyond the existing research agendas.
3. The data would be patient/participant led rather than researcher led and thus a better way to advocate the perspective of patients.
4. This approach could generate new hypotheses on this subject.

The practical advantages were: -

1. It was considered relatively easy to access patient participants.
2. Data could be gathered from a smaller number of participants.
3. It posed relatively few ethical challenges.

The assumed disadvantages of the approach were centred on the fact that a qualitative approach is still relatively new in audiological research and not regarded as a high status piece of research.

Since the social constructivist paradigm suggests that meaning is constructed on an individual and socially shared basis, these meanings are by their very nature specific to the individual and therefore cannot be generalised to another set of individuals and circumstances (Silverman, 2000).

### **Sampling: The data studied**

The sampling approach to grounded theory investigation is often referred to as theoretical sampling in that the sampling forms part of the overall strategy to develop theory (Strauss, 1987). In practice, this means that sampling is often conceptually led e.g. a participant may be selected in the expectation that their data may reveal a new dimension to a previously identified concept (Strauss and Corbin, 1998). To investigate the process of coping in KKS, there were a number of decisions to be made regarding the source of data. Firstly, the case definition for cases to be explored was that individuals had been identified with this clinical label, so the investigations would take place

with a clinical sample. The next main consideration was that the potential sample would include sufficient contrast in terms of themes and experiences to allow for constant comparison of emerging concepts.

One of the most challenging aspects of the grounded theory method is that it requires the use of theoretical sampling to seek contrast with each case. This is challenging in an applied and clinical setting as by implication: -

1. The researcher cannot pre-determine a 'sample size'.
2. The researcher cannot identify in advance where to sample appropriate cases.
3. The researcher cannot predict who will make up the final sample.

There are considerable ethical and data protection issues that such an approach challenges. Within the NHS ethical framework of the time it was necessary to state an approximate sample size for the data set, the route to accessing patient data and the locations from which cases would be approached. In practice, this study employed a combination of theoretical and purposeful sampling methods. This implied a move away from the entirely inductive approach outlined by Glaser (1978) in which future sampling is based entirely on the theoretical constructs that emerge from the data. This approach proposes that the researcher cannot know who should form part of the sample or what approach to take in identifying future participants until the study is under way, the data are gathered and analysed and concepts begin to emerge. However, the approach adopted by Strauss and Corbin (1998) proposes that instead the researcher should look for opportunities to 'compare events, incidents or happenings to determine how a category varies' (Strauss and Corbin, 1998; Boychuk, Duscher and Morgan, 2004).

A further and related difficulty is the role of the researcher in forming pre-conceived ideas about the nature of the phenomenon under investigation. Glaser proposes that researchers must not approach their research area with any pre-conceived ideas e.g. little background reading or experience as this ensures that the theoretical concepts that emerge from the data are grounded entirely in the data gathered (Glaser, 1978). In theory the

researcher should not know in advance who to recruit to provide contrast in theoretical categories. However, Strauss and Corbin (1998) reflect on the fact that researchers are innately social beings and therefore have a role in creating social processes and, as such, the researcher's prior experiences are worthy of contributing to the development of theory. In this case, the author's clinical background meant that she had begun to form some idea of relevant concepts in advance of entering the field as a researcher. Therefore the sampling strategy was informed by clinical perspective and experience. In this case it was identified that people of different ages, different genders and different socio-economic circumstances may have different perspectives on communication and thus on their role as communicators which would be relevant to coping with this type of hearing difficulties. The contingencies were such that it was necessary to purposefully rather than exclusively theoretically sample. The ontological position was that the experience of coping in KKS was a matter of individual interpretation and construction and that the best approach to learning more about it was to examine, in depth, the reports of individuals themselves who were living first hand with the experience.

However, this approach crosses the inductive and deductive paradigm and in doing so, the study aims to identify a theory that could be considered to be a form of subjective 'truth' that had the power to explain the experiences of all people with KKS. The approach was informed by the grounded theory methods proposed by Strauss and Corbin (1998) rather than Glaser (1978). Initially to gain a rich data set the researcher pre determined a set of criteria to provide contrast in the data set.

These criteria were: -

- Age
- Gender
- Socio-economic group (determined by occupation and postcode)
- Degree of help-seeking (i.e. primary and secondary care consultations)

In addition, as the process of sampling and analysing data progressed, more specific qualities were sought such as contrast in the type of clinical encounters (e.g. with different professional groups within audiology). In practice, to achieve this contrast, two centres were involved in recruiting potential participants: the Hearing Therapy and Audiology clinics in Bath and the Audiology clinics at the Welsh Hearing Institute in Cardiff.

### **Access to participants**

To comply with data protection the researcher was required to use clinical colleagues to identify a possible range of cases and approach them in the first instance with information sheets and consent forms. The researcher could then approach those who consented to participate directly. Clinical colleagues examining case notes and referring new patients who met the criteria for a KKS diagnosis identified participants. These patients were sent information sheets and consent forms. Those who consented to participate were then passed to the researcher.

Strauss and Corbin (1994) recommend sampling occurs in three stages to match the stage of data analysis: -

1. Open sampling
2. Relational sampling
3. Discriminate sampling

### **Open sampling**

This initial phase of the sampling process is considered to provide an opportunity to start gathering codes and themes from a variety of data. The precise choice of case is less critical at this point as the overall aim is to gather a range of themes.

In this study the open sampling phase consisted of interviews with six cases that were chosen to provide contrast in terms of age, gender and employment. It was considered possible from prior clinical experience that

these factors might influence the type of coping strategies used and experienced. For example, different working environments in which individuals may perceive themselves to have differing degrees of control over their environment might influence the type of coping approach used. Likewise, gender and age contrast were considered a possible way of providing contrast in social and cultural approaches to coping with not hearing. The six cases were chosen consecutively to gather a wide range of possible themes from the initial data analysis.

### **Relational sampling**

At this point themes are being compared from different accounts and the sampling becomes more purposeful in an attempt to identify cases where a different or new dimension to a theme may be represented. Grounded theorists sometimes refer to this stage continuing until there is a point of 'saturation' in the data, where no further new dimensions to themes emerge. As analysis continues the theoretical development directs the sampling strategy. Here, an initial theme to emerge was that the understanding of the hearing difficulties seemed to relate to the strategies employed. To gain greater insight into the relationship between the development of an understanding of hearing difficulties and the use of strategies, participants who reported differing degrees of clinical help were sought. This was to identify whether cases of people who had had considerable therapeutic intervention might perceive strategies and the hearing difficulties themselves differently compared to individuals who were on waiting lists for further help. In other words, the characteristics of the sample became more important in determining which cases were selected for inclusion. In practice this meant that accounts were analysed and cases selected purposefully to provide contrast. This phase lasted approximately four months.

### **Discriminate sampling**

This is the stage of the sampling process where cases are selected to provide potential contrast to the developing theory. This includes searching

for 'negative cases'. Cases were sought to challenge the developing theory. In this case, colleagues identified participants who expressed little interest in clinical help. Their accounts informed the developing core category, which was concerned with clinical explanations for hearing difficulties. As a result of such 'negative cases' the core category was refined.

### **The two phases of this study**

The study used data that were collected from new accounts to develop and refine the theory. The theory was then compared deductively with a previous six accounts, which had also been gathered by the author. These accounts had been gathered during a similar investigation into the role of emotional responses to KKS. In describing that phenomenon the nature of the perceived hearing difficulties and ways of coping, including help-seeking attempts were described. The data set was considered to have some similar accounts that might provide comparison with the current study data. Therefore, in this study the data gathering and analysis were essentially conducted in two phases. The first phase was generating inductive theory with new data. The second phase deductively compared the developed theory with the previously gathered accounts.

As grounded theory differs from other qualitative methods in its use of deductive as well as inductive stages of theory development, it crosses the epistemological divide into a positivist search for a truth in a theory that could form a hypothesis for deductive testing.

As a researcher in a healthcare setting, such a dimension to the research is appealing as it is seen to meet the requirements to be applicable to the patient group, generalisable, and thus, clinically valuable and more readily acceptable to NHS ethical and governance bodies.

## The participants

Participants ranged in age from 20s to late 60s and came from a wide range of socio-economic backgrounds. Of the 19 new cases, eight were male and eleven female. Of the cases used to check the theory, 2 were male and three female with one male to female transsexual. Details of each participant are listed in table 1. The participants were recruited from Hearing Therapy clinics at St Martins Hospital, Bath and from the Welsh Hearing Institute. All had been diagnosed with KKS and presented with hearing difficulties despite normal audiometric thresholds. The difficulties with hearing range from not hearing entire utterances to mishearing parts of utterances.

For details of the participants in the first and second phases please see table one.

| Sex | Age group | Occupation                 | GP | ENT/<br>Audiological<br>Medicine | Audiology<br>assessment | Hearing<br>Therapy<br>Assessment | Hearing<br>Therapy<br>Treatment | Discharged |
|-----|-----------|----------------------------|----|----------------------------------|-------------------------|----------------------------------|---------------------------------|------------|
| M   | 20s       | professional               | X  | X                                | X                       | X                                |                                 |            |
| F   | 40s       | clerical                   | X  | X                                | X                       | X                                | X                               | X          |
| F   | 40s       | clerical                   | X  | X                                | X                       | X                                | X                               | X          |
| F   | 40s       | clerical/long<br>term sick | X  | X                                | X                       | X                                | X                               |            |
| F   | 30s       | professional               | X  | X                                | X                       | X                                | X                               | X          |
| M   | 40s       | factory worker             | X  | X                                | X                       | X                                | X                               | X          |
| M   | 40s       | professional               | X  | X                                | X                       | X                                |                                 |            |
| M   | 30s       | professional               | X  | X                                | X                       |                                  |                                 |            |
| F   | 50s       | student                    | X  | X                                | X                       | X                                |                                 |            |
| F   | 40s       | clerical                   | X  | X                                | X                       |                                  |                                 |            |
| F   | 50s       | clerical                   | X  | X                                | X                       |                                  |                                 |            |
| M   | 50s       | professional               | X  | X                                | X                       |                                  |                                 |            |
| M   | 40s       | professional               | X  | X                                |                         |                                  |                                 |            |
| M   | 30s       | clerical                   | X  | X                                |                         |                                  |                                 |            |
| F   | 20s       | student                    | X  | X                                | X                       | X                                |                                 | X          |
| F   | 40s       | clerical                   | X  | X                                |                         |                                  |                                 | X          |
| F   | 60s       | retired                    | X  | X                                |                         |                                  |                                 | X          |
| F   | 40s       | clerical                   | X  | X                                | X                       |                                  |                                 |            |
| M   | 50s       | professional               | X  | X                                |                         |                                  |                                 |            |
| F   | 50s       | professional               | X  | X                                | X                       | X                                | X                               | X          |
| F   | 30s       | clerical                   | X  | X                                | X                       | X                                | X                               | X          |
| F   | 40s       | professional               | X  | X                                | X                       | X                                | X                               | X          |
| M   | 40s       | professional               | X  | X                                | X                       | X                                | X                               |            |
| M   | 20s       | unemployed                 | X  | X                                | X                       |                                  |                                 | X          |
| M   | 60s       | retired                    | X  | X                                | X                       |                                  |                                 |            |

**Table 1: The participant's stage of help-seeking on the treatment pathway from GP referral to ENT and on to Audiology for diagnostic testing and to Hearing Therapy for specialist testing and therapy.**

## **How data were obtained**

Data were obtained by interviews, which were open to exploring issues reported by the participant but which were structured by a schedule of topics so that as theoretical concepts developed, the participants could be asked about them directly. Each interview lasted on average one hour and with two exceptions all the interviews took place at the participant's home, generally in the weekday evenings or on a Saturday. Each interview was auditorily digitally recorded.

Immediately following each interview notes were made about the topics discussed, key points that arose and reflections on how the process of the interview went and possible questions to be explored further. The interview recordings were downloaded to secure computer files and were then transcribed in full.

### **Interview schedule**

The interview schedule consisted of a list of general topics prompted in the initial stages by open questions such as 'tell me the story with your your hearing' and progressing to more closed questions where it was necessary to check a point or a theme that was developing i.e. 'does anyone else in your family have hearing problems?'

The list of topics:-

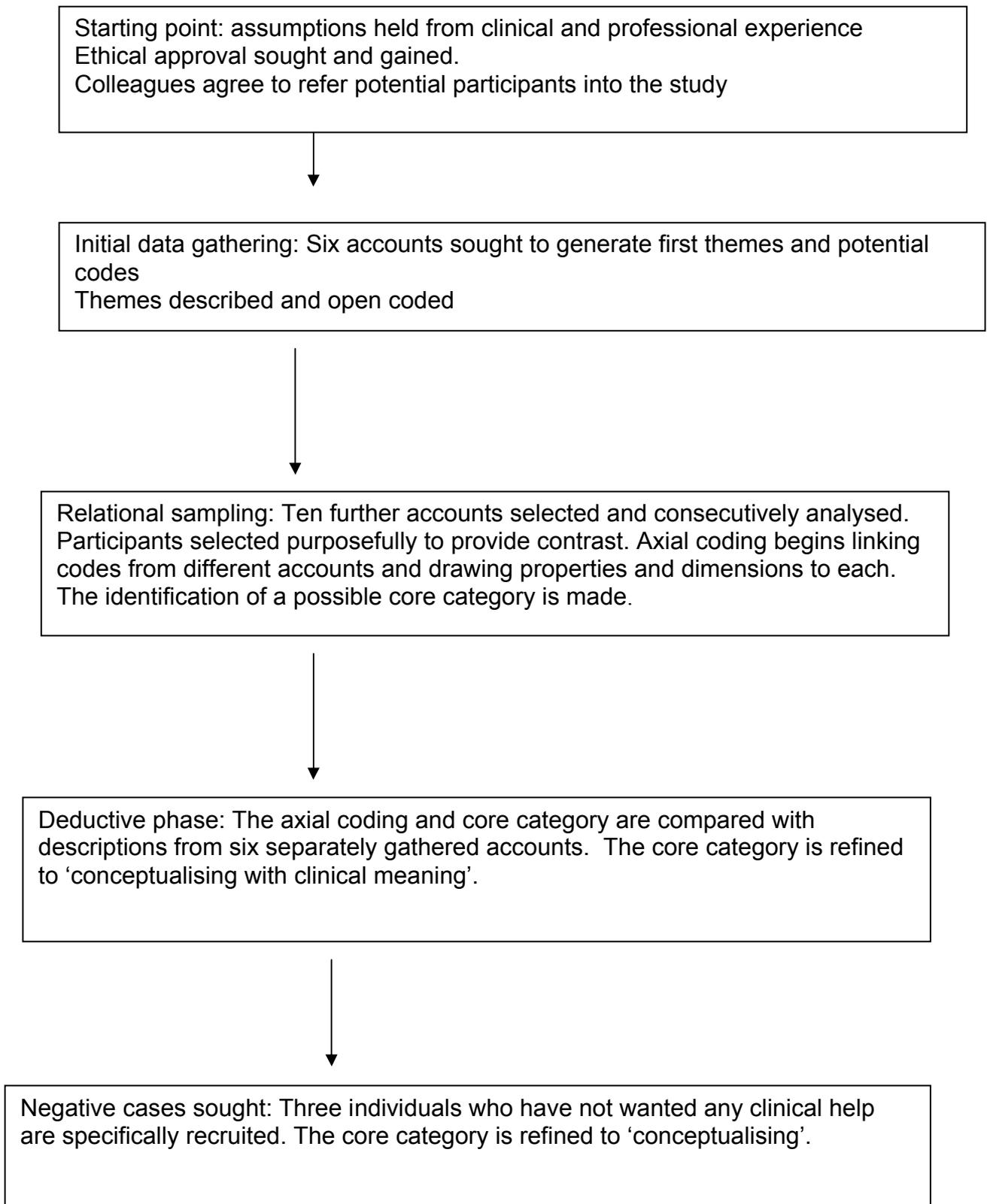
- History of hearing
- Help-seeking with hearing
- Reactions from others about hearing
- Ideas about causes of hearing difficulties
- Coping strategies

## **Reflexivity**

As a Hearing Therapist and a hearing aid user there were inevitable complications to the role of researcher. The epistemological underpinnings of qualitative work are that all meanings are socially constructed and that the nature of the meanings generated by these data is likely to be a particular product of the two people involved. Therefore it is reasonable to consider that there are some points that might colour the data. In this case the researcher was a Hearing Therapist and, thus, the participants may have assumed something of a patient role in the encounter, particularly at the outset. For example, the early parts of the interviews sound similar to a clinical case report with participants summarising their difficulties. However, as the interview progressed and as the researcher did not adopt a clinical role in response to the accounts, the dynamics appear to change and the participant accounts became broader and less focussed on particular symptoms. An additional factor that may have influenced the data was the fact that the researcher was a hearing aid user. This may have influenced the way in which perceptions of hearing loss were reported. In order to become aware of any possible aspects of the encounter that particularly coloured the type of data recorded, notes were made immediately following the interview to contextualise the interview data. In addition, particular efforts were made to include participants who were from the Welsh Hearing Institute so that there was no clinical relationship between them and the researcher.

## Flow chart to illustrate data gathering and analysis study one

NB. Data gathering and analysis proceed simultaneously



### **Why were these methods chosen?**

Interviews are frequently described as a way of generating inductive, participant led theory (Glaser and Strauss, 1967; Strauss and Corbin, 1998; Strauss 1987).

In order to identify participant perspective on the process of coping, the interview method was considered to be the most likely way to generate inductive theory. This method allowed for participant's own descriptions of the experience to form the data set. By giving descriptions verbally, participants were able to explain fully how they experienced coping in different settings and situations. It should be acknowledged that this approach also involves a mutual construction of meanings and that the interaction between researcher and participant is crucial to the type of descriptions obtained. It is likely that the accounts were constructed to present a socially acceptable series of descriptions about the way in which the participant saw himself or herself coping.

What did not always emerge, until subsequent analyses, were the implicit meanings that very often revealed more about the process of coping than the general descriptions of strategies undertaken.

The aspiration of this approach was that a non-judgemental acceptance of the participant's story would enable honest reflection on the process that occurred. One important factor in the choice of interview as a data gathering strategy was the researcher's previous training and experience in using counselling skills such as active listening, paraphrasing and reflection. These skills allowed for a deeper level of discussion about the issues around the hearing difficulties and enabled the researcher to spend the time with the participant trying to really listen to how their experience was, allowing her to 'walk in their shoes' as far as possible and thus put aside any preconceptions in favour of the participants' view.

## **What claims can be made about these data?**

The accounts from which the themes that form the theory are derived are all from people who have sought help for the problems they describe with their hearing. Therefore the data did not include people who had not sought any form of clinical help. There may be fundamental differences between such groups in terms of coping. However, the sample of clinical help-seekers included a demographic mix, mix of gender and mix of perceived level of difficulty arising from hearing. This sample is clearly not required to be a statistically representative sample of the clinical population but rather to illustrate the views of individuals who are defined as members of the clinical population.

### **How the data were analysed**

The data were analysed in a structured approach according to the procedures described by Strauss and Corbin, 1998. Such approaches have been criticised for being too procedural and limiting (Eaves, 2001) and for 'forcing' theory (Glaser, 1978). However, the clarity of the procedural approach had a clear appeal, as did the transparency of the method to explain to others how the analysis was conducted. Further details of the transcript coding are available in appendix I.

### **Respondent validation**

Following data gathering and analysis, the core category was considered in the light of the literature on coping. In fact there was a concept in health psychology literature that almost completely matched the description of the core category that had been defined in the data. The category was termed 'conceptualising the hearing difficulties' and it was clear that this was similar to a concept known as 'causal attributions'. The close relationship between them implied that the concept appeared to 'fit' in terms of existing knowledge about coping mechanisms.

In terms of credibility, the findings from each individual transcript were discussed with the relevant participant from the study in follow up telephone calls which recapped on their own data to check that interpretation of what was discussed was accurate. Participants were also asked to comment on the role of 'conceptualising'.

## **Triangulation**

Triangulation refers to an attempt to get an accurate view of data themes by combining viewpoints or methods (Silverman, 2000). In this case, an additional view of the data was sought. An academic colleague with experience of using grounded theory methods but no prior knowledge of this field was asked to generate codes from the transcripts independently. These transcripts were un-marked. These codes developed were checked with the original. There were considerable similarities in the codes and themes identified. The overall axial coding and selective coding methods were discussed.

## **Findings : The nature of KKS**

The codes were derived from the transcripts by grouping the codes in the data under the headings: -

- causal conditions
- phenomenon
- action/interactional strategies
- context
- intervening conditions
- consequences

These headings are recommended by Strauss and Corbin (1998) as a way of systematically examining how a process occurs. In this case coping is regarded as a process and the codes under each heading are described here to illustrate how coping occurs and is mediated. To structure the report of findings, each coded area is presented along with its properties. A set of codes are available as appendix I. The qualitative data here also describe

the lived experience of having KKS. The data include descriptions of living with the hearing difficulties themselves and of living with the clinical categorisation. This includes descriptions of the relationship with the clinicians encountered in the process of help seeking, which will be explored further in the section on the social factors described.

It should be noted that this evidence is not intended to exclude possible mechanistic bases for KKS symptoms including such currently unexplored possibilities as the presence of neuropsychological deficits.

### **Descriptions of living with KKS**

The 'causal condition' (Strauss and Corbin, 1998) under investigation is the experience of not hearing. This experience forms the stressor that precipitates a coping response. It includes the identification of signs as symptoms by the patient. Mis-hearing is based on the individual's assessment that they were not performing in hearing, as they would expect. The participants describe two distinct dimensions to this experience. Firstly missing parts of speech and secondly finding it difficult to attend to sounds when there was competing auditory information. The second aspect of this resulted in many descriptions of having to make more than usual effort to communicate.

Mishearing ranges from a perception that they mishear part of a conversation to mishearing the whole utterance and losing the thread in conversation. These descriptions appear very similar to those from people with sensorineural hearing losses, for example they are focussed on discrimination: -

*'I'm not as good as everyone else at being able to pick out words' (8)*

*'I heard things like a tartan skirt as a tart in a skirt'(2)*

*'I could hear sound, I just didn't know what the word was' (2)*

There is also a sense of comparing hearing performance against an expected ability and that this results in poor appraisal of their performance in listening. Interestingly, descriptions tend to focus on participants' own ability rather than the environment as responsible for the difficulties. There is a sense that participants accept full responsibility for the communication breakdown.

*'I knew myself that I couldn't hear what people were saying to me' (3)*

*'I find that I'm missing half of conversations' (11)*

*'Part of the time I can put the gist together but part of the time I don't know what they're talking about cause I've mis-heard the most important word' (11)*

This performance results in an experience of being unable to participate.

*'I'm still missing out in group conversations.'*(6)

### **Concentration Difficulties**

Participants frequently described their problem as concentrating on one particular sound, rather than a problem of hearing clearly. This is likely to be a reflection of the heterogeneity of this population and the fact that for some individuals, the symptoms are characterised as sensitivity of hearing with subsequent difficulties in filtering out intrusive noise. Again it is their own performance that is attributed the difficulty, rather than the environment. Therefore, descriptions imply a sense of personal responsibility and ownership for the difficulties. Here the descriptions move from hearing to attending to sound.

*' Even though I knew I could hear it I wasn't actually processing it'(1)*

*' I can hear things alright but I can't always understand what's being said to me' (4)*

Distraction by other sounds is another part of the problem:-

*'I tended to hear conversations from other tables as well' (7)*

*'It's hard to pick out which you should be listening to' (8)*

Hearing and listening are characterised as effortful processes, requiring more than usual degrees of concentration.

### **How hearing difficulties are interpreted**

*'I don't want to get like that'*

Participants described concerns having witnessed the difficulties that their parents had with their hearing in older age. These difficulties have informed their perception of the consequences of not hearing and their own hearing performance. These findings resonate with those from previous work into perceptions of hearing loss from individuals whose family members also had hearing difficulties (Stephens, Kramer and Espeso,2006) .

*'The thing I dread is the frustration with my father the reaction... people sort of say 'oh' and get really frustrated and actually dreading him coming on the phone..I'd always thought I might end up like him.'*(16)

*'We do find it annoying when she's sat in the back of the car and we're having a conversation and she's shouting and I don't want to get like that.'*(11)

The perceptions held about the hearing difficulties were crucial to informing the coping behaviours that the participant would undertake. As such the attributions that the participant described were coded as the 'core category' in the qualitative data. The core category is the category that explains most

of the variation in processing the problem including the choice of coping behaviour and whether or not to seek help. All categories relate to it and it occurs frequently in the data, in every participant's interview and several times in each transcript.

The code that determines whether the participant will employ a coping strategy, including seeking help, more than any other is the coherent idea that the participant develops about their hearing difficulties.

So participants describe feeling more willing to employ coping strategies once they have an idea what the hearing problem might be:-

*'I can take steps because, even if there's nothing that can be done, it's unlikely to get considerably worse.'*(7)

### ***'Knowing there's something'***

Once participants describe having a concept of what the problem might consist of, then it becomes easier to identify ways of managing it.

*'I'll know what my disadvantages are and I will make every effort to put those disadvantages as far back as I possibly can.'*(6)

Where participants report that they do not have an overall concept of a hearing disorder then it becomes harder to direct coping to use of strategies.

*'Well, I'm confused myself at the moment about what my problems actually are'* (15)

The actual concept of what was happening with their hearing varied between a specific hearing disorder and a general sense that their hearing was normal for their age. It appeared that the nature of the attributions held did not matter. It was the presence of some form of attribution that was important. So the degree of coherence of the symptoms as attributed to a particular idea about the hearing difficulties was critical in formulating coping

strategies. For example, participants could apply a coherent concept of their hearing difficulties where they attributed it to normal ageing.

*'Is it something that happens to quite a few people at our age.'*(11)

This interpretation could be regarded as an 'emotion focussed' coping mechanism with the participant describing how they are coming to terms with the presence of the difficulties. As a result of this interpretation the participant could, again, employ a strategy to cope, in this case, disclosing:-

*'In fact since I've told people my own age, they go 'oh I get that as well' (11)*

A coherent concept of the hearing difficulties could be enhanced through interaction with a clinician. When a clinician is able to give an explanation of the presence of the difficulties in the context of normal hearing thresholds, participants describe this enabling coping.

*'I found it helpful that I suddenly knew this reason why I was missing conversation...I wasn't going mad.'*(18)

*'Having a bit of background that was very useful.'*(6)

An important finding is that, contrary to what one might assume, a reassurance that their hearing is not measurably impaired does not reduce distress. This seems to be because the participant needs to reconcile the presence of the symptoms with the information that they are given. Such reassurances that did not address the presence of the symptoms confounded coping by obscuring the search for a cogent explanation and attributions. Instead participants describe such reassurances as dismissive: -

*'My hearing is in the normal ranges so nothing to worry about...oh no you hearing's fine off you go.'*(5)

The process of conceptualising involves reconciling information gained with the symptoms experienced. The clinical implications of this are that participants are likely to employ strategies that reduce distress where they feel that the problems have been acknowledged and given some explanation. It could be considered that this effectively validates their position as a help-seeker and removes any hidden assumption of blame from the individuals themselves.

### **Findings: Social factors**

Here interview transcripts and the accounts found in them were coded and analysed for descriptions of social meanings of experiencing hearing difficulties in KKS, living with such difficulties and coping with them including help-seeking for them.

The data on coping are grouped around two properties, help seeking and strategies.

The category, help seeking, includes prompts to seek help, characteristics of positive and negative consultations and the role of the clinical encounter in forming overall coping strategies. The social factors described influence both the detection of the symptoms and the decision to seek help with them. The influence of family and friends views of the participants hearing was an important prompt to seek help and, thus, to the ultimate diagnosis.

*'Well over the years my wife said to me 'get your hearing sorted out because you're not picking up everything.'*(24)

*'Somebody else sort of saying it to me sort of pushed me to make an appointment.'*(10)

For some participants, the prompt from other people is key to the decision to seek help. The clinical label acquired through that process is an almost accidental consequence of responding to this request. This provides

evidence for a social dimension to the process of becoming an audiology patient.

As with help seeking, significant others (partners and families) had a role in the detection of the symptoms of hearing difficulty itself.

*'I thought my hearing was alright. My husband kept saying to me 'you're deaf.'*(17)

*'They'd make comments such as 'can't you hear that?'*(19)

*'My wife noticed the problem more so.'*(14)

In the ecological sense, this represents a communication difficulty shared by both the participant and their communicative partners. However, there remains an assumption that communication breakdown is the result of one person (the participant) being unable to interact.

*' Various people would get annoyed at having to repeat things cause there wasn't any reason why I shouldn't hear.'*(3)

*'my wife genuinely thinks I'm ignoring her.'*(14)

The partner's view could re-enforce the perception that the participant has of their hearing problems: -

*'they'd all laugh when I said what I thought they'd said but they just put it down to age and the fact that lots of people get like that.'*(2)

In terms of coping strategies, families and friends influenced the type of coping behaviour the participant described using in communication. As such, the role of communicative partners was a contextual theme.

Participants have a variety of coping approaches, which vary according to the situation, the social circumstances and the perception the individual has

of the importance of the communication. Depending on the context, participants will vary their behaviour. Participants describe deciding what to do if they don't hear as:-

*'It depends who I'm with.'*(13)

*'It depends who's talking to me. If it's something really important like my boss telling me some information, then I will just say 'pardon' till I've got it.'*(15)

The social context changing would produce new communicative challenges. Participants would choose to seek help because they perceived their environment might pose more hearing challenges e.g. going to university. An environmental, social change again prompted the decision to seek help, beyond the presence of the symptom itself.

*'Well I thought that I would have problems at university hearing lecturers.'*(9)

Help-seeking was prompted by anticipation of possible future difficulties. In particular there was a perception that help-seeking could lead to new resources in the way of coping to manage new challenges in communication. The motivation to seek help is not necessarily the removal of symptoms as much as the desire that 'something could be done'.

*'I was hoping something could be done about it - that was the main hope.'*(6)

### **Clinical help-seeking**

Participants were included who were at different stages in the help-seeking process. All had been through GP and attended outpatient ENT/Audiological Medicine appointments at which they had had a hearing test and been given the diagnostic label (even if not directly, several participants did not know the terms King-Kopetzky syndrome, Auditory Processing Disorder or Obscure Auditory Dysfunction etc.). From this point some participants had received further testing and counselling appointments from Hearing Therapists which

included advice about maximising hearing in difficult situations .One participant had attended a communication group, whilst a number of the participants in Cardiff were waiting for further testing appointments. Two had requested no further help. These two participants deemed their current coping to be sufficient and perceived no benefit in pursuing help. Their accounts were to prove useful in refining the core category (see ‘negative cases’).

### **Characteristics of ‘Positive’ Consultations**

The key characteristic that determined a positive appraisal of the consultation was the patient’s perception that their account of the illness had been taken seriously by the clinician, and that the clinician had given a satisfactory explanation of the symptoms.

*‘to explore that there’s a reason that you can’t hear I think that helps enormously’ (16)*

*‘it was a huge relief because...there was something and there was a reason behind why I couldn’t hear words and different sounds and that helped enormously cause to me it was oh I’ve got something that’s recognised really’ (3)*

The naming of the condition led to a sense that the illness claim was validated.

*‘it makes you feel a bit vindicated really.. it makes you feel as if you’re not just making it up to get sympathy.’ (16)*

This sense of validation contributed to coping, both in terms of emotional adjustment and in terms of using strategies.

*‘I realised there were other people that were the same and that actually it wasn’t a really negative thing about me, it was just me.’ (3)*

*'I've got more courage now to say 'I didn't hear you because' rather than saying nothing before' ( 3)*

The decision to adopt a particular strategy is influenced by social circumstances, partners and significant other's views and the symptoms perceived. There are clear subtleties in the motivation for seeking help beyond the simple eradication of symptoms. Instead participants describe responding to social pressure and seeking information about their hearing. When clinical encounters responded to the social need to validate the illness claim and were able to provide additional information, the encounter was deemed a positive experience.

### **Negative consultations**

Unfortunately, the overwhelming description of the clinical encounter was negative. Negative consultations were those in which the patient reported one or more of the following characteristics:

- *Dismissal* – a sense that symptoms were not recognised or accepted as legitimate by the clinician
- *Time wasting* – concern that the clinician's time had been wasted, or, that the clinician felt this to be so.
- *Confusion* - over the rationale for testing and the meaning of test results.
- *Questioning of test results* – on grounds of validity and sensitivity.
- *Increased anxiety* – where the patient leaves the consultation more worried than before.

These characteristics are explored below.

## **Dismissal**

One of the key themes in a negative encounter was a sense of being dismissed. For example a simple 'reassurance' that there was nothing measurably wrong with the patient's hearing was sometimes interpreted as dismissal or invalidation of the sickness claim. This reflected a mismatch between how the patient experienced the symptoms and how they were interpreted medically.

*'they say your hearing is normal and they don't consider there's a problem. They're not interested.'* (Transcript 21)

*'they told me there's absolutely nothing wrong'* (Transcript 19)

## **Confusion**

Descriptions of the clinical encounter are marked by a lack of understanding about the process of diagnostic testing.

*'I don't know what they're going to do next I don't know what the tests are about'* (transcript 10)

The confusion links to a sense that the tests themselves are unreliable and that the patient's own evidence for their hearing difficulties refutes the audiological findings. In other words there is a sense of doubt about the validity of testing:-

*'the test was a fairly old mechanism and maybe I should go back and have something more contemporary'* (transcript 12)

*'I did sort of wonder if I cheated a bit'* (transcript 8)

*'I think I need a test when I'm in the middle of something and that's not possible'* (transcript 13)

Patients do not always fully understand why particular diagnostic tests have been applied, or what the clinical significance of test results is, or what they

mean. This is coupled with questioning the validity of the tests that are conducted, for instance, that it might be possible to inadvertently 'cheat' and produce a false negative result, or that the tests might not pick up a problem, that is only apparent in a natural setting.

### **Time wasting**

The patient's sense of having symptoms dismissed by the clinician can be accompanied by concern about wasting the time of the clinician:

*'I thought am I imagining it, am I wasting everyone's time' (2)*

*'I felt like a bit of a fraud for being there.'*(10)

The lack of clear evidence from test results can lead to an ambiguity about entry to the 'sick role' (Parsons, 1964; Wainwright, Calnan et al.,2006) The participant belief appears to be that conclusive evidence of pathology is required to legitimate the patient's entry to the sick role and help seeking behaviour. When this evidence of pathology is absent it leads to confusion

### **Increased anxiety**

Negative encounters could increase anxiety about alternative causes for the symptoms. Some participants disclosed fears about their mental health that they did not disclose to the clinician. These fears include the possibility that the symptoms indicate the start of senility or dementia, brain tumours, or more generalised mental health problems, for example:

*'there must be something wrong with me mentally' ( 5).*

*'how do they know I haven't got a brain tumour?'* (4)

These concerns were often compounded where other members of the patient's social network reinforced the sickness claim:

*'I can't hear properly there's no getting away from it...other people, even my colleagues at work have noticed it so it's not in my mind' (16)*

### **Strategy use**

The strategies described resemble those undertaken by people with a hearing loss in general. The strategies described can be viewed as proactive e.g. planning the interaction to pre-empt difficulties or reactive such as repairing communication breakdown by asking for repetition or attempting to maintain communicative flow by bluffing.

These include concentrating to piece together the communicative message and concentration is viewed as a strategy regardless of whether the description of the hearing difficulty itself is one of concentration or miss hearing. Again this reflects a sense of the individual responsibility in performance that was apparent in descriptions of hearing difficulties. The descriptions of strategies contain a sense of personal responsibility. The participant describes their attempts to maintain their social role by concentrating hard, bluffing and lip-reading.

*'I have to really focus.'* (5)

*'I've got to concentrate on what people are saying to me, if I don't that's when I get things wrong.'*(17)

*'I'm trying to make out what she's saying from fragments.'*(4)

*'I almost have to think really hard about what it is they've said and then I can process it.'*(1)

### **Bluffing**

Other reactive strategies reflect the need to save face in a communication breakdown and not draw attention to hearing difficulties that have occurred.

*'I just have to wing it.'*(14)

*'You try to guess.'*(5)

This need to manage the communication breakdown themselves and not disclose when breakdown has occurred extends into more formal strategies such as **Lip-reading**.

*'I pick up an awful lot of lip-reading.'*(6)

*'I've started to pick up lip-reading.'*(21)

*'I must look at people when they speak.'*(18)

Above all the aim of these strategies is to avoid appearing deviant in communication and to take responsibility for managing the communication breakdown without involving others.

*'Sometimes it's easier just to go 'mmm' (18)*

*'I tend to sort of stay quiet which is not me.'*(10)

### **Proactive approaches**

Depending on the context and intervening conditions participants do also involve others in assisting them with communication. The aim appears to be to recruit help to rescue the communication breakdown whilst maintaining a sense of individual responsibility for it.

For example, asking others to accommodate a hearing problem.

*'I've told people and they tend to tap me or they'll come around to my side and speak to me.'*(18)

*'I'll ask somebody to say it again.'*(12)

This can extend to attempting to manage a difficult listening environment to pre-empt difficulties.

*'I try controlling the meeting.'*(5)

*'I got up and moved over to where I could hear better.'*(2)

*'I've turned to them and said 'do you mind if we sit a bit closer' (7)*

**Disclosure** is another strategy that participants use to pre-empt communication breakdown, again their sense of ownership and responsibility for the difficulties becomes apparent.

*'I told tutors in college that I suffer from it in case I sometimes look a bit vague.'*(2)

This disclosure could lead to use of humour to remove tension from a communication difficulty.

*'I end up making a joke of it and going 'oh you know me deaf as a post' (5)*

These strategies are influenced by the concept that the participant forms about the nature of the hearing difficulties.

### **Negative cases – non help-seekers**

The core category originally reflected only the conceptualising that took place following help seeking e.g. a clinical interpretation of the nature of the hearing difficulties. However, through investigation of 'negative cases' (interviews 17 and 18) the 'conceptualising' that took place frequently reflected participant beliefs about ageing as well or about a 'normal' hearing performance in a noisy context. Thus it led to a revision of the core category from a concept that had been derived from clinical labelling i.e. 'King-Kopetzky syndrome' to a concept of hearing difficulties due to usual life

experiences (age or difficult listening situations). The non help-seekers displayed a similar coping process that was informed by the concept they developed of their hearing difficulties. In their case, the concept was informed by a sense that such hearing difficulties were normal for their age or were something that many people experienced and were a normal experience in communication. In other words they had a sense of a cogent set of difficulties but they attributed these difficulties to external factors. In regarding their hearing as 'normal for my age' they were able to manage their difficulties.

### **Discussion -Fittingness**

The concept of fittingness is important in assessing qualitative research. To consider how the conceptualising the hearing difficulties assists effective coping, the literature on coping was re-examined.

Zeidner and Saklofska (1996) have defined criteria against which to judge the effectiveness of a coping strategy. An effective strategy should:-

- Reduce psychological distress.
- Resolve conflict or a stressful situation.
- Promote normative social functioning.
- Reduce physiological or biochemical reactions.
- Enable return to pre-stress activities.
- Maintain positive self-esteem

The ability to conceptualise the hearing difficulties in a way that enables future management is crucial in enabling a positive coping strategy.

Likewise, participants who are unable to identify the nature and extent of the hearing difficulties are less likely to form positive coping strategies.

One crucial aspect of conceptualising the difficulties is having a sense of a cause for the problems. This has been identified in the coping literature as 'causal attribution.'

Causal attributions are recognised to assist psychological adjustment to difficulties (Cameron, Leventhal and Leventhal, 1993; Roesch and Weiner,

2001; Moss-Morris Petrie and Weinman, 1996). They do this directly e.g. having an understanding of a cause for the difficulties in itself promotes psychological adjustment and also indirectly, as they affect psychological adjustment through enabling coping. Attributions aid the process of reconstructing the assumptions an individual has and these provide a framework for future decisions as well as a guide to interpreting past experiences. (Cameron, Leventhal and Leventhal, 1993; Roesch and Weiner, 2001; Moss-Morris Petrie and Weinman, 1996).

In this way, the code 'conceptualising' would seem to fit with the model of causal attributions and fulfil a similar role. Where help seeking has resulted in enhanced understanding of causal attributions through an explanation for the difficulties, then coping has been more positive and successful in reducing emotional distress. It is important that clinicians aim to provide patients seeking help with MUHD with explanations of the nature of the difficulties. Simple reassurances that there is nothing medically wrong have been seen to compound the problem by increasing emotional distress and fear that the problem may represent something more sinister or that the individual must be 'crazy'.

An alternative interpretation of the findings is that they correspond to the 'difference-signal' interpretation of Borg and Stephens (2003). The difficulties in hearing result in disruption between an individual and their environment and that this disruption can be minimised through use of strategies. However, that model did not attempt to explain what motivates individuals to employ more or less successful coping strategies.

Strategies have been described in the coping literature as representing 'approach' or 'avoidance' (Andersson and Willebrand, 2003; Lazarus and Folkman, 1984). 'Approach' strategies aim to eliminate the stressor through actions, 'avoidance' strategies aim to avoid the problem altogether. These descriptions relate closely to 'pro-active' and 'reactive' strategies that I have identified participants employ to manage communication and hearing difficulties.

The strategies can also be defined as 'problem-focussed' or 'emotion focussed' forms of coping (Lazarus and Folkman, 1984). Problem focussed coping occurs when an individual makes alterations to their environment e.g.

request changes of speakers, change position in room etc. Emotion-focussed strategies are also described in the findings. In this way the findings from this study can be seen to 'fit' within the theoretical frameworks that exist in the coping and illness perceptions literature.

## **Chapter five:**

### **Exploring illness perceptions in King-Kopetzky Syndrome**

The aim of this study was to identify whether any patterns of illness perceptions exist which differentiate help-seekers from non help-seekers who describe similar symptoms. The theoretical framework for this was Leventhal's self-regulatory model of illness perceptions (Leventhal, Nerenz and Steele, 1984; Leventhal and Nerenz, 1985).

The five component parts of Leventhal's self-regulatory model form the basis for the Illness Perceptions Questionnaire (IPQ), which was developed to provide a quantitative assessment of illness perceptions (Moss-Morris, Weinman, Petrie, Horne, Cameron and Buick, 2002).

KKS patients present in a context where people with a biological impairment in hearing will take between 8 and 20 years to seek help with it (Carson, 2000; Brink, Wit, et al., 1996; Getty and Hetu, 1994; Kyle, Jones and Wood, 1985; Watson and Crowther, 1989) Could it be that there is a pattern in the illness representations this group hold about their hearing that contributes to their decision to seek help?

#### **The starting hypotheses were:**

That illness perceptions held might distinguish groups of help-seekers from non help-seekers alongside audiological factors. In effect that the illness perceptions held may be associated with help seeking and thus inform the fundamental case definition.

#### **Study Plan**

**Theoretical starting point:** Individuals have perceptions about their hearing that affect how they interpret the difficulties they have.



**Hypotheses;** could illness perceptions held be a factor that determines whether or not someone will seek-help with their hearing? (I.e. the null hypothesis is that there are no significant differences in the odds of holding a specific belief recorded between the two groups)



**Data collection:** An examination of hearing status and illness perceptions held by a group of patients referred to Hearing Therapy in Bath and North East Somerset Primary Care Trust and a group of staff and student volunteers who perceived themselves to have similar difficulties but who had not sought clinical help for them.



**Findings:** Regression analysis to examine the factors that are significant in determining help seeking.



**Hypothesis:** Confirmed or rejected



### **Revision of theory**

This study assumes that there is a positivist truth to be uncovered by examining a set of pre-defined variables. The advantages of this approach were considered to be: -

1. Repeated observations of this type would be able to identify possible patterns of illness perceptions held by people with KKS who seek help.
2. It would be possible to recruit both help-seekers and non help-seekers who display similar perceptions of hearing difficulties from populations to which access could be gained in Bath and Bristol.

## **Rationale for the 'help-seeking and 'non help-seeking' classification**

The nature of KKS is that it is the act of clinical help-seeking that prompts the clinical labelling of the individual into an Audiology patient. Chapter one has questioned the objective bio-medical reality of the condition and highlighted that along with other medically unexplained symptoms it is the choice of help-seeking in other words the coping behaviour that differentiates the clinical case (patient) from the average and normal day to day experience of periodically mis-hearing. Therefore it was considered that the act of help-seeking could be considered to be the factor that could differentiate clinical cases from non clinical controls. In this case non help-seeking controls were recruited by volunteering to the question about whether they considered themselves to have hearing difficulties. By recording audiological data, a comparison of their audiological performance and that of clinical patients was possible.

### **The make up of the help seeking group**

Patients were recruited from the usual caseload in Hearing Therapy at St Martin's Hospital, Bath. Consecutive new patients were sent information sheets and consent forms for the study with their appointment letters. Those who consented were then asked to complete the Illness Perceptions Questionnaire – Revised (IPQ-R) questionnaire in the waiting room, just prior to their appointment with the Hearing Therapist. The appointment then proceeded as usual with the IHR test battery being used to establish possible significant factors for each case. Counselling and treatment also proceeded as usual and the data set comprised the anonymised IPQ-R questionnaire and a summary sheet outlining their auditory performance in the IHR test battery was passed on to the researcher.

The help-seeking history of this group was to initially consult their GP, then attend an outpatient ENT consultation including audiological investigation, and finally, to attend a Hearing Therapy assessment and treatment appointment. Therefore, all patients had been assessed to establish normal

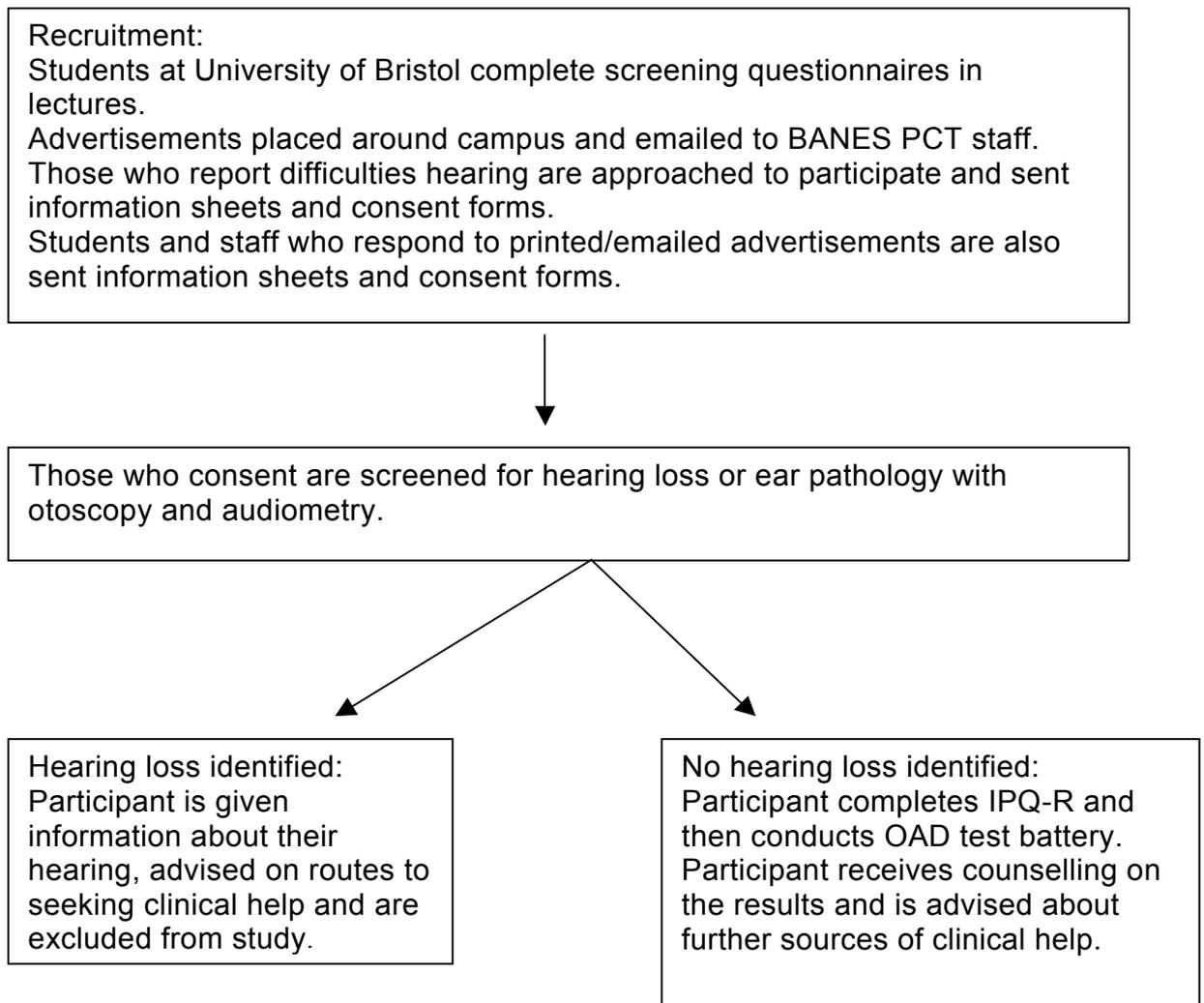
audiometric thresholds (<20dBHL), normal otoscopy and tympanometry had been established during their audiological investigations.

### **The make up of the non help seeking group**

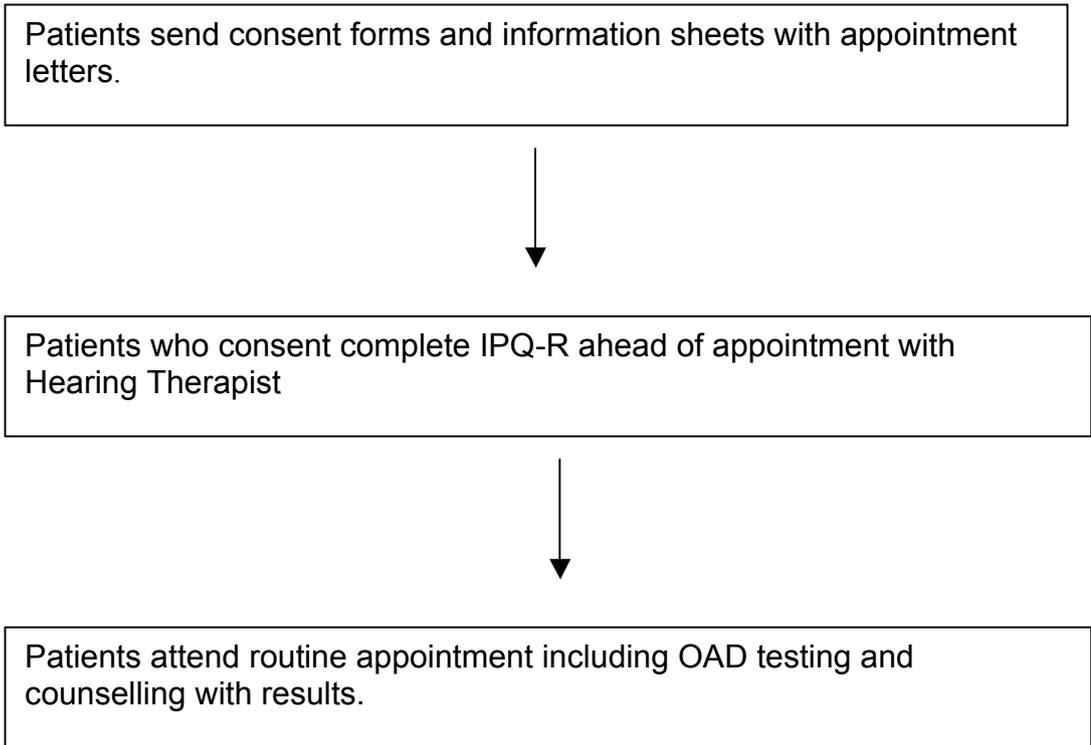
The non help seeking group were recruited from the staff and student population at Bath and North East Somerset Primary Care Trust, the Universities of Bristol and Bath and from advertisement at the University of Bristol. Students in large groups (law lectures, physiology lectures, audiology lectures, psychology lectures and geography lectures) were asked to complete a screening questionnaire, which asked whether they had any hearing difficulties in noise, and to supply an email contact. Staff from Bath and North East Somerset Primary Care Trust were invited to participate by email advertisement and paper posters.

All those who responded identifying that they did have periodic difficulties were approached to consent to participate in the study via a follow up email with a direct request. Those who responded to the email were approached for an appointment.

## Flow chart to illustrate data gathering procedure for non help-seekers



**Flow chart to illustrate data gathering procedures for help-seekers**



The backgrounds of the two groups (help-seekers and non help-seekers) are presented in Table 2. The non help-seeker group was skewed in terms of age. The overwhelming proportion of women to men was consistent between both groups and was considered to reflect the clinical population. As the groups were recruited sequentially, case-control matching was not employed but rather accounted for by controlling for age and sex throughout.

The make up of both groups in terms of occupation was recorded. Here the employed group include both full and part-time workers, and thus includes some of the student population who also work.

**Table 2: Comparison of demographic factors between the help-seekers and non help-seekers**

|                        | <b>Help-seekers<br/>(n=47)</b> | <b>Non help-seekers<br/>(n=53)</b> | <b>P</b> |
|------------------------|--------------------------------|------------------------------------|----------|
| Median age (IQR) years | 37(28,43)                      | 30 (20.5,45.5)                     | .061     |
| Female                 | 31 (66% )                      | 44(83% )                           | 0.049    |
| Employed               | 34(72% )                       | 31(58% )                           | 0.15     |
| Full-time education    | 7(15%)                         | 30 (57%)                           | <0.001   |

| <b>Education</b> | <b>N=41</b> | <b>N=53</b> |       |
|------------------|-------------|-------------|-------|
| Has A'levels     | 75.6% (31)  | 83% (44)    | 0.046 |
| Has degree       | 36.6% (15)  | 41.6% (20)  | 0.668 |

### **Educational level**

Given the different populations from which the samples were drawn the educational level of participants was examined. Data were available for 94 of the 100 participants (53 non help-seekers and 41 help-seekers). Data were

missing from clinical case notes of the remaining six help-seekers. There was found to be significant variation between the groups with regard to further education to A' level ( $p = 0.046$ ) but not to degree level education ( $p = 0.668$ ) (this is not surprising given the student population involved). Therefore, A' level education was introduced as a covariate in all analyses along with age and gender. However, as this reduced the overall sample size the multi-variable analysis was conducted with missing variables coded as 'no A' levels' and with missing variables excluded. The inclusion of missing data revealed no significant changes in the odds presented and therefore the adjusted odds can be attributed to the inclusion of A' level (e.g. educational status) as a covariate, rather than to the reduced sample size.

### **Procedure for the non help seeking group**

Non help-seekers were sent information sheets and consent forms to complete. After participants had consented, an appointment was made to meet for up to two hours with the author/researcher. These participants were seen either at St Martin's hospital using the same room and testing equipment as the patient group or at the clinical test rooms used by the University of Bristol audiology services. All equipment in both locations was calibrated prior to the start of the study and after the first year. Appointments were offered to suit each individual and included evening and weekend appointments.

The non help seeking group were assessed with otoscopy and audiometry to check for measurable hearing impairment and the presence of wax or ear infections. Where a hearing loss was detected, the participant was given advice about the extent of the hearing loss, possible consequences on speech perception and advice about the route to help seeking. No unilateral losses or other sinister pathologies were detected at this stage. Those who presented with a hearing loss were not taken forward into the rest of the testing and did not complete the IPQ-R questionnaire.

## Measures

- a. The screening questionnaire. (Appendix II)
- b. The Illness Perceptions Questionnaire (revised) (Moss-Morris, Weinman, Petrie, Horne, Cameron and Buick, 2002). (Appendix III)
- c. IHR Nottingham Test package (which assesses psychoacoustic, cognitive performance and patient estimation of performance) (Appendix IV)

### **The screening questionnaire**

This questionnaire consisted of one side of A4 with a brief set of questions about degree of hearing difficulties experienced. Attached was a separate sheet for name and email address and phone number.

The listening difficulties questionnaire is attached as appendix II. It was derived from the work of Max Dutson, Nicola Morgan and Josie Higson from the MRC Institute of Hearing Research (Stephenson, Higson, Haggard, Dutson, Rogers and Schilder, 1997). Higson had used this measure to recruit a student population to investigate acoustic reflexes in KKS patients and student controls (Morgan, 1992).

### **The Illness Perceptions Questionnaire (revised) (IPQ-R)**

This measure is used to identify participant beliefs about the identity, cause, timeline, cure, controllability and consequences of their illness (or in this case, hearing difficulties). It was developed to provide a quantitative measurement of these five components of Leventhal's self-regulatory model (Leventhal et al. 1984; Moss-Morris et al., 2002). Different methodologies have been used over time to explore the self-regulatory model of illness perceptions. Leventhal et al. (1984) originally used semi-structured interviews to explore patients representations in detail and other researchers used questionnaire measures (e.g. Lacroix, 1991) but no others were theoretically derived or evaluated with more than one type of patient group (Weinman, Petrie, Moss-Morris and Horne, 1996). The measure has previously been applied to patient groups with heart disease (Cooper et al.,

1999), rheumatoid arthritis (Murphy et al., 1999), cancer (Buick, 1997), psoriasis (Fortune et al., 2000), chronic fatigue syndrome (Heijmans, 1998), diabetes (Griva et al., 2000) and Addisons disease (Heijmans, 1999).

### **Reliability**

Data collected from myocardial infarction (MI) and renal samples suggests that IPQ scales have good levels of internal consistency and test-retest reliability.

(The Cronbach Alpha score:- 'identity' = .82, 'timeline' = .73, 'consequences'=.82 and 'control/cure' = .73) (Weinman et al., 1996)

Further assessment of the revisions made to the IPQ measure demonstrated Cronbach alpha's ranging from .79 for timeline-cyclical dimension to .89 for timeline –acute/chronic dimension (Moss-Morris et al., 2002).

### **Concurrent validity**

This has been assessed by examining MI responses to this measure, to the Sickness Impact Profile and to doctor visits (Bergner, Bobbit, Carter and Gilson, 1981). This demonstrated that the identity scale was positively related to disability. The 'timeline' scores were negatively correlated with perceived control over heart disease and self-rated health (Moss-Morris et al., 2002). The scores on the 'consequences' scale were positively related to ratings of health distress, disability and doctor visits. From samples with asthma the 'cure-control' scale was compared with an asthma specific version of the Multidimensional Health Locus of Control scale (Wallston, Wallston and DeVellis, 1978; Weinman et al, 1996).

### **Discriminant validity**

IPQ profiles were compared from patients with different health conditions to establish the extent to which the measure could discriminate between different illnesses (in this case, rheumatoid arthritis, chronic fatigue and chronic idiopathic pain). These revealed differences such as higher 'identity',

belief in serious consequences and 'timeline' scores amongst patients with chronic fatigue than chronic pain. Rheumatoid arthritis patients had stronger illness identity and timeline scores than those with chronic pain and patients with diabetes (Weinman et al., 1996).

Results suggest that the IPQ measure was able to distinguish between patient groups even when the central symptoms was similar (e.g. chronic pain and rheumatoid arthritis) (Weinman et al., 1996).

Subsequent assessment of the IPQ with the Positive and Negative Affect Schedule (PANAS) (Moss-Morris et al., 2002) identified that whilst there was some association between negative affect and strong illness identity, chronic and cyclical timeline, beliefs in serious consequences and psychological, risk factor and immune attributions, personal control and treatment control beliefs were unrelated to negative affect.

### **Predictive validity**

Myocardial Infarction (MI) patients completed the IPQ in hospital with subsequent follow up at three and six months. This revealed 'timeline' scale to be significantly related to both three and six month ratings of the likelihood of further MI. The 'cure control' scales were significantly related to patients three and six month ratings of control over their heart problem and were negatively related to perceived likelihood of future MI at both time points. (Weinman et al., 1996).

The original IPQ was designed to measure the cognitive components of patients' illness representations and had overlooked the emotional representations component of the Leventhal model (1984). In addition it was proposed that the measure should be revised to improve internal consistency by increasing the number of items and developing new items to assess cyclical timeline beliefs (Moss-Morris et al., 2002). The importance of assessing emotional representations is that Leventhal's model proposes that people develop cognitive and emotional representations to health threats, which directly lead to problem-focussed and emotion focussed coping strategies respectively. Care was taken in the revision process to ensure that emotional representations should measure the emotional responses

generated by the illness and not general mood. The revision process also enabled the measure to be assessed as a tool of internal coherence of the patient beliefs about their illness.

The questionnaire is worded with the word 'illness' throughout so that individual groups may change the word for the name of the condition under investigation. The phrase 'hearing difficulties' was chosen as being sufficiently neutral to avoid pre-judging mechanisms or degree of restriction in function or activity and this phrase was substituted for 'illness' throughout.

The current form of the revised illness perceptions questionnaire as used in this study (Appendix III) is as follows: -

1. A scale to measure hearing difficulties 'identity' consisting of nine common 'symptoms' of hearing difficulty coupled with the statement 'I have experienced this' and a yes/no response and 'This is related to my hearing difficulties' and Yes/No response. The items consist of seven specifically hearing related symptoms and two general symptoms. The seven hearing related symptoms are 'cannot hear tv', 'cannot hear speech one to one', 'cannot hear speech in a crowded room', 'cannot hear doorbell', 'find everyday sounds uncomfortably loud', 'cannot hear speech on the telephone' and 'experience ringing or buzzing noises in my ears or head'. The two general symptoms items are 'cannot socialise as I would like' and 'experience headaches'. The sum of the symptoms scored as related to the hearing difficulties forms the illness identity subscale.
2. The second part of the questionnaire consists of a series of statements relating to the hearing difficulties and a five point Likert scale. These items assess identity, consequences, timeline- acute/chronic, timeline-cyclical, coherence and emotional representations. These items are presented in mixed order. They are reverse scored and calculating the mean score derives a total score for each component.

3. The causal dimension is presented as a separate section with a series of 18 causes presented and a five point Likert scale to rate them. These items had been generated from illness specific studies using the IPQ (Moss-Morris et al., 2002; Petrie et al., 1996; Pimm and Weinman, 1998) and are not specific to hearing or communication related symptoms for example, 'stress or worry', 'a germ or virus', 'chance or bad luck', 'poor medical care in my past' etc

The IPQ-R has been widely used to assess patients' representations of their illness. It has not, up to now, been used to assess symptoms based on communication or hearing difficulties. However, there was no reason to suppose that the measure could not be used to assess emotional representations and beliefs about hearing symptoms and the measure could capture some of the beliefs held by patients with medically unexplained hearing symptoms.

### **The Nottingham Institute of Hearing Research (IHR) OAD test battery**

This test battery was derived from a series of experimental studies, conducted between 1989 and 1992, to determine factors that contribute to patients presenting with symptoms of hearing difficulty. The test battery is, at time of writing, the only available 'off the shelf' package designed to assess the auditory profile of this patient group and is still available for sale through the IHR. The test battery was derived from a series of studies designed to identify factors that differentiate patients from matched controls (Saunders, Field and Haggard 1992). The four variables that best differentiated patients from controls were: -

- Pseudo free-field speech in noise test.
- The discrepancy between the actual measurement of hearing ability and the subjectively assessed outcome.
- Poor masked thresholds in notched noise.
- Poor performance in dichotic listening.

These four tests classified 80% patients and 90% controls correctly. Versions of the four tests were compiled into a test package along with a structured

interview (Saunders, Field and Haggard, 1992). The test package included detailed protocols for the presentation of tests, an adaptor box to allow the tests to run from a standard clinical audiometer and cassette or cd player, recommendations for counselling and management in relation to the patient profile from the tests.

Further investigation in 1994 attempted to replicate the classification of a further control and patient group to confirm that the tests were fulfilling their clinical purpose of providing a specific combination of diagnostic information for OAD patients (Higson, Haggard and Field, 1994). Here tests were carried out on a further sample of 59 patient participants and 64 matched control participants. The study replication of the previous findings confirmed the validity of the authors three factor model and the robustness of the test package in discriminating between patient and control participants.

The test battery was sold to approximately seventy NHS departments (IHR, personal communication) although it is not known how regularly it is actually used.

The test battery is employed in this context for both patient (help-seeker) and control (non help-seeker) groups to establish an auditory performance profile on speech in noise and to provide some diagnostic information about peripheral and central auditory factors that are apparent in each group. This will provide a measure of functional ability with which to interpret illness beliefs held. In addition the final part of the questionnaire allows for an exploratory analysis of the beliefs that are held by both help seeking and non help seeking groups about hearing difficulties.

## Statistical analysis

The groups of help-seekers and non help-seekers were compared with respect to their audiological profiles and patterns of illness perceptions held. The help-seeking status was the dependent variable and illness perceptions and audiological profile were the independent variables. Firstly, the odds of each variable being associated with help seeking were calculated (controlling for age, sex and educational level). Secondly, multivariate logistic regression analysis was used to indicate the relative importance of the different independent factors in determining help seeking status. Finally, the principal components of the causal attributions section of the IPQ-R were analysed through principal components analysis to identify clusters of beliefs about causal attribution that were held. SPSS version 14 was used for the analysis and regression analysis was conducted controlling for age, educational level and gender throughout.

## Findings: Clinical factors – The results from the IHR OAD test battery

The factors considered here are the diagnostic variables from the test battery defined as 'normal' or 'not normal' in keeping with the recommendations of the test.

- Speech in noise (BKB sentences in noise) – a measure of functional performance
- Discrepancy between subjective and objective thresholds on speech in noise test
- Dichotic listening test
- Masked thresholds

The proportions of help-seekers and non help-seekers who scored 'not normal' in each test are presented in table 3.

**Speech in noise** was significant in determining whether or not someone would seek help with his or her hearing difficulty. Chi-square testing suggest the differences between the help seeking and non help seeking groups are statistically significant ( $p < 0.001$ ). The odds of 'not normal' speech in noise being associated with help-seeking are presented in table 4. The status of 'not normal' in hearing speech in noise was significantly associated with help-seeking status. ( $P < 0.001$ , OR 7.3, CI 2.995 -17.564). When controlled for age, sex and education to A' level this increased ( $P < 0.001$ , OR 12.8, CI 4.18-39.24). This is interesting as all participants here report some difficulties hearing speech in noise at the outset, yet the odds of being a help-seeker are significantly increased in those with 'performance deficit' (Saunders and Haggard, 1989).

**The discrepancy between self-rated and actual performance** on speech in noise was not significantly associated with help seeking, ( $P = 0.1$ , OR 2.12 CI 0.859-5.24 controlling for age, sex and A' level status). So the chances of an individual accurately gauging their own hearing ability on the test can be seen to be similar between the two groups.

**Dichotic listening test** was significantly associated with help seeking. Help-seekers have ten times the odds of a ‘not normal’ result compared to non help-seekers. This test result is affected by both peripheral and central auditory difficulties. It is combined with the masked threshold result to differentiate between peripheral and central problems. Therefore the result may reflect the association with help-seeking in the speech in noise and masked threshold tests.

**Masked threshold** initially appeared strongly associated with help seeking with 32 of the 47 participants scored as ‘not normal’ (p 0.027). This suggests that a peripheral factor (i.e. early cochlea changes) could contribute to the hearing difficulties. This result became more pronounced with the inclusion of age, sex and A’ level status as covariates. Those with a not normal result were three times as likely to be help-seekers (p=0.019).

**Table 3: Help-seekers and non help-seekers with ‘not normal’ classification on OAD test battery.**

| <b>Test result</b> | <b>Number of help-seekers with ‘not normal’ result<br/>N=47</b> | <b>Number of non help-seekers with ‘not normal’ result<br/>N=53</b> | <b>P</b> |
|--------------------|---|---|----------|
| Speech in noise    | 33 (70%)  | 13 (25%)  | <0.001   |
| Discrepancy        | 22 (47%)  | 16 (30%)  | 0.102    |
| Dichotic listening | 14 (29%)  | 4 (7%)  | 0.004    |
| Masked threshold   | 32 (68%)  | 24 (45%)  | 0.027    |

**Table 4: Odds ratio\* (95% CI) of having a ‘not normal’ clinical test result for help-seekers versus non help-seekers**

| <b>Clinical test Factor</b> | <b>Odds ratio [95% CI]</b> | <b>P</b> | <b>Adjusted for age, A' level and sex odds ratio [95%CI]</b> | <b>P</b> |
|-----------------------------|----------------------------|----------|--|----------|
| Speech in noise             | 7.253<br>[2.995-17.564]    | <0.001   | 12.8<br>[4.18-39.24]   | <0.001   |
| Discrepancy                 | 2.035<br>[0.896-4.62]      | 0.89     | 2.12<br>[0.859-5.24]   | 0.103    |
| Dichotic listening test     | 5.197<br>[1.572-17.18]     | 0.007    | 10.277<br>[2.624-40.255]                                     | 0.001    |
| Masked threshold            | 2.578<br>[1.138-5.84]      | 0.023    | 3.115<br>[1.2 -8.08]   | 0.019    |

### **The diagnostic category**

The diagnostic category given by the test battery is derived from the combination of test results i.e. poor scores in both speech in noise and either dichotic listening and /or masked thresholds. Such categories could then be either peripheral i.e. evidence of early cochlea changes, central i.e. poor central auditory processing or psychological (categorised as a large discrepancy between actual and perceived performance). Table 4 summarises the results, which suggest that the peripheral category was associated with help-seeking status (with two times the odds). Interestingly the central category is negatively associated with help-seeking. This reflects the significant masked threshold results and confirms that the help-seekers were more likely to have difficulties that were attributable to peripheral auditory function and less likely to have difficulties that were attributable to

central auditory function. This supports the work of Zhao and Stephens (2000) that early peripheral factors may be associated with KKS.

**Table 5: Odds ratio\* (95% CI) of a particular clinical diagnosis for help-seekers versus non help-seekers (NB. Individual participants can be included in more than one category)**

| <b>Diagnostic category</b> | <b>Number of help seekers (n=47) with 'not normal' diagnosis</b> | <b>Number of non help seekers (n=53) with 'not normal' diagnosis</b> | <b>Adjusted for age, sex and A' levels odds ratio</b> | <b>P</b> |
|----------------------------|--|--|---|----------|
| Peripheral                 | 28 (60%)   | 23 (43%)   | 2.736 [1.088-6.88]                                    | 0.03     |
| Central                    | 13 (28%)   | 23 (43%)   | 0.332 [0.118-0.938]                                   | 0.04     |
| Psychological              | 24 (51%)   | 28 (53%)   | 0.82 [0.34-1.98]                                      | 0.66     |

The help-seekers did demonstrate greater odds of a not normal result on the OAD test battery. This supports the notion that there are audiological factors involved the presentation of KKS. However, these factors appear to reflect peripheral auditory factors rather than central auditory factors.

## **Findings: Psychological factors: the role of illness perceptions**

Study two enabled a comparison of illness perceptions held by 'patients' who have sought clinical help for hearing difficulties and non help seeking volunteers who also experience hearing difficulties.

### **Illness perceptions**

Illness perceptions were compared in help- seekers versus non help- seekers. Table 6 summarises the results. The independent t test comparison of means identifies some significant differences between help-seekers and non help-seekers. The emotional representations are scored significantly more highly by help-seekers ( $t(97) = 2.76, p = 0.01$ ). Likewise, illness coherence ( $t(97) = 2.47, p = 0.02$ ) and consequences ( $t(79) = 4.7, p < 0.001$ ) are significantly higher for the help seekers.

The odds ratios for holding salient beliefs about hearing difficulties were calculated. Table 7 illustrates the illness perceptions odds calculated individually, individually controlling for age, sex and education (A' level status), and in multivariable model with the OAD test results. Allowing for group differences in age, sex and education, the illness perceptions recorded suggest that emotional representations are significantly associated with help-seeking with 1.2 times the odds ( $p = 0.01$ ). The perceived consequences of hearing difficulties were significantly associated with help seeking with 1.3 times the odds of being a help-seeker ( $p < 0.001$ ). Illness coherence is also highly associated with help-seeking with 1.2 times the odds of being a help-seeker ( $p = 0.01$ ).

**Table 6: Illness perceptions mean (SD) scores**

| <b>Illness perception</b>    | <b>Help-seekers<br/>Mean (SD)</b> | <b>Non help-<br/>seekers<br/>Mean (SD)</b> | <b>P</b> |
|------------------------------|-----------------------------------|--|----------|
| Identity                     | 4.9 (2.6)                         | 4.7 (3.1)                                  | 0.68     |
| Timeline                     | 18.3 (1.9)                        | 17.6 (1.6)                                 | 0.08     |
| Consequences                 | 15.8 (3.7)                        | 12.8 (2.7)                                 | <0.001   |
| Personal control             | 17.3 (2.3)                        | 17 (2.9)                                   | 0.7      |
| Treatment control            | 14.8 (1.3)                        | 14.4 (1.6)                                 | 0.15     |
| Illness coherence            | 16.4 (3)                          | 14.8 (3.4)                                 | 0.02     |
| Timeline cyclical            | 9.5 (4)                           | 10 (3.5)                                   | 0.47     |
| Emotional<br>representations | 14.8 (3.9)                        | 12.8 (3.3)                                 | 0.01     |

**Table 7: Odds ratio\* (95% CI) of holding beliefs about hearing difficulties for help-seekers versus non help-seekers**

| <b>Illness belief domain</b> | <b>Odds ratio [95% CI] (p)</b>  | <b>Odds ratio (adjusted for age, sex and A' level status) [95% CI] (p)</b> | <b>Multivariable model IPQ and OAD test variables Odds ratio (adjusted for age, sex and A' level) [95% CI] (p)</b> |
|------------------------------|---------------------------------|--|--|
| Illness identity             | 1.03<br>[0.898-1.18]<br>(0.68)  | 0.99<br>[.847-1.16]<br>(0.89)  | 0.9 [0.697-1.17]<br>(0.44)   |
| Timeline                     | 1.24<br>[0.97-1.57]<br>(0.08)   | 1.21<br>[.931-1.568]<br>(0.155)  | 0.9 [0.589-1.426]<br>(0.7)   |
| Consequences                 | 1.37<br>[1.17-1.58]<br>(<0.001) | 1.33<br>[1.12-1.58]<br>(0.001)   | 1.27 [0.987-1.634]<br>(0.06)   |
| Personal control             | 1.03<br>[0.88-1.21]<br>(0.68)   | 1.03<br>[.872-1.214]<br>(0.73)   | 1.087 [0.829-1.425]<br>(0.55)  |
| Treatment control            | 1.23<br>[0.923-1.66]<br>(0.16)  | 1.137<br>[.834-1.548]<br>(0.417)   | 0.739 [0.443-1.231]<br>(0.25)  |
| Illness coherence            | 1.168<br>[1.03-1.33]<br>(0.02)  | 1.22<br>[1.049-1.424]<br>(0.01)  | 1.268 [0.999-1.61]<br>(0.05)   |
| Time cycle                   | 0.96<br>[0.86-1.07]<br>(0.46)   | 0.934<br>[0.825-1.057]<br>(0.28)   | .795 [0.643-0.984]<br>(0.04)   |
| Emotional representations    | 1.17<br>[1.04-1.32]<br>(0.009)  | 1.19<br>[1.04-1.36]<br>(0.012)   | 1.253 [0.978-1.606]<br>(0.08)  |

### **Multivariate analysis**

In order to consider the relationship between these variables, it was important to consider the possible statistical inference that they hold over each other. Are emotional representations confounded by time factors for example? In addition, it was important to consider the relationship between clinical findings and illness beliefs i.e. do poor functional performances confound illness beliefs or vice versa?

Table 7 (column three) describes the odds of each illness perception predicting help-seeking when controlling for age, sex, A' level status and the audiological test results. The relatively small sample size is likely to reduce the power of the relationship between variables. Here time cycle is shown to be negatively associated with help-seeking and illness coherence is shown to be positively associated (with 1.3 times the odds,  $p=0.05$ ). Belief in consequences of hearing difficulties is now shown to be of borderline significance.

The scores for the audiological test battery are presented in table 8.

**Table 8: Associations between help seeking and auditory test results**

|                         | <b>Multivariable model including A' level status, age, sex and all listed independent variables simultaneously</b> |
|-------------------------|--|
| <b>IHR test battery</b> | <b>Odds ratio [95% CI] (p)</b>   |
| Speech in noise         | 13.665 [2.705 – 69.034] (0.02)   |
| Discrepancy             | 1.606 [0.451-5.724] (0.47)   |
| Dichotic test           | 4.598 [ 0.696-30.395] (0.11)   |
| Masked threshold        | 0.895 [ 0.203-3.95] (0.88)   |

(NB. Odds of one point change on IP scales and deficit vs. normal on IHR battery)

Speech in noise is shown to be highly associated with help seeking (OR 13.7, CI 2.7-69, P=0.02) but the other speech tests are no longer significantly associated with help-seeking in the multivariable analysis.

In comparing audiological test results and illness perceptions the factor that is most positively associated with help-seeking is speech in noise which as a binary categorical variable each change in categorisation to 'not normal' gave a step size of 2.6 and 13.7 times the odds of being a help-seeker. The illness perceptions are numeric variables and the odds relate to a one point change in illness perception score. Illness coherence (i.e. the extent to which different signs are regarded as part of a coherent symptom set) is seen to be significantly associated with help seeking. Furthermore the beliefs around consequences of hearing difficulties and the emotional representation of the hearing difficulties were of borderline significance. The time cycle beliefs were found to have a negative relationship with help-seeking i.e. they are significantly less associated with help-seeking status (p=0.04).

This finding is echoed in the revision work to the measure undertaken by Moss-Morris (2002) who identified that cyclical timeline beliefs were negatively associated with illness coherence and positively correlated with

emotional representations. In this case, it may illustrate those participants who describe their hearing problems as less consistent have a less coherent sense of the hearing difficulties. They may also be less likely to seek help for them as they do not regard periodic difficulties hearing as part of an overall hearing problem. Conversely, individuals with greater sense of illness coherence are more likely to have emotional responses to the difficulties and to view them as a cogent symptom set. This cogent symptom set is associated with help seeking.

### **Multivariate analysis of diagnostic category and illness perceptions**

Repeating the analysis with diagnostic category and illness perceptions also reveals that illness beliefs are associated with help seeking (Table 9). Comparing illness beliefs and diagnostic category (i.e. the combined tests indicate this is the basis for the symptoms), beliefs about consequences of hearing difficulties in particular are associated with help-seeking status (OR 1.274, CI 1.029-1.578, P=0.026). In addition the 'central' diagnosis arising from a combination of poor performance in dichotic listening and speech in noise is significantly *negatively* associated with help seeking (OR 0.21, CI 0.046-0.962, P=0.04). This suggests that the illness perceptions held were associated with help-seeking but the diagnostic categories 'peripheral' and 'psychological' did not distinguish between help-seekers and non help-seekers. In other words, non help-seekers were as likely to be allocated one of these diagnostic categories. In addition, this reveals that non help-seekers were actually more likely to be classified with a 'central' diagnosis.

**Table 9: Multi-variable model of illness perceptions and diagnostic categorisation, adjusted for A' levels, age and sex**

| <b>Illness perception</b>  | <b>OR [CI]</b>       | <b>P</b> |
|----------------------------|----------------------|----------|
| Identity                   | 0.994 [.795-1.243]   | 0.96     |
| Timeline                   | 0.1.027 [.718-1.469] | 0.91     |
| Consequences               | 1.274 [1.029-1.578]  | 0.03     |
| Personal control           | 1.043 [.841-1.295]   | 0.7      |
| Treatment control          | 0.97 [0.639-1.474]   | 0.89     |
| Illness coherence          | 1.203 [0.991-1.462]  | 0.06     |
| Time cycle                 | 0.89 [0.74-1.06]     | 0.18     |
| Emotional representations  | 1.164 [ 0.967 – 1.4] | 0.11     |
| <b>Diagnostic category</b> |                      |          |
| Peripheral                 | 2.709 [0.818-8.969]  | 0.1      |
| Central                    | 0.210 [0.046-0.962]  | 0.04     |
| Psychological              | 0.904 [ 0.277-2.953] | 0.87     |

This study provides evidence for the role of illness perceptions, in particular the illness coherence and belief that consequences of not hearing are significant in determining whether an individual will seek clinical help with their hearing.

Study two enables a further examination of beliefs about the causes of hearing difficulties through the final section of the IPQ-R instrument.

### **Beliefs about causes of hearing difficulties**

Here participants rated a standardised series of items as relevant to their hearing difficulty (see IPQ-R section 3, Appendix III). The statements are reverse scored. Patterns of converging causes are then examined through principal component analysis. Principal component analysis is a way of examining variables by considering components of each that form a pattern.

Moss-Morris et al. (2002) grouped the belief variables as follows: -

- Beliefs about psychological attributions: -

Stress, mental attitude, family problems, overwork, emotional state and personality.

- Beliefs about risk factors: -

Hereditary, diet, poor medical care, my own behaviour, ageing, smoking, and alcohol

- Beliefs about immunity: -

Germ or virus, pollution and altered immunity

- Beliefs about accidents or chance:-

Chance or bad luck, accident or injury.

The principal components analysis aims to establish which linear components exist within the data and how a particular variable might contribute to that component. To improve interpretability, oblique rotation was applied to allow factors to be correlated.

The pattern matrix identifies four components that explain the variance in these data. The predominant factor appears to reflect beliefs in immunity (germ, altered immunity and pollution) and risk factors (hereditary, poor diet, poor medical care). This first component explains 33.8% of the variance in the data. Interestingly component two lists psychological attributions but is negatively associated. In other words, belief in psychological attributions is not considered a cause of hearing difficulties. Component two explains 10.6% of the variance in the data.

Factor three relates to chance and factor four to risk factors e.g. alcohol, smoking, ageing and, interestingly personality. It seems that personality is interpreted as a risk factor rather than a psychological attribution. Possibly this reflects a belief that personality is a state that the individual does not have direct control over. Component three is responsible for 9% of the variance in the data and component four for 6%. Approximately 60% of the variance in the data is explained by these four components.

The pattern matrix summarises the loadings of each variable on each of the four components. The factors were rotated with oblimin rotation which converged in 21 iterations.

**Table 10 : Pattern matrix**

| <b>Variable</b>       | <b>Component 1</b> | <b>Component 2</b> | <b>Component 3</b> | <b>Component 4</b> |
|-----------------------|--------------------|--------------------|--------------------|--------------------|
| Germ or virus         | .704               |                    |                    |                    |
| Altered immunity      | .682               |                    |                    |                    |
| pollution             | .650               |                    |                    |                    |
| Chance or bad luck    | .595               |                    | .414               |                    |
| Own behaviour         | .542               |                    |                    |                    |
| Diet or eating habits | .521               | -.416              |                    |                    |
| Hereditary            | .485               |                    |                    |                    |
| Emotional state       |                    | -.921              |                    |                    |
| Stress or worry       |                    | -.886              |                    |                    |
| Overwork              |                    | -.799              |                    |                    |
| Family problems       |                    | -.796              |                    |                    |
| Mental attitude       |                    | -.588              |                    |                    |
| Smoking               |                    |                    | -.850              |                    |
| Alcohol               |                    |                    | -.567              | .425               |
| personality           |                    | -.410              |                    | .662               |
| Ageing                |                    |                    |                    | .618               |
| Accident or injury    | .413               |                    |                    | .491               |

This analysis identifies which of these causal beliefs are particularly important to those with medically unexplained hearing difficulties. The beliefs that seem most salient are clustered around what Moss-Morris (2002) refers to as 'immunity and risk factors'. The components are grouping variables i.e.

explaining variance in causes responsible for hearing difficulties. So for the whole group the causes of hearing difficulties are primarily considered to be external causes including risk factors along with immunity and accident (Moss-Morris, 2002) i.e. 'hereditary', 'germ or virus', 'diet or eating habits', 'chance or bad luck', 'poor medical care' and 'pollution'.

As PCA is only recommended for this section of the IPQ-R where  $n=85$  these whole group results are likely to give the best overall depiction of patterns of beliefs that may exist overall. To check further for difference between the groups, an independent samples t test was conducted on the mean scores from each component. This revealed no significant differences in mean scores on the principal components ( $p 0.081$ ).

These findings may reflect the lay perception that an external cause is most likely responsible for a perception of hearing difficulties. Conversely psychological attributions were a significant factor to be negatively regarded as likely causal factors. This finding reflects the implicit values held about psychological versus physical causes for difficulties experienced and the risk that the sick role becomes invalid if the difficulties are attributed to psychological causes.

### **Illness coherence, Consequences and emotional representations**

These findings suggest that illness perceptions around the coherence of hearing difficulties, the consequences of hearing difficulties and the emotional representations of such difficulties are likely to be associated with help-seeking status. It also appears that the diagnostic category predicted by the test battery does not differentiate help-seekers from non help-seekers as successfully as the illness belief 'consequences'. This suggests that the internal representation held by the individual about the nature of the hearing symptoms are more likely to be associated with the decision to seek help with hearing than functional hearing performance. It is intuitively likely that people who have a more coherent sense of hearing difficulties as a problem and who attribute more significance to the consequences of not hearing may have stronger emotional representations of their hearing difficulties.

It is also intuitively likely that such people will seek clinical help. What is interesting here is that this set of perceptions may be more relevant than the audiological categorisation of the individual in determining whether someone will seek help and thus assume the sick role of the KKS/APD 'patient'. However, the attributions section of the questionnaire suggests that psychological attributions are less likely to be considered valid as causes for hearing difficulties.

### **Multivariate model**

A model of the process of help seeking for KKS requires *both* poor performances on speech in noise testing and negative beliefs about the consequences of hearing difficulties.

This supports the Zhao and Stephens (2000) model of KKS as a multi-factorial experience. However, there is one important distinction. This evidence suggests that it is the presence of both psychological *and* peripheral factors together (rather than either psychological or otological) that distinguish patients from others who experience similar hearing.

### **Limitations to the evidence from the study of illness perceptions**

The illness perceptions study is an observational approach to investigating the relationships between pre-defined factors and help seeking. As such it can only provide a snap shot of one particular sample. Crucially it cannot explain the nature of the relationship between variables, merely describe where one exists. We cannot know how it is that help-seekers may differ in auditory profile or illness perception. We can simply identify that particular illness perceptions occur in help-seekers and speculate about the relevance of such psychological factors.

### **Sample limitations**

There is a trade off in this analysis between adjusting for any bias as a result of differences between the help-seeking and non help-seeking sample and the loss of power resulting from attrition in the help-seeking sample and the

increased number of factors in the multivariable model. It is possible that detection of significant illness perceptions and audiological factors was underpowered in this analysis. During the analysis, educational background was identified as a possible confounding variable. Therefore A' level status was retrospectively added to the data set. Unfortunately it was not possible to trace this variable for six help-seekers so there was attrition in the data set overall. Therefore, all adjusted odds ratios reflect a smaller, and less powerful, sample.

The representation of the sample is also questionable, both patient and non help-seeking samples were chosen from convenient accessible populations i.e. the clinic population from Hearing Therapy in BANES and the staff and student population at BANES and the Universities of Bath and Bristol. The non help seeking group are particularly highly educated and are likely to be successful, able communicators. They may, therefore, have fundamentally different experience in communication to those described by patients. The help seeking sample population in Bath were also highly educated. As this was the first study of this kind to examine illness perceptions with this population the convenience sample may be reasonable but future work should extend the sample involved.

This research has not considered psychological factors in depth. Levels of anxiety and depression were not recorded in the samples. It is possible that there are psychological differences between the help-seeking and non help-seeking groups that explain the illness perceptions held. Having identified that there appears to be a distinction between help-seekers and non help-seekers, in that help-seekers attribute serious consequences to hearing difficulties, there is now scope to examine whether the illness perceptions patterns are associated with somatisation and levels of anxiety and depression.

In addition the research has not investigated the possibility of neuropsychological deficits as factors that could contribute to the experience of perceived hearing difficulties.

A number of possibilities exist: -

- The help-seeking group also experience higher levels of psychological distress associated with somatisation and that their illness beliefs are part of a tendency to regard health symptoms as more significant in general. This may have consequences for the audiological care offered by clinicians who should address these psychological needs and make appropriate referrals to other agencies.
- Help-seekers do not experience higher levels of psychological distress but simply hold a set of beliefs and values about health and hearing difficulties which include that not hearing has serious consequences. This informs clinicians that the patient's beliefs are a core part of their experience and should therefore be addressed in clinic.
- Their functional performance leads to more frequent communication breakdown and because it is a more frequent experience, they consider consequences to be greater.
- These findings are a chance effect. A larger scale study into illness perceptions and help-seeking in KKS would be recommended.

## **Chapter six – Conclusions**

‘Men are disturbed not by things but by the view they take of them’ Epictetus  
(The Enchiridion, 135AD)

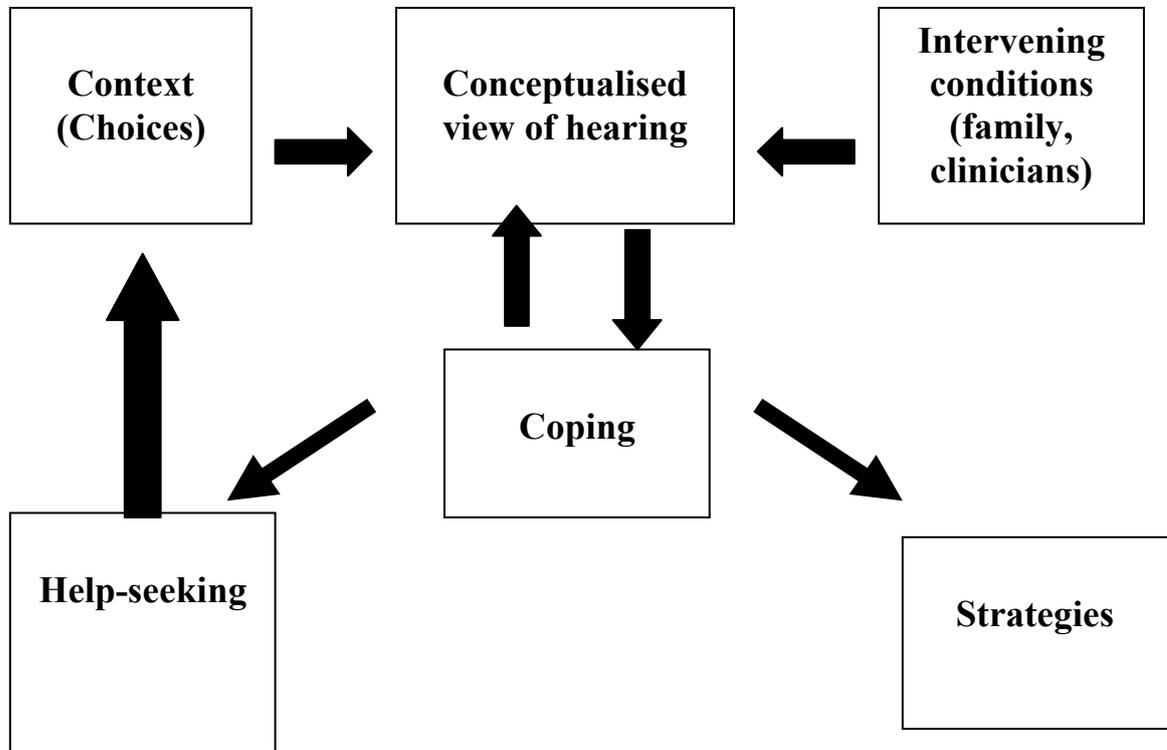
This thesis aimed to address a question about the nature of KKS. Why do some people present for help when their hearing thresholds are, audiologically speaking, normal? The original aims of the work were: -

1. To learn more about how KKS patients cope.
2. To learn how patients experience the clinical encounter with audiology professionals.
3. To learn more about the role of patient beliefs about illness in informing their decision to seek help with hearing difficulties.

### **How KKS patients perceive themselves to cope**

There is new evidence about the process of coping gained from the qualitative study conducted here. As with all qualitative work it is not intended to provide an objective, generalisable truth about the process of coping; but rather to shed new light on the topic and identify a new theory about the way coping is mediated. The process of coping is informed by many factors. The key factor that participants repeatedly discussed was the formation of a coherent internal concept of their hearing ability. This was coded as ‘knowing there’s something’. This process is interesting as conventional explanations for hearing difficulties (e.g. the presence of a hearing impairment) could not be used to explain the symptoms that the participants experienced. The process of coping is illustrated in figure 1. This highlights the relationship between intervening and contextual conditions, including social and clinical relationships in forming an overall coherent concept for the hearing difficulties, which was crucial in determining a coping strategy. The patient enters the model through coping with hearing difficulties.

**The process of coping in King-Kopetzky syndrome (Pryce,2006)**



This diagram illustrates and summarises how coping is mediated by the concepts that the participants held about their hearing. These concepts are formed as a result of the context in which they experience the hearing difficulties and the intervening conditions that affect their expectations of their hearing.

Coping behaviours led either to use of strategies to manage hearing difficulties and to help seeking. The role of the concept that participants develop about their hearing difficulties is to identify ways of managing them. Where participants report that they do not have an overall concept of a hearing disorder then it becomes harder to direct coping to the use of strategies. This qualitative evidence highlights the role for cognitions in coping and the decision to seek help as a coping strategy. This role was further illuminated through the observational study conducted into illness perceptions held by help-seekers and non help-seekers. This second study provides potentially generalisable evidence about the characteristics of the help-seeking population with KKS and identifies for the first time that psychological factors may differentiate the help seeking and non help seeking group. This finding is, of course, subject to possible confounding variables within the sample and should, therefore be replicated to ensure validity.

### **How patients experience the clinical encounter**

Qualitative descriptions suggest that patients experience the clinical encounter as positive or negative. The negative encounters revealed tension between conventional medicalised explanations of the symptoms including that there is nothing medically wrong. This finding is in keeping with the literature on medically unexplained symptoms. As Balint (1957, P.25) noted:-

‘ when a patient, after a series of careful and conscientious examinations, is told that nothing is wrong with him, doctors expect that he will feel relieved and even improve...in quite a number of cases just the opposite occurs.’

He suggests that such responses from clinicians raise a number of fears for the patient: -

- What has been found out is so frightening that the clinicians will not tell them.
- The clinicians have not found out and cannot tell them what is wrong.
- There is no opportunity to express fears and disappointments freely.

Current practice of reassuring people that there is no evidence of physical pathology for their symptoms can merely serve to raise other fears in the mind of the patient.

This sense of dismissal or invalidation has also been reported in relation to other medically unexplained syndromes, such as repetitive strain injury (RSI) where patient accounts include descriptions of not feeling believed due to the lack of visible signs to support the symptoms experienced (Reid, Ewan and Lowy, 1991). Likewise in chronic fatigue syndrome the concept of responsibility seems intertwined with the mental health diagnosis and that this in turn could be mis-interpreted by participants as accepting responsibility for the symptoms and thus blame for them (Heijmans, 1998).

In KKS there also seems to be a search for a legitimate explanation for the symptoms. One important aspect of the social construction of the 'sick role' is that it is implied to be a role that is beyond the individual's control by decision-making alone. In other words it is a legitimised state for which one is not directly responsible and one that is socially agreed to be undesirable. There is a perceived association between psychological illness or distress and lack of moral fortitude or weakness (Ferrari and Kwan, 2001). Thus there is a moral dimension to the patient's role described as feeling 'like a fraud' when medical signs cannot be readily identified as an explanation of symptoms experienced. Therefore, medically unexplained illnesses compromise the legitimacy of the 'sick role' as they imply ambiguity over psychological factors and by association, fault. The assumption appears to be that conclusive evidence of pathology is required to legitimate the patient's entry to the sick role and help seeking behaviour.

The responses to simple reassurances from clinicians suggest that it is not the removal of symptoms only that is the prime motivator for help seeking.

Rather help seeking is an attempt to both validate illness claims and to gain information. When participants are able to reconcile information gained with the symptoms they report reduced distress and a better sense of control over choice of coping behaviour. This evidence raises a new hypothesis; that KKS should be regarded as a medically unexplained condition with more in common with other such conditions (repetitive strain injury, fibromyalgia, chronic fatigue) and less with other hearing disorders. It shares the complex combination of biological and psychological underpinnings. It challenges the scripts adopted by clinicians (Epstein, Shields et al., 2006) that are geared towards the diagnosis of observable disorders. As a result the clinical encounter is vulnerable to communication breakdown with patients feeling invalidated in their search for a sick role. An important finding is that, contrary to what one might assume a reassurance that their hearing is not measurably impaired did not reduce distress. This seems to be because the participant needs to reconcile the presence of the symptoms with the information that they are given and a simple reassurance was perceived as a challenge to the validity of the symptoms. This echoes the documented experiences of those with repetitive strain injury (Reid, Ewan and Lowy, 1991), chronic fatigue syndrome (Dickson et al., 2007) and fibromyalgia (Hadler, 1996).

The process of conceptualising involves reconciling information gained with the symptoms experienced. The clinical implications of this are that participants are likely to employ strategies that reduce distress where they feel that the problems have been acknowledged and given some explanation.

The qualitative descriptions suggest that KKS patients cope by seeking help and by use of strategies to manage the hearing difficulties.

## **The nature of KKS/APD- the role of illness perceptions**

These findings contribute a new perspective about the nature of KKS. It suggests that psychosocial factors are an integral part of this clinical category. How does this fit with contemporary advice to audiologists?

The British Society of Audiology special interest group for APD states: -

1. That KKS is an older term for APD.
2. That the mechanisms in APD are primarily biological.

*‘Historically, APD was known by a variety of names e.g. Obscure Auditory Dysfunction, King Kopetsky (SIC) Syndrome, Central Auditory Processing Disorder....It is likely that APD will include a variety of different pathologies and abnormalities of auditory function.....’*

A further definition of the problem is as follows:-

*‘APD results from impaired neural function and is characterised by poor recognition, discrimination, separation, grouping, localisation or ordering of non-speech sounds. It does not solely result from a deficit in general attention, language or other cognitive processes.’ (BSA, 2007)*

This work challenges the assumption that APD and KKS are synonymous and the reliance on biological factors to explain help seeking is demonstrated to be inadequate.

The case definition is dependent on the individual deciding to seek help with hearing difficulties. The decision to seek help is informed by the illness perceptions held by the individual, in particular the perceived consequences and the coherence of the perceived symptoms.

The key finding of this study is that illness perceptions vary between those who seek help for these hearing difficulties and those who do not. The belief in serious consequences to hearing difficulties will better predict whether or not someone will seek help than any diagnostic audiology variable. This is the first time that this has been recorded. Given the nature of observational

research, this fuels hypotheses about the role of psychosocial factors rather than categorically answering questions about the nature of psychosocial factors in MUHD.

It is important that the definition of MUHD should reflect that it is a multi-faceted condition with psychosocial underpinnings as well as audiological features. Therefore the term 'Auditory Processing Disorder' could be deemed mis-leading as it implies that the hearing difficulties experienced are attributable to a 'disorder'. In fact this may not be a manifestation of a biologically based impairment at all but rather a decision to seek help influenced by decisions about hearing performance on the part of the individual or their immediate social network.

Given that those who do not seek help are equally likely to fall into diagnostic categories, the case definition cannot rely on these categories as a way of discriminating between those with KKS and those without.

### **King-Kopetzky Syndrome as a Medically Unexplained Hearing Difficulty**

The earlier literature review chapters have identified that all health symptoms occur in a social world and are influenced by social meanings. These shared social meanings have moral dimensions with higher values being placed on physical symptoms rather than psychological. It has also been identified that shared social meanings influence the individual appraisal of their health and inform how symptoms are interpreted. In some cases the individual psychological response is strong enough to influence physical states in the body (such as the placebo response). It is quite theoretically possible that MUHD is largely a manifestation of psychological needs or social expectations for some people. It is also possible that some people do have a biological difference in the way they hear speech in noise. This is not incompatible. What is absolutely clear is that psychosocial dimensions must be considered an inherent part of the perception of hearing difficulties in noise. The evidence from these two studies suggest that KKS can be considered a medically unexplained syndrome in the same way that chronic fatigue, fibromyalgia, pre-menstrual syndrome, sick building syndrome are. All these conditions may represent some biological differences. They certainly

represent psychosocial differences. The role of psychosocial factors appears to be two-fold. Firstly, that detection of symptoms of hearing difficulty is influenced by socially driven expectations of hearing performance. Secondly, the appraisal of those symptoms in coping (including the decision to seek clinical help) is influenced by individual beliefs. Cognitive models of psychology have long established that it is not the presence of difficulties per se but the way in which they are interpreted that determines whether or not someone will consider them as symptoms and seek help with them.

The evidence supplied by these two investigations supports the theoretical notion from the literature in illness perceptions and behaviours that people seek help with hearing difficulties for a variety of reasons. These may include biological changes but which, crucially, also include patterns of beliefs about hearing difficulties. Regardless of the mechanisms behind the actual difficulties experienced, it seems that the perceived consequences of hearing difficulties are a core factor in determining whether an individual will seek help with them. Thus, the BSA case definition above requires revision to include the role of psychosocial factors.

### **Coping in KKS**

So what is the role for audiologists in addressing these psychosocial factors? The coping study inductively develops the hypothesis that developing causal attributions for the hearing difficulties enhances coping. It seems that emotional distress can be reduced if people are able to understand what the hearing difficulties are and can receive some form of explanation for them. This explanation should integrate the clinical information available with an acknowledgement of the reality of the experience for the patient. Indeed, explanations alone have been found to be therapeutic even when they are in effect 'placebo explanations' (Goldacre, 2008). Thomas (1987) studied 200 patients in general practice that presented with medically unexplained or ambiguous symptoms. The patients were randomly allocated to 'positive' or 'negative' consultations. The positive consultations included a definite, clear diagnosis (a placebo explanation), the negative consultations consisted of the doctor telling the patient that they did not know what was wrong with

them. Both positive and negative consultations groups were divided into treatment and control arms. The treatment offered was a placebo and controls were offered no further treatment, but advised to come back if they needed to. After two weeks the patients were asked to rate their satisfaction with the encounter. The patients from the 'positive consultations' were significantly more satisfied with the encounter. In addition, 64% of them were also feeling better compared to 39% of the negative consultations. The same number of treated and control patients from the positive consultation had felt better. In other words the encounter alone was sufficient to bring the benefit of the placebo treatment. This highlights a frequently overlooked point. Consultation with the clinician alone is of tremendous potential benefit and 'healing' is brought about by a helpful and positive interaction. In this case a clear diagnosis from a positive sounding clinician.

It could be argued that in doing so the patient is really benefiting from the legitimised 'sick role' that such an explanation confers. Certainly when audiologists give such an explanation, people cope better with their difficulties. This is in keeping with the literature on coping as explored in chapter two. In particular, it reflects the work of Pennebaker (1980) in identifying the role of talking through problems in processing strategies to manage them. It also reflects fact that the patient often requires a name for their illness if they are to cope with it (Balint, 1957). However, directive information giving alone may not be adequate. Close examination of patient reports about what they valued from encounters with clinicians is the fact that they felt listened to as well. So it is important that the patient is able to fully describe their anxieties and concerns about their hearing difficulties. From the data gathered inductively in the coping study, it seemed that if this opportunity is denied to them, they do not feel reassured by clinician explanations but can interpret them as dismissive. This theory is also supported from the examination of the literature on doctor-patient communication, which highlighted the importance of the patient-centred approach in enabling a productive and satisfactory interaction between doctors and patients (Ong et al., 1995). Such an approach could in theory, increase the patient's sense of self-efficacy (Bandura, 1977) and in turn increase a sense of personal control over their symptoms, thus enabling

adaptive coping. This hypothesis requires empirical testing in a future study to establish whether audiology professionals should adapt current practices.

### **The role of the audiologist**

In the light of this evidence, what should the Hearing Therapist be concerned with in Mrs Smith's case? The hypotheses derived from the grounded theory data suggests that patients benefit most when audiologists assume a role beyond merely diagnosing the presence of hearing difficulties but attempt to engage with their patient in developing coping.

It seems that recognising the psychological needs of the patient to have a clear identity for their hearing difficulty and to be enabled to understand likely consequences of hearing difficulties could facilitate coping. Certainly the process of listening to the patient as well as advising and reassuring seems crucial. Audiologists do indeed have a responsibility to engage with the psychosocial dimensions of the patient's help-seeking behaviour. Therefore, the therapist should listen to Mrs Smith's concerns about her hearing in full and should provide a meaningful explanation. It may be that further audiological assessment aids this explanation, but the role of illness perceptions needs to be included. S/he could advise her that many people experience similar problems, and these problems tend to result from the way our bodies and minds work together. That once people know a bit more about the difficulties, they often find they manage them well. S/he can advise her about hearing tactics and work through the problems Mrs Smith describes in detail, allowing Mrs Smith to find her own solutions wherever possible.

### **'The opportunity cost' of the bio-medical approach**

'Opportunity cost' refers to cost to healthcare of missing an opportunity because of distraction by less productive activity (Goldacre, 2008).

The real danger with pursuing the idea of finding and diagnosing 'auditory processing disorders' is not only that it may be logically flawed as an approach (missing the role of social and psychological factors) but that it distracts clinicians and researchers from the work that could be taking place that would directly benefit patients. We need to quantify the extent of the

healing that might be done by an audiologist giving a clear explanation. We need to know what therapeutic options there are for people with medically unexplained hearing losses. Until we move our research agenda towards a bio-psychosocial framework and value the therapeutic human interaction as highly as the technical analysis we will miss an opportunity to learn more about what actually helps. We will distance ourselves from our patients. We will find these patients hard to work with. We will argue amongst ourselves about peripheral and central auditory factors. We will perpetuate the confusion about what the problems actually are.

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## Appendix I: Coding details

**Table one: example of open coding**

| Transcript 15   | Coding  |
|---|---|
| <p>I noticed it more so when we go out in company</p> <p>People would say things and I'd say 'pardon' and then it got worse. I work in a kitchen and if people were behind me and they spoke I would catch some of it but I wouldn't catch all of it</p> <p>.....</p> | <p>Context 'company'</p> <p>Strategy 'pardon' – repeat</p> <p>'It got worse' – prior to help-seeking</p> <p>Environment – kitchen</p> <p>Partial miss-hearing</p> |
| <p>So I went to the doctors and this must have been three years ago and she referred me and then I had my appointment this summer.....</p>  | <p>Help-seeking</p> <p>Wait</p>   |
| <p>I just thought that was me not paying attention, as you do, but I'm alright but I must look at people when they speak if they're behind me and they mumble, there's no chance.</p>   | <p>Interprets 'not paying attention'</p> <p>'I'm alright' – reduced distress</p> <p>strategy- lip-reading</p> <p>negative consequences without strategy</p>       |

(Pryce,2006)

## **Axial Coding**

The axial coding stage is the point where accounts are compared to organise the codes into a description of process. In addition the dimensions and properties of the codes are defined (Strauss and Corbin, 1998). The codes are linked into a paradigm, which outlines the factors that influence the process of coping. Thus the data is examined so that codes are linked into:-

Causal conditions > Phenomenon > Context > Intervening conditions >  
Action/interaction Strategies> Consequences

### **Causal conditions**

The conditions codes are those that refer to sets of events that influence phenomena. Causal conditions are those that pre-empt the phenomena (Strauss and Corbin, 1998). In this case it refers to the conditions that pre-empt an incidence of not hearing or communication breakdown.

### **Phenomenon**

The codes that refer to the phenomena are those describing the experience of not hearing, the evaluation of the hearing ability and the consequent coping actions.

## **Context**

These codes refer to the context within which the phenomenon occurs. In this case this refers to the social or psychological factors that determine how the phenomenon occurs.

## **Intervening conditions**

These are the factors that mitigate or otherwise impact causal conditions on the phenomena (Strauss and Corbin, 1998). For example, in this case the relationship held with the communicative partner might influence the experience of miss-hearing.

## **Action/interactional strategies**

This code category refers to strategic tactics to cope with the difficulties experienced. This refers to both emotion focussed and problem-focussed strategies.

## **Consequences**

The consequences codes are those that refer to the outcomes of the strategies that are unemployed.

The table below illustrates how this system was applied to the data in the present study.

**Table two:**

| <b>Causal conditions code</b> | <b>Properties</b> | <b>Dimensions</b>              |
|-------------------------------|-------------------|--------------------------------|
| Miss-hearing                  | Concentration     | From miss-hearing odd words to |
|                               | Attention         | not hearing any part           |
|                               | Hearing           |                                |

| <b>Phenomenon code</b> | <b>Properties</b> | <b>Dimensions</b>  |
|------------------------|-------------------|--|
| Coping                 | Strategies        | Proactive to reactive strategies   |
|                        | Help-seeking      | Seeking assessment and treatment to rejecting assessment and treatment                       |
|                        | Conceptualising   | Developing a coherent concept of the hearing situation to confusion about hearing situation. |

| <b>Context code</b> | <b>Properties</b>   | <b>Dimensions</b>                                |
|---------------------|---------------------|--|
| Situation changing  | Life stresses       | Prompt more or fewer changes in managing hearing |
| Environment         | Poses challenges to | Move to a more or less                           |

|  |         |                         |
|--|---------|-------------------------|
|  | hearing | challenging environment |
|--|---------|-------------------------|

| <b>Intervening conditions</b> | <b>Properties</b>            | <b>Dimensions</b>   |
|-------------------------------|------------------------------|---|
| Families                      | Role in identifying symptoms | Normalising the experience to<br>pathologising the experience |
|                               | View of hearing performance  | More or less frustrated with hearing performance              |
| Clinicians                    | Clinical services            | Regarded with suspicion to regarded as helpful                |

| <b>Action/Interaction strategies.</b> | <b>Properties</b>   | <b>Dimensions</b>                |
|---------------------------------------|---|----------------------------------|
| Pro-active strategies                 | Changing environment or speaker's behaviour                   | More or less frequently employed |
| Reactive strategies                   | Reacting to environment, repairing breakdown in communication | More or less frequently employed |

| <b>Consequences code</b> | <b>Properties</b> | <b>Dimensions</b>                         |
|--------------------------|-------------------|---|
| Emotional distress       | Anger             | Emotional distress increases or decreases |

|  |            |  |
|--|------------|--|
|  | Anxiety    |  |
|  | Depression |  |

### **Selective Coding**

This stage in the coding process continues the integration that occurred in axial coding. Here the aim is to identify the key category that explains the variance in the process described through the paradigm. Strauss and Corbin (1998) propose several criteria including:-

1. The category must be central all other categories must relate to it.
2. It must occur frequently in the data.
3. There must be a logical relationship between the central category and the other categories.
4. The concept should be able to explain variation.

In this case the central category was identified as it explained the variation in the coping strategy chosen by the participant. It occurred in every transcript and was clearly related to all stages of coping.

## Appendix II

### Listening Difficulties Questionnaire

[This questionnaire is amended from the one devised by Max Dutson, Nicola Morgan and Josie Higson, IHR, Nottingham 1991 to recruit students to serve as 'proto-OAD' subjects in a study of acoustic reflexes and OAD.]

**Many people have difficulties hearing, especially in noise. Some students experience these difficulties in lecture room. We are investigating these difficulties so that we might learn more about the best way to help such people.**

Please circle the answer that best fits your experience and place the form in the box provided.

Do you suspect you may have more difficulty than other people in following a conversation against background noise (eg heavy traffic, pub etc.)

SAME AS OTHERS/ MORE DIFFICULTY/ MUCH MORE DIFFICULTY

Do you suspect you may have more difficulty than others in hearing what is said in lectures or at meetings?

SAME AS OTHERS / MORE DIFFICULTY/ MUCH MORE DIFFICULTY

Do you ever turn the wrong way when someone calls you; or are you unable to quickly locate a person who is speaking if you can't see them?

NEVER/ RARELY/ QUITE OFTEN/ VERY OFTEN

How difficult do you find it to follow someone's conversation when other people are also talking close by?

NO DIFFICULTY/ SOME DIFFICULTY/ GREAT DIFFICULTY

Are you aware of having had ear infections as a child?

YES/ NO

Do you have ear infections or blocked ears nowadays?

YES/ NO

## Appendix III

### Your views about your hearing

We are interested in your own personal views of how you now see your hearing.

Please indicate how much you agree or disagree with the following statements about your hearing by ticking the appropriate box.

Listed below are a number of areas of difficulty that you may have experienced with your hearing. Please circle the answer or tick the box that best reflects your experience.

|  | I have experienced this |    | This is related to my hearing difficulties |    |
|--|-------------------------|----|--|----|
|  | YES                     | NO | YES  | NO |
| Cannot hear TV                                       | YES                     | NO | YES  | NO |
| Cannot hear speech in crowded room                   | YES                     | NO | YES  | NO |
| Cannot hear speech one to one                        | YES                     | NO | YES  | NO |
| Cannot hear doorbell                                 | YES                     | NO | YES  | NO |
| Cannot hear speech on the telephone                  | YES                     | NO | YES  | NO |
| Find everyday sounds uncomfortably loud              | YES                     | NO | YES  | NO |
| Cannot socialise as I would like                     | YES                     | NO | YES  | NO |
| Experience headaches                                 | YES                     | NO | YES  | NO |
| Experience ringing or buzzing noises in ears or head | YES                     | NO | YES  | NO |

**Please indicate how much you agree or disagree with the following statements about your hearing by ticking the appropriate box.**

|      | <b>Views about your hearing</b>  | Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |
|------|--|-------------------|----------|----------------------------|-------|----------------|
| IP1  | My hearing difficulties will last a long time                            |                   |          |                            |       |                |
| IP2  | My hearing difficulties are likely to be permanent rather than temporary |                   |          |                            |       |                |
| IP3  | My hearing difficulties will last a long time                            |                   |          |                            |       |                |
| IP4  | These hearing difficulties will pass quickly                             |                   |          |                            |       |                |
| IP5  | I expect to have hearing difficulties for the rest of my life            |                   |          |                            |       |                |
| IP6  | My hearing difficulties are serious                                      |                   |          |                            |       |                |
| IP7  | My hearing difficulties have major consequences on my life               |                   |          |                            |       |                |
| IP8  | My hearing difficulties do not have much effect on my life               |                   |          |                            |       |                |
| IP9  | My hearing difficulties strongly affect the way that others see me       |                   |          |                            |       |                |
| IP10 | My hearing difficulties have serious financial consequences              |                   |          |                            |       |                |
| IP11 | My hearing causes difficulties for those who are close to me             |                   |          |                            |       |                |
| IP12 | There is a lot which I can do to control the difficulties                |                   |          |                            |       |                |
| IP13 | What I do can determine whether I hear better or worse                   |                   |          |                            |       |                |
| IP14 | The course of my hearing depends on me                                   |                   |          |                            |       |                |
| IP15 | Nothing I do will affect my hearing difficulty                           |                   |          |                            |       |                |
| IP16 | I have the power to influence my hearing difficulty                      |                   |          |                            |       |                |
| IP17 | My actions will have no affect on the outcome of my hearing difficulty   |                   |          |                            |       |                |

|      |  |  |  |  |  |  |
|------|--|--|--|--|--|--|
| IP18 | My hearing ability will improve in time  |  |  |  |  |  |
| IP19 | There is very little that can be done to improve my hearing                                |  |  |  |  |  |
| IP20 | My treatment will be effective in curing my hearing difficulties                           |  |  |  |  |  |
| IP21 | The negative effects of my hearing difficulties can be prevented (avoided) by my treatment |  |  |  |  |  |
| IP22 | My treatment can control my hearing difficulties   |  |  |  |  |  |
| IP23 | There is nothing that can help my hearing difficulties                                     |  |  |  |  |  |
| IP24 | The symptoms of my hearing difficulty are puzzling to me                                   |  |  |  |  |  |
| IP25 | My hearing difficulties are a mystery to me  |  |  |  |  |  |
| IP26 | I don't understand my hearing difficulties   |  |  |  |  |  |
| IP27 | My hearing difficulties don't make any sense to me   |  |  |  |  |  |
| IP28 | I have a clear picture or understanding of my hearing difficulties                         |  |  |  |  |  |
| IP29 | The symptoms of my hearing difficulties change a great deal from day to day                |  |  |  |  |  |
| IP30 | My symptoms of hearing difficulty come and go in cycles                                    |  |  |  |  |  |
| IP31 | My hearing is very unpredictable   |  |  |  |  |  |
| IP32 | I go through cycles in which my hearing difficulties get better and worse                  |  |  |  |  |  |
| IP33 | I get depressed when I think about my hearing difficulties                                 |  |  |  |  |  |
| IP34 | When I think about my hearing difficulties I get upset                                     |  |  |  |  |  |
| IP35 | My hearing difficulties make me feel angry   |  |  |  |  |  |
| IP36 | My hearing difficulties do not worry me  |  |  |  |  |  |
| IP37 | Having these hearing difficulties makes me feel anxious                                    |  |  |  |  |  |
| IP38 | My hearing difficulties make me feel afraid  |  |  |  |  |  |

## Causes of my hearing difficulties

We are interested in what you consider may have been the causes of your hearing difficulties. As people are very different there is no correct answer for this question. We are most interested in your own views about the factors that caused your hearing difficulties rather than what others, including doctors or family may have suggested to you. Below is a list of possible causes for your hearing difficulties. Please indicate how much you agree or disagree that they were the causes for you by ticking the appropriate box.

|     | Possible causes  | Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |
|-----|--|-------------------|----------|----------------------------|-------|----------------|
| C1  | Stress or worry  |                   |          |                            |       |                |
| C2  | Hereditary – it runs in the family                           |                   |          |                            |       |                |
| C3  | A germ or virus  |                   |          |                            |       |                |
| C4  | Diet or eating habits  |                   |          |                            |       |                |
| C5  | Chance or bad luck   |                   |          |                            |       |                |
| C6  | Poor medical care in my past                                 |                   |          |                            |       |                |
| C7  | Pollution in the environment                                 |                   |          |                            |       |                |
| C8  | My own behaviour   |                   |          |                            |       |                |
| C9  | My mental attitude e.g. Thinking about life negatively       |                   |          |                            |       |                |
| C10 | Family problems or worries                                   |                   |          |                            |       |                |
| C11 | Overwork   |                   |          |                            |       |                |
| C12 | My emotional state e.g. feeling down, lonely, anxious, empty |                   |          |                            |       |                |
| C13 | Ageing   |                   |          |                            |       |                |
| C14 | Alcohol  |                   |          |                            |       |                |
| C15 | Smoking  |                   |          |                            |       |                |
| C16 | Accident or injury   |                   |          |                            |       |                |
| C17 | My personality   |                   |          |                            |       |                |
| C18 | Altered immunity   |                   |          |                            |       |                |

In the table below, please list in rank-order the three most important factors that you now believe caused your hearing difficulties. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:

- 1.
- 2.
- 3.

## **Apendix IV**

**The OAD test battery.**

**<http://www.ihr.mrc.ac.uk/products/index.php?products=15>**

## **Appendix V**

### **Related publications**

**Pryce H.**, 2006. What is the process of coping in King-Kopetzky Syndrome?

Audiological Medicine, 4:60-67

Publisher: Taylor and Francis

DOI : 10.1080/16513860600747813

**Pryce H. and Wainwright D.**, 2008. Help seeking for medically unexplained hearing difficulties: a qualitative study. International Journal of Therapy and Rehabilitation 15(8) 1-7.

Publisher: MA Healthcare Ltd.

ISSN: 1741-1645



